2016 Autism Research Priorities Survey Report

FINAL REPORT

Dr Olivia Gatfield
Ms Cheryl Mangan
Ms Tori Haar
Ms Abbie Kinniburgh
Prof Sylvia Rodger AM

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Autism CRC Ltd *Cooperative Research Centre for Living with Autism*
Level 3, Foxtail Building, Long Pocket Campus, The University of Queensland, Q 4072
80 Meiers Road, Indooroopilly
PO Box 6068, St Lucia Q 4067 | +61 7 3377 0600 | info@autismcrc.com.au
ABN 55 162 632 180
autismcrc.com.au

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Dr Olivia Gatfield
Project officer, Autism CRC

Ms Cheryl Mangan
Research Manager, Autism CRC

Ms Tori Haar
Autism CRC Research Academy Alumni

Ms Abbie Kinniburgh
Autism CRC Research Academy Alumni

Prof Sylvia Rodger AM
Director or Research and Education, Autism CRC

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The Autism CRC and the authors wish to sincerely thank the participants in this study for their time and their willingness to share their insights and ideas. Without contributions such as this, the CRC would not be possible.

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 Research Academy members, the terms , 'on the autism spectrum' and 'on the spectrum' will be used in this report. The exception is where direct quotes are used.

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.

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1. Introduction

Autism is amongst the most complex, prevalent and heritable of all neurodevelopmental conditions. The ABS (2012) Survey of Disability, Ageing and Carers indicates males are four times more likely to be on the autism spectrum when compared to females, and 115,400 Australians (0.5%) as on the spectrum. This represents a 79% increase from the 2009 ABS Survey of Disability, Ageing and Carers, in which 64,400 Australians were estimated to be on the spectrum.

Research has indicated that people on the spectrum have poorer outcomes than neuro-typical people in areas such as education, identify formation, post-school transitions, community inclusion, employment and social outcomes (DePape & Lindsay, 2016; Gray et al., 2014; Howlin, 2000; Hurlbutt,& Chalmers, 2002; Mawhood, Howlin & Rutter, 2000). Autism is a lifelong condition with National estimated annual support costs potentially exceeding $7 billion (Williams, MacDermott, Ridley, Glasson & Wray, 2015).

The Research Priorities Survey was launched by Autism CRC in 2015 to enable the identification of research and development priorities that will optimise outcomes for people on the autism spectrum and those who support them. This report provides a summary of the findings- indicating the research priorities of the autistic and autism communities. This information is a critical first step in establishing Australian priority research needs in the future.

2. Research Design

RESEARCH AIMS

The aims of the study were to identify a) what autism research will improve the lives of people on the autism spectrum, and b) what age group/s autism research should focus on, according to:

- people on the autism spectrum;
- people living with autism, being family members and carers of people on the spectrum; and
- professionals including autism researchers and practitioners.

A subsequent aim was to determine between stakeholder group whether there were any differences in research and age group priorities.

ETHICAL CONSIDERATIONS

The study adhered to the National Statement on Ethical Conduct in Human Research and received ethical approval through the University of Queensland's Behavioural and Social Sciences Ethical Review Committee (approval number 2015001074).

3. Method

PARTICIPANTS

There were 158 participants comprising 50 adults on the autism spectrum, 88 people living with autism and 20 professionals. As shown in Table 1, the majority of participants were female (n=142, 90%) with the most common age group of participants being 35-49 years (n= 81, 51%). This was consistent across each of the stakeholder groups with the exception of professionals; the majority of whom identified in the age group of 25-34 (n=8, 40%). Most participants resided in city/urban areas (n=119, 75%) and this was consistent across stakeholder groups.

Table 1. Participant demographics

	All participants	On the autism spectrum	Living with autism	Professionals
	n=158	n= 50	n= 88	n= 20
Gender				
Female	142 (90%)	38 (76%)	85 (97%)	19 (95%)
Male	16 (10%)	12 (24%)	3 (3%)	1 (5%)
Age group				
18 – 24 years	14 (9%)	8 (16%)	3 (3%)	3 (15%)
25 – 34 years	27 (17%)	11 (22%)	8 (9%)	8 (40%)
35 – 49 years	81 (51%)	21 (42%)	55 (63%)	5 (25%)
50 – 64 years	32 (13%)	8 (16%)	20 (23%)	4 (20%)
65 + years	4 (3%)	2 (4%)	2 (2%)	-
Region				
City/urban	119 (75%)	37 (74%)	65 (74%)	17 (85%)
Rural/remote	37 (23%)	12 (24%)	22 (25%)	3 (15%)
Did not disclose	2 (1%)	1 (2%)	1 (1%)	-

MEASURES

The survey was based on the survey of research priorities undertaken by Autistica, developed in collaboration with the James Lind Alliance for distribution within the UK (see autistic.org.uk). Consultation regarding questions, wording and layout was undertaken with a Project Advisory Group, comprising six people, including four people on the spectrum.

The survey, as seen in Appendix A, included three sections as follows:

1. Demographic information: age, gender, locality of residence and connection to autism, e.g. parent, on the spectrum, work with people on the spectrum;
2. Identification of the three most important areas for autism research; and
3. Identification of what age group autism research should focus on (prior to school, school years and/or adult years) and qualitative rationale.

ADMINISTRATION, RECRUITMENT AND INCLUSION CRITIERA

The survey was administered online via Qualtrics and was available for completion from June to September, 2015. To recruit participants, the survey was distributed through Autism CRC networks- including University, service provider and industry partners. Recruitment was also undertaken through promotion of the survey on the Autism CRC website, newsletters and social media - Twitter and Facebook. Reminders of survey closing date were published through these channels one week prior to cessation.

The criteria for inclusion was that the person was aged 18 or older, resided in Australia and identified as at least one of the following:

- A person on the autism spectrum - including of those who do not have a formal diagnosis and those with other diagnoses;
- A parent, carer, relative, partner/spouse or child of a person on the spectrum;
- A professional or practitioner working with people on the spectrum; and
- A researcher in the area of autism.

ANALYISIS

Quantitative Data

Analysis was undertaken using Excel 2013. The nature of the data and small sample frame for the professionals' stakeholder group precluded analysis beyond descriptive statistics and frequency distributions.

Qualitative Data

Qualitative data were analysed using manual content and thematic analysis procedures (Patton, 2002). Initial broad brush coding was undertaken independently by the first and second authors. Through comparison, areas of disagreement were discussed and recoded on consensus. The established meta- and sub- themes, and raw data contained within each theme, were submitted to two autistic reviewers for code verification. Divergence from initial coding was discussed where this occurred and in each instance feedback pertaining to allocation of raw data to additional themes, as suggested by autistic reviewers, was adopted.

4. Summary of findings

PRIORITIES FOR AUTISM RESEARCH

Table 2 shows the top three priorities for autism research, and the two most frequently identified research topics within these priorities. ***The most frequently identified priority for autism research was 'therapies, issues and management'*** (94 responses). This priority incorporated data pertaining to *therapies* such as early intervention and gene therapies, *issues* such as 'coping' and program effectiveness and efficacy, and the *management* of attributes such as anxiety and sensory processing. Within this priority item, **anxiety and 'coping'** was the most commonly identified topic for research (23 responses). Examples of responses contained within this theme were:

> *Coping strategies how can people on the spectrum better interface with the world?* (person on the spectrum)
>
> *Effective types of psychology to manage anxiety for people with ASDs* (professional).

The second most frequently indicated topic for research encompassed within the ‘therapies, issues and management’ priorities was ‘**development and behaviour**’ (21 responses). Data contained within this theme included development of motor skills, eating and life skills, and the management of certain behaviours. Several examples of participant responses include:

> *Recognizing facilitators for positive behavior* (parent of a person on the spectrum)
>
> *How to foster flexibility in children* (spouse of a person on the spectrum)

Table 2. Priorities for autism research

	Priority/ topic	**No. of responses (total=323)**
Priority 1	Therapies, issues and management	94
Topic 1	Anxiety and ‘coping’	23
Topic 2	Development and behaviour	21
Priority 2	Understanding autism	52
Topic 1	Causes	11
Topic 2	Diagnosis	9
Priority 3	Educating	44
Topic 1	Children on the spectrum	31
Topic 2	Teachers and schools	7

The second priority for autism research was ‘understanding autism’ (52 responses). This priority encompassed participant responses relating to autism presentation - such as autism in females, epidemiology and sub-types, understanding the lived experience, and pragmatic understandings such as neuroplasticity and causation. The most frequently identified research topic within the theme ‘understanding autism’, was causes of autism (11 responses) followed by diagnosis (9 responses). With regard to causation it was indicated:

> *Is autism genetic* (person on the spectrum)
>
> *Why are children born this way i.e. is there a cause or is it hereditary* (parent of a person on the spectrum)

Participant responses relating to diagnosis included the following:

> *Better procedures for diagnosing* (person on the spectrum)
>
> *Diagnosis - improving identification of autism, especially in later life and in people with very subtle autism characteristics* (person on the spectrum and autism researcher)

The third most frequently identified priority for autism research was 'educating'. This research priority included responses pertaining to the education of children on the spectrum and adults in tertiary settings, teachers and schools, and healthcare professionals- such as Doctors and Psychologists. Research relating to **education of children on the spectrum** (31 responses) was most commonly mentioned within this theme, and included responses such as:

> *Research about educating children on the spectrum* (person on the spectrum)
>
> *Educating autistic children and teens* (parent of a person on the spectrum)

Educating teachers and schools was the second most common theme within the education research priority and included data relating to educating teachers and schools in effectively teaching and including students on the spectrum. To highlight:

> *Reviewing the training of education providers regarding ASD - what their knowledge is of the disorder, what training they have received, how they perceive the needs of students with ASD* (autism researcher and carer of a person on the spectrum)
>
> *Research about education for teachers for students on the spectrum* (carer of a person on the spectrum)

PRIORITIES BY STAKEHOLDER GROUP

The top three priority for autism research identified by the three stakeholder groups was ***'therapies, issues and management'***, described in the previous section. As shown in Table 3, this ranked as the most important priority for research by people living with autism (87 responses) and professionals (18 responses), and as the second most important by people on the spectrum (30 responses). There was disparity, however, with regard to the most important research topics within the priority are. Anxiety and 'coping' was paramount to those on the spectrum and those living with autism (9 and 23 responses respectively), while 'programs, effectiveness and efficacy' was the highest priority by professionals.

'***Understanding autism'*** was a research priority topic indicated in the top three by people on the spectrum (36 responses) and those living with autism (87 responses) - see previous section for description of priority topic. There was discrepancy, however, between topics for research contained within this priority item. Specifically, the lived experience and research regarding females on the spectrum were indicated as the most important topics by people on the spectrum (20 and 7 responses respectively). In contrast, research regarding causes and diagnosis were cited most frequently by those living with autism (13 and 8 responses respectively).

Table 3. Priorities for autism research by stakeholder group

	On the spectrum	Living with autism	Professionals
Total no. of responses	**157**	**263**	**57**
Priority 1	Understanding autism (36)	Therapies, issues & management (87)	Therapies, issues & management (18)
Topic 1	Lived experience (10)	Anxiety & 'coping' (23)	Programs, effectiveness & efficacy (5)
Topic 2	Females on the spectrum (7)	Development & behavior (22)	Sensory (4)
Priority 2	Therapies, issues & management (30)	Educating (44)	Adulthood (11)
Topic 1	Anxiety & 'coping' (9)	Children on the spectrum (31)	Post-school transition (6)
Topic 2	Sensory (6)	Teachers and schools (10)	Ageing/ elderly (3)
Priority 3	Society (18)	Understanding autism (41)	Health (8)
Topic 1	Community attitudes/acceptance (13)	Causes (13)	Mental health (4)
Topic 2	Community engagement/ culture/ coproduction (7)	Diagnosis (8)	Comorbidity (3)

AGE GROUPS FOR AUTISM RESEARCH

The most frequently identified age group that autism research should focus on was adult years, being 17+ years of age (118 responses), as shown on Table 4. Comparison between groups showed this as priority for people on the spectrum (47 responses) and professionals (16 responses), with people living with autism indicating school years, being 5-17 years of age, as the priority group for research.

Table 4. Priority age groups for autism research

		No. of responses		
	All groups	**On the spectrum**	**Living with autism**	**Professionals**
Prior to school years (about 0-5 years)	80	21	49	10
School years (about 5-17 years)	118	37	68	13
Adult years (17+ years old)	124	47	61	16

5. Conclusion

This research has indicated the most important priorities for autism research to be:

(a) therapies, management and issues related to anxiety and 'coping', and development and behavior,

(b) causes, diagnostic criteria and practices, and

(c) educating children on the spectrum, teachers and schools.

Further, the age group that autism research should focus on according to participants was the adult years, being 17+ years of age.

The results from this preliminary study, however, should be interpreted with caution due to the relatively small sample size and the small stakeholder sub-group sample sizes, and consequent analytic restrictions. Further, these data may not include the opinions of those who are on the spectrum and have an intellectual disability. Nonetheless, this study has provided a first step towards establishing broad Australian research priorities from the perspectives of the autistic and autism communities.

6. References

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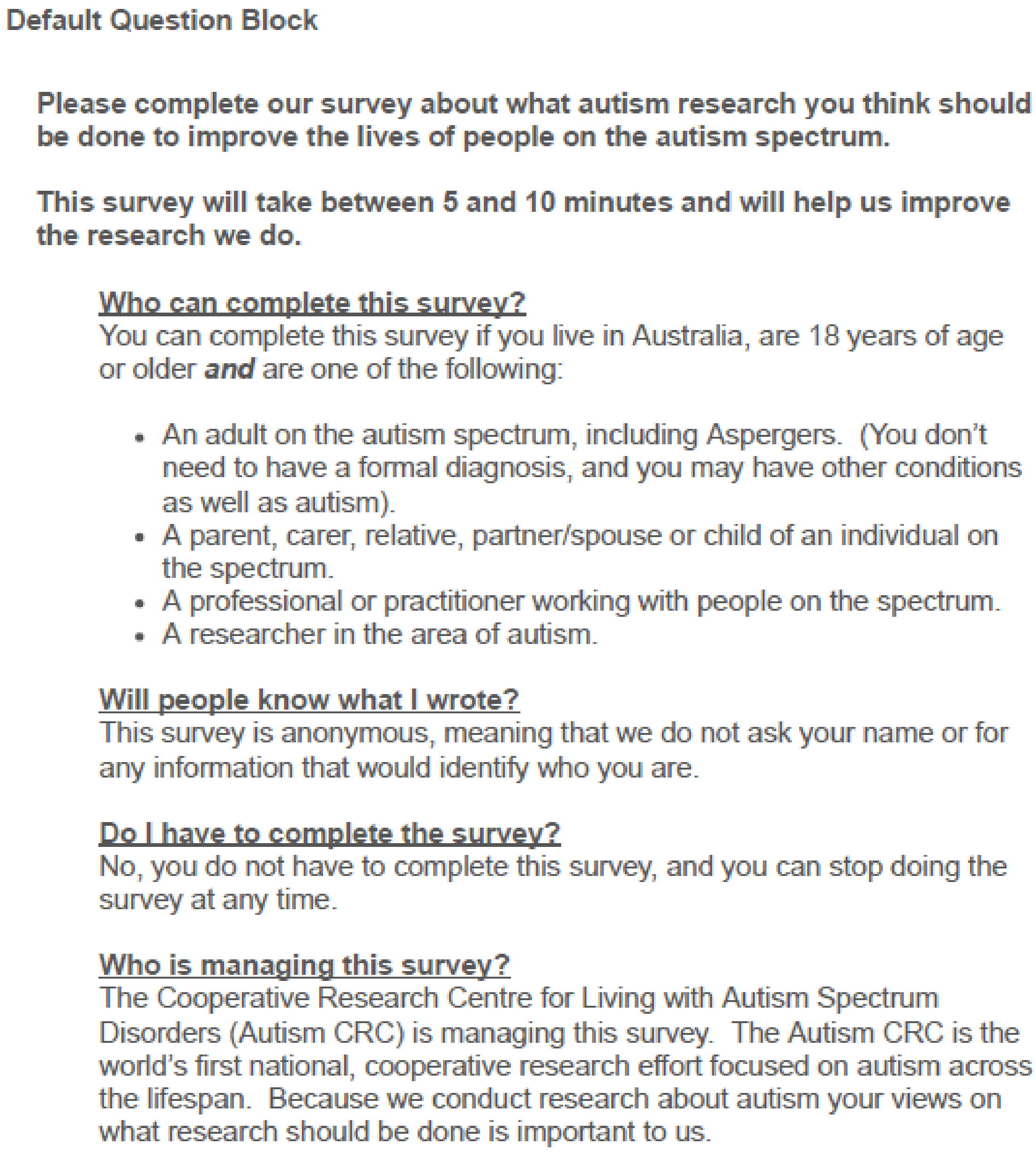
Appendices

APPENDIX A: RESEARCH PRIORITIES SURVEY



Default Question Block

Please complete our survey about what autism research you think should be done to improve the lives of people on the autism spectrum.

This survey will take between 5 and 10 minutes and will help us improve the research we do.

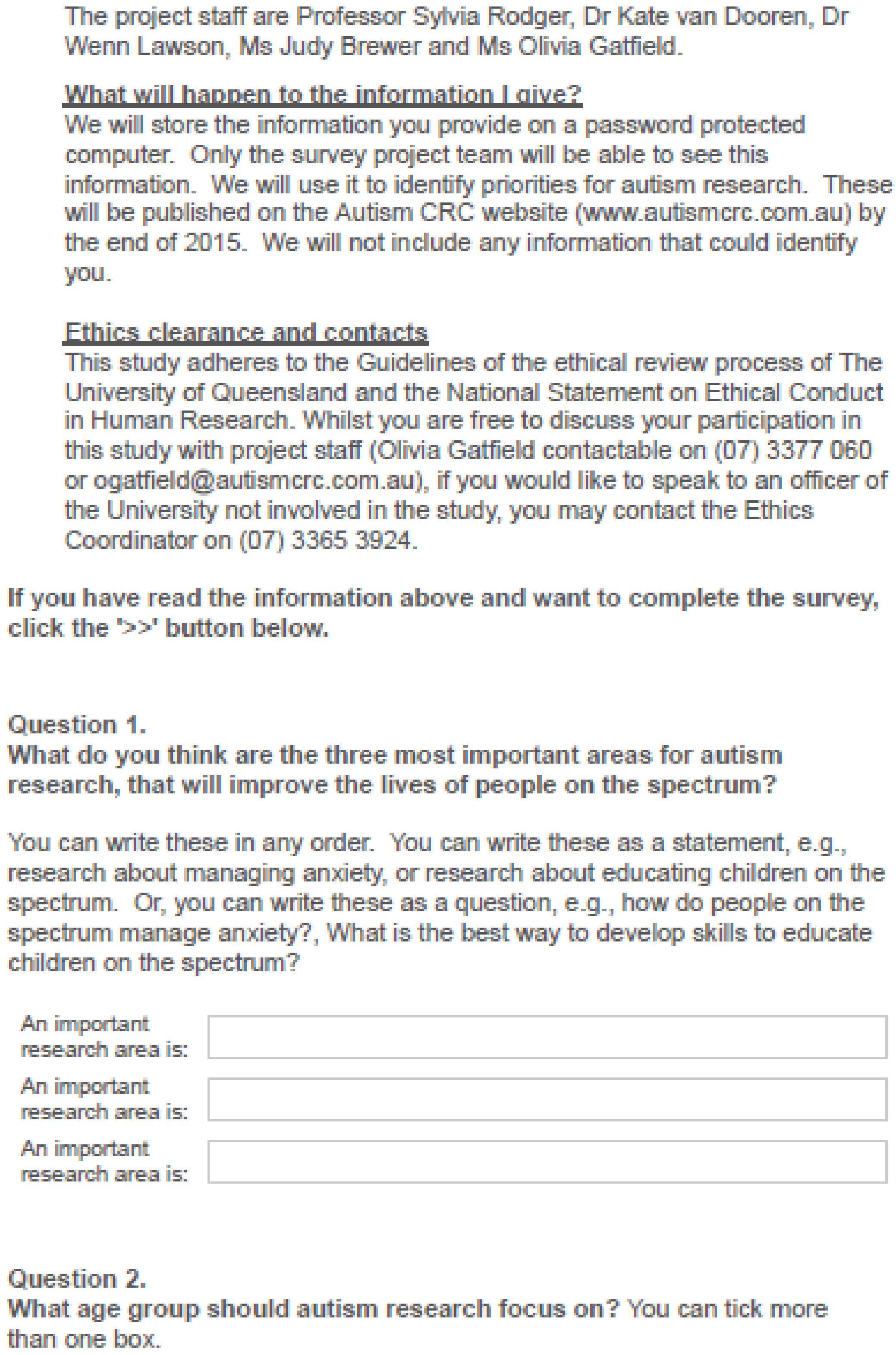
Who can complete this survey?
You can complete this survey if you live in Australia, are 18 years of age or older ***and*** are one of the following:

- An adult on the autism spectrum, including Aspergers. (You don't need to have a formal diagnosis, and you may have other conditions as well as autism).
- A parent, carer, relative, partner/spouse or child of an individual on the spectrum.
- A professional or practitioner working with people on the spectrum.
- A researcher in the area of autism.

Will people know what I wrote?
This survey is anonymous, meaning that we do not ask your name or for any information that would identify who you are.

Do I have to complete the survey?
No, you do not have to complete this survey, and you can stop doing the survey at any time.

Who is managing this survey?
The Cooperative Research Centre for Living with Autism Spectrum Disorders (Autism CRC) is managing this survey. The Autism CRC is the world's first national, cooperative research effort focused on autism across the lifespan. Because we conduct research about autism your views on what research should be done is important to us.



The project staff are Professor Sylvia Rodger, Dr Kate van Dooren, Dr Wenn Lawson, Ms Judy Brewer and Ms Olivia Gatfield.

What will happen to the information I give?

We will store the information you provide on a password protected computer. Only the survey project team will be able to see this information. We will use it to identify priorities for autism research. These will be published on the Autism CRC website (www.autismcrc.com.au) by the end of 2015. We will not include any information that could identify you.

Ethics clearance and contacts

This study adheres to the Guidelines of the ethical review process of The University of Queensland and the National Statement on Ethical Conduct in Human Research. Whilst you are free to discuss your participation in this study with project staff (Olivia Gatfield contactable on (07) 3377 060 or ogatfield@autismcrc.com.au), if you would like to speak to an officer of the University not involved in the study, you may contact the Ethics Coordinator on (07) 3365 3924.

If you have read the information above and want to complete the survey, click the '>>' button below.

Question 1.

What do you think are the three most important areas for autism research, that will improve the lives of people on the spectrum?

You can write these in any order. You can write these as a statement, e.g., research about managing anxiety, or research about educating children on the spectrum. Or, you can write these as a question, e.g., how do people on the spectrum manage anxiety?, What is the best way to develop skills to educate children on the spectrum?

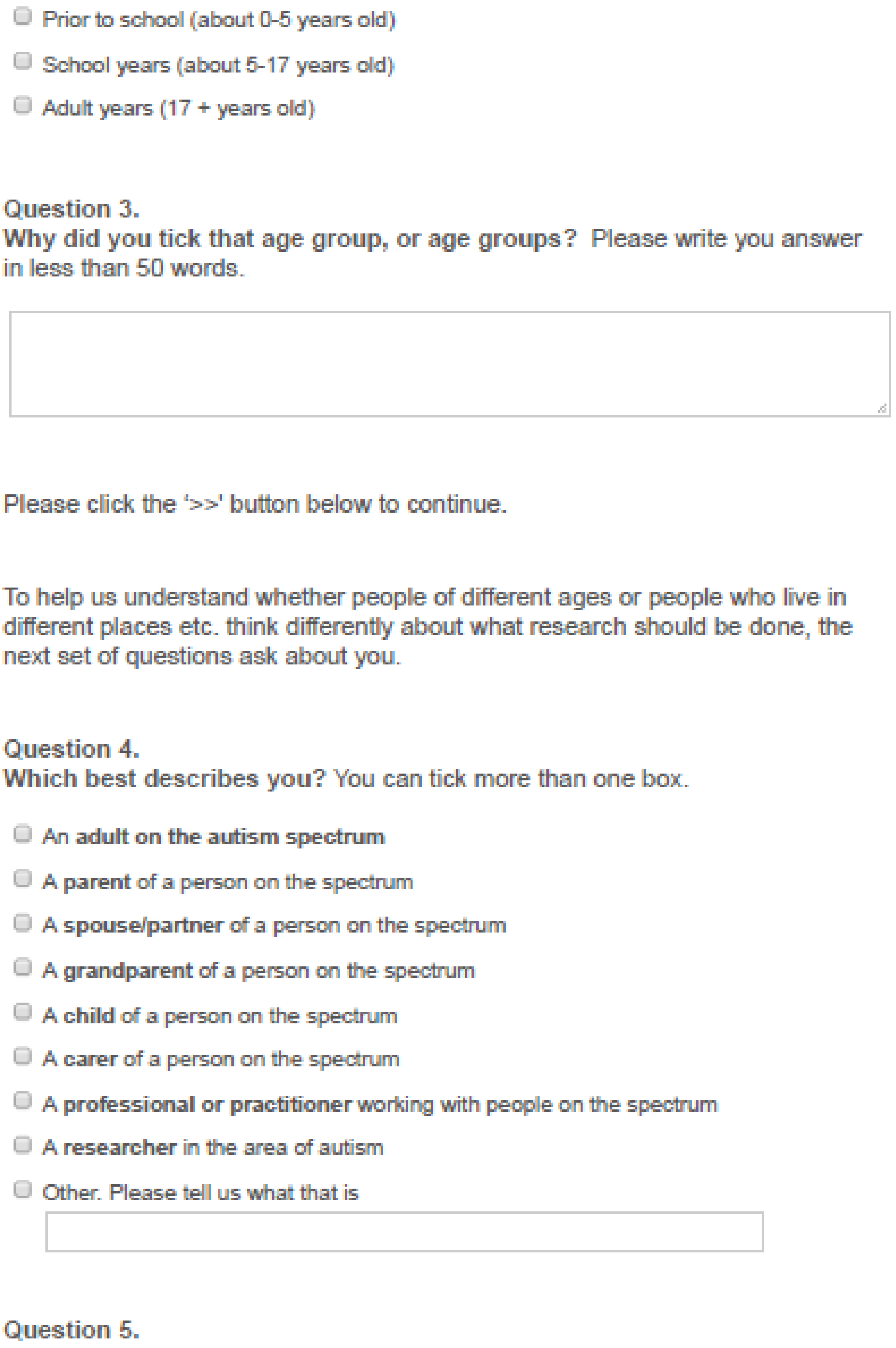
An important research area is: ☐

An important research area is: ☐

An important research area is: ☐

Question 2.

What age group should autism research focus on? You can tick more than one box.



☐ Prior to school (about 0-5 years old)

☐ School years (about 5-17 years old)

☐ Adult years (17 + years old)

Question 3.
Why did you tick that age group, or age groups? Please write you answer in less than 50 words.

Please click the '>>' button below to continue.

To help us understand whether people of different ages or people who live in different places etc. think differently about what research should be done, the next set of questions ask about you.

Question 4.
Which best describes you? You can tick more than one box.

☐ An **adult on the autism spectrum**

☐ A **parent** of a person on the spectrum

☐ A **spouse/partner** of a person on the spectrum

☐ A **grandparent** of a person on the spectrum

☐ A **child** of a person on the spectrum

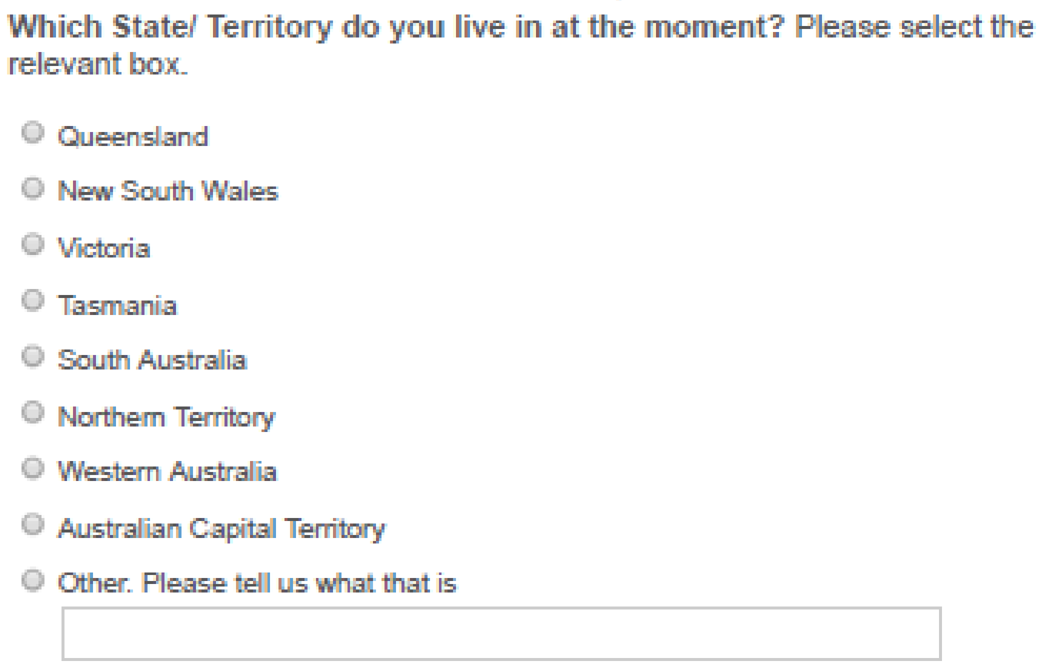
☐ A **carer** of a person on the spectrum

☐ A **professional or practitioner** working with people on the spectrum

☐ A **researcher** in the area of autism

☐ Other. Please tell us what that is

Question 5.



Which State/ Territory do you live in at the moment? Please select the relevant box.

○ Queensland

○ New South Wales

○ Victoria

○ Tasmania

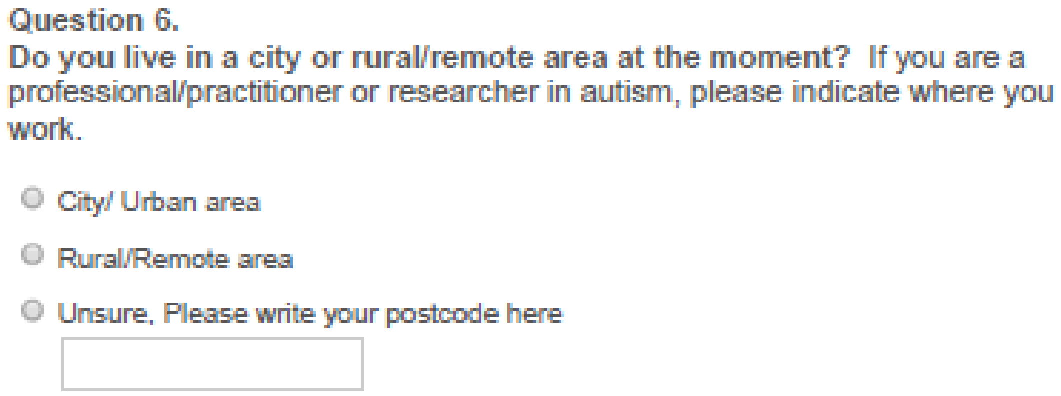
○ South Australia

○ Northern Territory

○ Western Australia

○ Australian Capital Territory

○ Other. Please tell us what that is



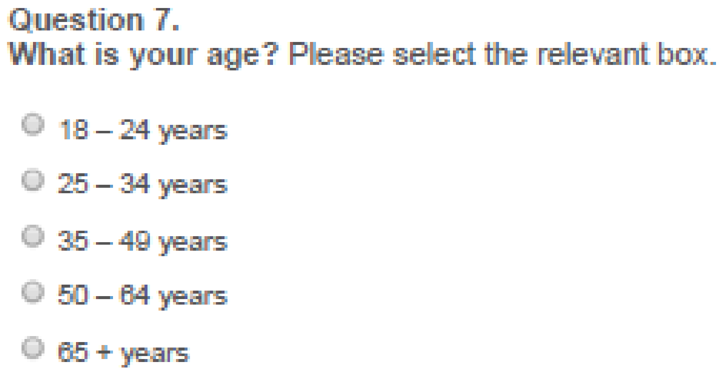
Question 6.

Do you live in a city or rural/remote area at the moment? If you are a professional/practitioner or researcher in autism, please indicate where you work.

○ City/ Urban area

○ Rural/Remote area

○ Unsure, Please write your postcode here



Question 7.

What is your age? Please select the relevant box.

○ 18 – 24 years

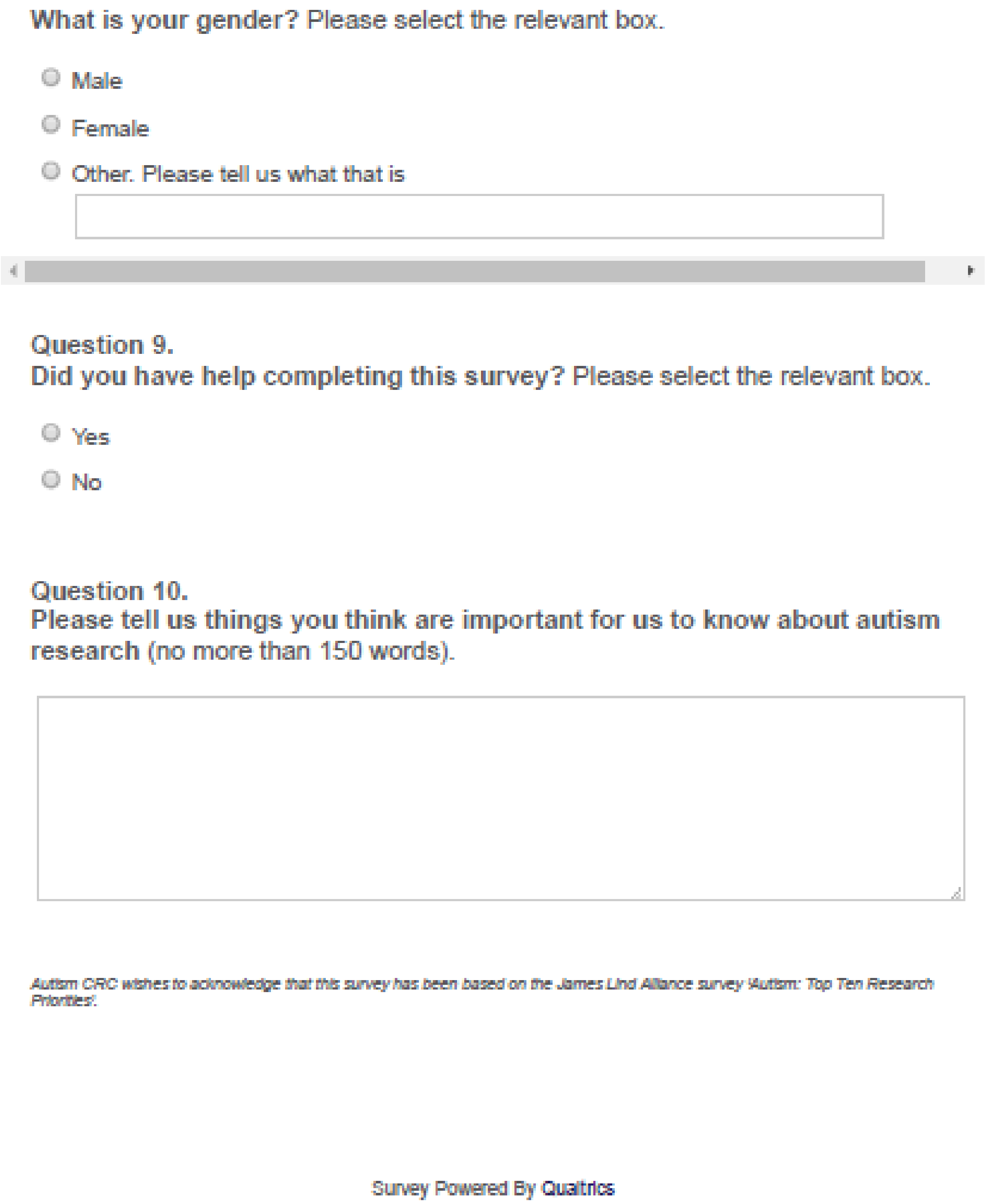
○ 25 – 34 years

○ 35 – 49 years

○ 50 – 64 years

○ 65 + years

Question 8.



What is your gender? Please select the relevant box.

○ Male

○ Female

○ Other. Please tell us what that is

☐

Question 9.
Did you have help completing this survey? Please select the relevant box.

○ Yes

○ No

Question 10.
Please tell us things you think are important for us to know about autism research (no more than 150 words).

☐

Autism CRC wishes to acknowledge that this survey has been based on the James Lind Alliance survey 'Autism: Top Ten Research Priorities'.

Survey Powered By Qualtrics

APPENDIX B: ESTABLISHED META- AND SUB-THEMES

Meta-theme	**Sub-theme**
Services and supports	Access to
	For people on the spectrum
	For parents/ families
Society	Community attitudes/ acceptance
	Community engagement/culture/coproduction
Understanding autism	Lived experience
	Causes
	Diagnosis
	Epidemiology
	Sub-types
	Neurology/ neuroplasticity
	Females on the spectrum
	Other
Therapies, issues & management	Early intervention
	Programs, effectiveness & efficacy
	Alternative therapies
	Social/emotional
	Developmental/ behavioural
	Sensory
	Anxiety & coping
	Communication
	Abuse & trauma
	Gene therapy
Health	Comorbidity
	Biomedical
	Diet/ gut health/ allergies
	Mental health
	Other
Employment	Support in the workplace/ accommodations
	Support to find employment
	Employment
Educating	Children on the spectrum
	Teachers and schools
	In tertiary settings
	Doctors and psychologists
Adulthood	Post-school transition
	Ageing/elderly
	Independence/ independent living
	Other
Families & relationships	Parenting children on the spectrum
	Relationships