Optimising the recruitment and retention of adults for longitudinal autism spectrum research: a mixed methods study

REPORT

Kaaren Haas
Dr Debra Costley
Dr Torbjorn Falkmer
Dr Amanda Richdale
Dr Kate Sofronoff

September 2014

Autism CRC Ltd *Cooperative Research Centre for Living with Autism Spectrum Disorders*
Level 3, Forestry Building, Long Pocket Campus, The University of Queensland, Q4072
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

An Australian Government Initiative

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Kaaren Haas
Research Assistant
Autism Spectrum Australia

Dr Debra Costley
Director, Aspect Practice and Research Leader
Autism Spectrum Australia

Dr Torbjorn Falkmer
Senior Research Fellow
Curtin Health Innovation Research Institute
Curtin University

Dr Amanda Richdale
Principal Research Fellow
Olga Tennison Autism Research Centre
La Trobe University

Dr Kate Sofronoff
Head of Research in Disability
Parenting and Family Support Centre
The University of Queensland

Suggested citation: Haas, K., Costley, D., Falkmer, T., Richdale, A. & Sofronoff, K. (2014). Optimising the recruitment and retention of adults for longitudinal autism spectrum research: a mixed methods study. Full report. Cooperative Research Centre for Living with Autism Spectrum Disorders, Brisbane.

ISBN: 978-0-9941641-0-0

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Acknowledgements

The authors acknowledge the financial support of the Cooperative Research Centre for Living with Autism Spectrum Disorders (Autism CRC), established and supported under the Australian Government's Cooperative Research Centres Program. Staff and non-staff in kind were provided by Autism CRC participants - Autism Spectrum Australia, Curtin University, The University of Queensland, La Trobe University and Minds and Hearts Pty Ltd.

The authors wish to acknowledge the contributions of Dr Trevor Clark, Director of Education at Autism Spectrum Australia and Susanna Baldwin to the establishment and design of the project; and the valuable work of the following researchers and research assistants in implementing the participant recruitment and data collection for this study:

- Lahna Bradley, La Trobe University
- Dr Susan Bruck, Autism Spectrum Australia
- Dr Marita Falkmer, Curtin University
- Dr Heidi Stieglitz Ham, Curtin University
- Emma Hyland, The University of Queensland
- Damian Santomauro, The University of Queensland

The Autism CRC and the authors wish to sincerely thank the participants in this study for their time and their willingness to share their opinions and ideas. Without these contributions, this study would not have been possible.

Terminology and abbreviations

1. A number of participants in this study rejected the use of the term' disorder' to describe their experience of autism. For this reason, the authors of this report have chosen to use the terminology '*the autism spectrum*', '*people on the autism spectrum*' and '*autism spectrum research*' when referring to the conditions described in the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) as '*autism spectrum disorder*'.

2. This report adopts the scientific convention of using abbreviations for each of the categories of participants who took part in this study; for example:
    - Participants with high functioning autism/Asperger's Syndrome (HFA/AS)
    - Participants on the autism spectrum with an intellectual disability (ASD+ID)
    - Carers of participants on the autism spectrum with an intellectual disability (Carers)
    - Neuro-typical participants (NT).

   This use of abbreviations is not a 'labelling' of any individual participant or group of participants. It has been adopted for brevity, clarity in reporting and ease of reading.

The Cooperative Research Centre for Living with Autism Spectrum Disorder (Autism CRC)

The Cooperative Research Centre for Living with Autism Spectrum Disorder (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 practical solutions for governments, service providers, education and health professionals, families and people with autism. Autism CRC aims to solve complex problems with innovative solutions that can only come from having the best minds collaborating as one team - the Autism CRC Team www.autismcrc.com.au

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Abstract

For researchers, the recruitment and retention of adults who are on the autism spectrum poses difficulties; longitudinal studies face particular challenges.

To date, factors influencing the recruitment and retention of adults for autism spectrum research have been unexamined in the literature.

This paper reports on a mixed methods study undertaken in 2014 for the *Cooperative Research Centre for Living with Autism Spectrum Disorders* to identify factors that influence the participation of adults in longitudinal autism spectrum research.

Conducted across four Australian states, the study used a variety of recruitment methods to enlist 167 participants in four categories: high functioning autism/Asperger's adults; adults on the autism spectrum with an intellectual disability; carers of these adults; and neuro-typical adults.

Quantitative and qualitative data were collected via a card sort exercise, focus group discussions, interviews, questionnaire and online survey.

The results of the study showed that the motivators, inhibitors and enablers of participation of adults in longitudinal autism spectrum research differed distinctly both between and within each category of participants. While helping others was a key motivator across all categories, participants also sought 'personal benefit' from participation. 'Personal benefit' differed markedly between categories; for adults on the autism spectrum, it was interpreted according to their individual preferences and needs. Results indicate that the inconvenience of time and travel required, and insensitivity to an individual's personal needs and preferences for engaging with the world and others are key inhibitors; maximising choice for all aspects of participant involvement is a vital enabler; and the use of financial and other extrinsic rewards is problematic.

Implications of these findings for future autism spectrum research are also canvassed.

1. Introduction

The *Cooperative Research Centre for Living with Autism Spectrum Disorders* (Autism CRC) Core Program 3 ***Adults with Autism - Finding a Place in Society*** addresses three distinct areas:

1. Finding a Place Post School in Higher Education
2. Finding a Place in the Workplace and Community
3. Enhancing Health and Well-Being in Adolescents and Adults with Autism Spectrum Disorders (ASD) and their Families.

These studies will form the basis of CRC research into social, educational, vocational and health supports for adults on the autism spectrum. Thus, Program 3 research projects will target younger, middle aged and older adults on the autism spectrum and matched neuro-typical participants. These participants will be tracked over four years and outcomes on productivity, physical and mental health, well-being and societal participation will be documented.

However, Program 3 recognises that recruitment and retention of adults on the autism spectrum is likely to pose some difficulties and a challenge will be to recruit participants who are willing to be tracked over four years.

To successfully recruit participants into Program 3 and undertake these longitudinal studies, Program 3 has initiated this first study *Optimisation of Recruitment*, in order to explore how to best recruit and retain adult participants for the duration of the longitudinal studies. The literature suggests that offering incentives to complete questionnaires can be successful in motivating individuals to initially complete questionnaires and in continuing to participate in research. Due to the unique social-communicative profile associated with the autism spectrum, adults on the autism spectrum may be more reluctant than those in the general population to be involved with new people and experiences, which may affect their willingness to participate.

However, an understanding of the factors that influence the recruitment and retention of adult participants for autism spectrum research is to date unexamined.

Thus, the study reported here **- Optimising Recruitment and Retention for Longitudinal Autism Spectrum Research -** is a precursor to the Program 3 research projects to be undertaken in the three defined areas, and in particular, the two longitudinal studies that will address factors related to these areas.

The aim of this study was to identify factors that would influence the participation of adults (both on and not on the autism spectrum) in longitudinal autism spectrum research.

Using both quantitative and qualitative methods for data collection and analysis, the study was conducted from November 2013 to July 2014, with data collection occurring between May and July 2014, across four Australian states, as a collaboration of four essential participants in the Autism CRC:

- Autism Spectrum Australia (Aspect), as lead partner
- Olga Tennison Autism Research Centre, La Trobe University
- Curtin University
- The University of Queensland.

This report presents the findings of this study and outlines the implications of these findings for the design and implementation of strategies to optimise participant recruitment and retention in future CRC Program 3 research projects and in particular, the two longitudinal studies. A comprehensive review of the literature pertinent to this topic offers further insights for fellow Autism CRC Program 3 researchers at the design and establishment phase of their projects.

2. Literature Review

2.1 SCOPE OF THE LITERATURE

The literature on factors influencing the recruitment and retention of participants into longitudinal studies, particularly in fields related to health and quality of life, yields a plethora of possible mechanisms, incentives and strategies that have been employed by researchers. It also reports on the varied rates of success of different approaches to participant recruitment and retention.

However, our search of the literature indicates that the study of participant recruitment and retention in qualitative or non-clinical longitudinal research has been less extensive. Fry (2008a, p. 1458) also notes that *"most of the studies in this area have focused on participation in clinical intervention and cohort studies, and less so on participation in non-intervention research (e.g. community-based epidemiological research, descriptive surveillance studies, attitudes surveys/polls, etc.").*

Most notably for this literature review is that the investigation of factors specific to research about the autism spectrum is to date unexamined. However, some studies have explored how to improve participation for people with an intellectual disability in research and thus provide useful insights relevant to some aspects of autism-related research (e.g., Beadle-Brown et al., 2012).

The considerable number of individual studies reporting on the efficacy of a recruitment and retention strategy designed to influence that study's target population are mostly limited to 'lessons learned' (Robinson, 2007, p. 757) and thus may have limited application in recruiting people on the autism spectrum.

2.2 ANALYSING AND CATEGORISING PARTICIPANT RECRUITMENT AND RETENTION STRATEGIES

A number of studies do provide a 'higher-level' perspective on recruitment and retention strategies, including a number of systemic reviews that proffer a range of different ways to categorise the various strategies observed. The following section provides an overview of these studies.

In exploring how a set of experienced researchers understood the mechanisms that motivate and facilitate participants to engage in qualitative research, Clark (2010) categorises these mechanisms as either *personal to the participant* (subjective interest, enjoyment, curiosity, introspective interest, social comparison, therapeutic interest, material interest and economic interest) or *collective* (representation, political empowerment, and informing change).

This dichotomy of the personal and the social is commonly observed in the literature on motivations for participation in research.

Hunter, Corocran, Leeder and Phelps (2012, p. 84) concluded from their investigation into the potential motivations of patients at a primary health service to participate in a longitudinal survey that: "*while altruism motivates participation in medical research, for many potential participants, the opportunity to benefit directly was the primary, and sometimes the only motive to participate*."

Investigating Canadians' views about participation in a large, longitudinal population-based study on health and aging, Kirkland et al. (2009, p. 239 - 240) found that: *"participants were willing to go to considerable lengths to participate in such a long-lasting and information-rich study, but in turn, they expected the study to be cognizant of their needs"* and that *"while participation was not seen to involve personal gain, recognition of individual contributions to the study was clearly valued."*

Barton et al. (2012) also identified a combination of social motivations (the perception of the worth and importance of the study; the benefits that others may derive from the study; being happy to help others and to find cures); and personal benefits (gaining information relevant to their own health) in a study of the reasons given by adults in Tasmania, Australia for ongoing participation in a longitudinal cohort health study.

Mein et al. (2012, p. 2345) observe that rather than being motivated wholly by altruism, as had been assumed by the researchers, participants in the Whitehall II longitudinal health study in the United Kingdom were also motivated by the personal benefits they perceived, particularly the medical information and care received, and the sense of loyalty and membership associated with being part of the study, which the authors refer to as ‘conditional altruism’.

Applying a different lens on motivations for participation in research, Robinson, Dennison, Wayman, Pronovost and Needham et al. (2007, p. 762) compare 368 retention strategies from 21 varying health-related studies and classify these retention strategies into 12 themes:

1. Community involvement
2. Study identity
3. Study personnel
4. Study description
5. Contact and scheduling methods
6. Reminders
7. Visit characteristics
8. Benefits of study
9. Financial incentives
10. Reimbursement
11. Non-financial incentives
12. Special tracking methods.

Reporting on difficulties encountered in recruiting participants to intellectual disability research, Nicholson et al. (2013) group the factors found to influence participant recruitment into seven themes:

- Participant attributes
- The research process
- The researcher’s standing and style, as perceived by the participant
- The impact of the participant’s previous experience with research
- The attitudes of the participant’s family and carer(s)
- The use of an ‘active’ recruitment approach
- Motivators.

2.3 PARTICIPANT MOTIVATION AS A MULTI-DIMENSIONAL CONSTRUCTION

Of particular relevance to this CRC study is that, based on the findings of their systemic reviews and categorisation of recruitment and/or retention strategies, Beadle-Brown (2012 p. 16), Mapstone, Elbourne and Roberts (2007), and Robinson et al. (2007) each recommend that future researchers seeking to optimise participant retention are best advised to combine a greater number of retention strategies from across a wider variety of themes.

Mapstone et al. (2007) further concluded that a participant’s ongoing involvement in research is influenced by a range of factors. These include participants’ individual preferences and motivations specific to the barriers and incentives inherent in any particular research study, together with the perceived social benefits and costs of participation.

These findings correlate with the observations of Fry (2008b, p. 44) that “p*articipant motivation is a multi-dimensional construction*” and his conclusion that “*the relative salience of these types of research participation incentives and barriers varies across participant group, research focus and setting*”, a view that is shared by other researchers in this field (e.g., Tishler and Bartholmae, 2002).

However, Fry also asserts that "*In spite of this variability … there is notable consistency in the self-reported reasons for research participation where a number of core themes emerge independently of the type of research in which people are participating*." (Fry, 2008b, p. 44), and identifies these consistent reasons and core themes as:

- Factors that can motivate participation (e.g., information access, economic gain, altruism, expected therapeutic benefit)
- Factors that may discourage participation (e.g., inconvenience, risk, discomfort).

Certain individual personality traits may also possibly act as either enablers or barriers to participation in research. A study of the relationship between the propensity to volunteer for research and personality types observes that volunteers for follow-up research were more extraverted, more open to experience and more narcissistic than non-volunteers (Marcus and Schutz, 2005). Examining possible methods that encourage hard-to-reach populations with a high proportion of non-associative members to participate in research, Thompson and Phillips (2007, p. 1298) identify that the stigma engendered by negative public attitudes to disability, and the resultant low self-esteem and reluctance of people living with disability to identify with a particular condition (such as autism), act to discourage their participation in research.

A further factor identified in the literature is the participant-researcher relationship and related to this, the participant's perceptions of the researcher. A systemic review also seeking to identify barriers and facilitators to capturing the views of people who are 'seldom–heard' in research concludes that, researcher assumptions about the efficacy or validity of including particular types of people, their conventional views about what data should look like, and evidenced stereotyped views about people outside of the 'mainstream' can significantly influence research design and lead to the exclusion of certain groups of people (Beadle-Brown et al., 2012 p. 12). Drawing on their study of participant recruitment for research in a clinical nursing setting, Penckofer, Bryn, Mumby and Ferrans (2011) propose that Peplau's theory of interpersonal relations provides a pertinent framework for conceptualising the participant-researcher relationship as the single most important factor in recruiting and retaining research participants.

2.4 RECRUITMENT AND RETENTION OF PARTICIPANTS WITH AN INTELLECTUAL DISABILITY

The literature that is specific to intellectual disability research commonly discusses the particular challenges that recruiting participants for this endeavour poses. In doing so, it also identifies a number of common motivators and barriers to participation that are specific to this group and the nature of their lives.

A review of intellectual disability studies conducted in Canada in the 20 years up to 2006 (Cleaver, Ouelette-Kuntz and Sakar, 2010, p. 187) confirmed that certain factors influenced the participation of people with an intellectual disability and concluded that: "*researchers seeking the participation of adults with ID must incorporate actors influencing participation into study designs to ensure robust results and effective use of research resources.*" The review found that higher participation rates were achieved in those studies where:

- investigators had direct access to participants;
- data collection was non-invasive; and
- consent was required from substitute decision makers only.

Evaluating the effectiveness of three different recruitment strategies employed in a randomised controlled trial (RCT) aiming to improve health advocacy of people with an intellectual disability, Lennox et al. (2005, p. 301) concluded that recruitment was best achieved through direct contact from a staff member of a service provider to the adult with an intellectual disability and their caregivers.

These findings are consistent with those of Ouellette-Kuntz, Lunsky, Lysaght, Marton and Saaltink (2013), who reviewed six varied studies conducted in Ontario, Canada using a range of strategies to recruit participants with an intellectual disability. The review found that participation rates were positively influenced by offers of financial compensation and incentives, though the effective type of financial incentive was unclear. They also concluded that recruitment of participants with an intellectual disability was most successful where:

- there was an established relationship between the participant and a member of the research team; and
- if a third party was involved in assisting with recruitment, it was made very clear to the participant and their family and carers as to which person(s) and which organisation was conducting the research;

and was least successful in those cases where:

- the study relied on a third party for recruitment;
- there was a considerable time lag between the participant's expression of interest and their engagement in the research; and
- data collection relied on face-to-face interviews.

Beadle-Brown et al. (2012, p. 19) identify the potential for gatekeepers (such as general practitioners, care managers, support workers, carers and parents) of people with an intellectual disability to form a barrier when they are either selecting potential participants or seeking to 'protect' them.

2.5 COMMONLY-IDENTIFIED MOTIVATORS AND BARRIERS TO PARTICIPATION IN LONGITUDINAL RESEARCH

Based on a synthesis of these findings, together with our existing knowledge of the very broad range of individual (and sometimes idiosyncratic) personal attributes and preferences of adults on the autism spectrum (Aspect, 2013; Tantam, 2014), our search sourced a selection of studies across a wide range of sample populations to summarise commonly-identified motivators and barriers to participation in longitudinal research projects (Table 1). These can be categorised as intrinsic, extrinsic and procedural.

TABLE 1. COMMONLY-IDENTIFIED INCENTIVES AND DISINCENTIVES TO PARTICIPATION IN LONGITUDINAL RESEARCH

INCENTIVES

Intrinsic incentives

- Desire to help others and contribute to valued research (Barton et al., 2012; Bell, 2011; Brodaty et al., 2013; Kirkland et al., 2009; Marcantonio et al., 2008)
- Gain information and personal insight gained about self (Barton et al., 2012;, Hunter et al., 2012, Mein et al., 2012)
- Voice and share experiences and concerns (Bell, 2011)
- Participation as therapy (Bell, 2011)
- Belonging to a community (Mein et al., 2012, Robinson et al., 2007)

Extrinsic incentives

- Monetary payments and gifts (Booker, Harding and Benzeval, et al., 2011; Croft, Festinger, Dugosh, Marlowe and Rosenwasser, 2007; Leonard et al., 2003; Marcantonio et al., 2008; Tishler and Bartholomae 2002)
- No travel required or travel provided (Marcantonio, et al., 2008)
- Tell-a-friend rewards (Bonk, 2010)

Procedural incentives

- Birthday cards (Bonk, 2010; Frank, Nader, Zive, Broyles and Brennan, 2001; Leonard et al., 2003)
- Annual drinks reception to report results (Bonk, 2010)
- Same researcher throughout study (Gillis et al., 2001)
- Reminders (Booker et al., 2011, Leonard et al., 2003; Robinson et al., 2007)
- Choice of how and when to participate (Marcantonio, et al.; 2008, Mein et al., 2011)
- Manner and perceived credibility of researchers (Nicholson, Coyler and Cooper, 2012; Robinson et al., 2007)
- Project updates/newsletters (Leonard et al., 2003)

DISINCENTIVES

Intrinsic disincentives

- Lack of faith in researcher (Marcantonio, et al., 2008)
- Suspicion or anxiety about the study (Bonk, 2010; Lennox et al., 2005; Nicholson et al., 2012)

Extrinsic disincentives

- Lack of time (Brodaty et al., 2013; Nicholson et al., 2012)
- Travel (Beadle-Brown et al., 2012; Marcantonio et al., 2008)
- Time required (Barton et al., 2012; Bonk, 2010)

Procedural disincentives

- Excessive paperwork (Brodaty, et al., 2013)
- Inadequate explanation of research (Beadle-Brown et al., 2012; Brodaty, et al., 2013, Nicholson et al., 2013, Robinson et al., 2007)
- Concerns re privacy of personal data (Kirkland et al., 2009)

2.6 RECRUITMENT AND RETENTION OF ADULT PARTICIPANTS FOR LONGITUDINAL AUTISM SPECTRUM RESEARCH

As noted earlier, no literature was located that has addressed in any detail the recruitment and retention of adult participants for autism spectrum research.

Of the 18 identified articles reporting on results drawn from longitudinal studies involving adults on the autism spectrum as participants, 15 of these articles drew on data from participants who were initially recruited into the longitudinal study in childhood. Thus, these 15 studies provide no insights into techniques for recruitment and retention of adults on the autism spectrum (see Section 7, References for a separate listing of these 18 articles). Magiati, Tay and Howlin (2014) also conducted a systemic review of longitudinal follow-up studies of the cognitive, language and social behavioural outcomes for adults on the autism spectrum. However, each of the 25 studies examined in the review had also initially recruited the participants as children.

Of the remaining three studies, Gerber et al. (2011) make no reference to the recruitment or retention of participants. Both Cederlund, Hagberg, Billstedt and Gillberg (2008) and Madriaga (2010) describe the recruitment approaches adopted in their work but do not examine the effectiveness of participant recruitment nor any factors influencing the participants' decisions to take part in these studies.

Although not a longitudinal study, Balfe and Tantam (2010) examine the living, employment and psycho-social situation of 42 adults and adolescents with Asperger's Syndrome. Describing the strategies employed by the study to recruit potential respondents from both the adolescent and adult populations, they note that techniques that may be effective in recruiting younger children are not necessarily suitable for the recruitment of adults and school leavers as "*adults and older adolescents are not 'captive populations' in the same way that children are.*" (Balfe and Tantam, (2010, p. 2). They claim their study to be original in its approach to recruitment, as instead of recruiting through charitable organisations or health/treatment clinics, they employed a general media awareness campaign using posters, articles in local newspapers, and information distributed via social work, employment and disability care networks. However, they do not examine any factors influencing the participants' decisions to take part in the study.

Reporting on a recent study of ten higher education students on the autism spectrum, MacLeod, Lewis and Robertson (2014) describe using participatory research methodology to overcome barriers to participation faced by these participants in dealing with a neuro-typical world. They conclude that this approach was successful in engaging participants. They note that, for various reasons, when given a choice of how to engage with the study most participants opted for face-to-face interviews. They also observed the participants' high degree of interest in research about the autism spectrum, reporting that participants expressed the wish to improve understanding of autism and help others, demonstrated commitment to the project, and viewed themselves as "potential agents of change" (Macleod et al., 2014, p. 47).

Thus, a comprehensive examination of factors influencing the recruitment and retention of adult participants into research about autism spectrum is still open for investigation. In particular, the possible motivators and barriers to participation in research for people on the autism spectrum are yet to be identified and examined in any depth.

3. Research Design

3.1 RESEARCH QUESTION

In seeking to establish an understanding of the range of factors that may influence the recruitment and retention of adult participants into research about the autism spectrum, the initial design of this study focussed on identifying those factors that would either act as motivators, or barriers to participation in longitudinal autism spectrum research for adults (both on and not on, the autism spectrum).

3.2 RESEARCH METHODS

The study employed a range of participant recruitment methods and both quantitative and qualitative methods for data collection and analysis.

3.2.1 Participant numbers and demographics

The study investigated the views of a total of 167 participants. Participants were mainly from major Australian cities (Sydney, Melbourne, Brisbane and Perth), with a smaller proportion from rural and regional areas.

All participants were adults (defined for this study as aged 18 years and over).

Participants were recruited in four categories:

1. Adults diagnosed with high functioning autism/Asperger's Syndrome (HFA/AS)
2. Adults diagnosed with an autism spectrum disorder and an intellectual disability (ASD+ID)
3. Carers of ASD+ID adults (Carers)
4. Neuro-typical adults (NT).

No screening was conducted for age or gender either within or between participant groups. Points to note with reference to the age and gender balance in the sample are:

- There is a 4:1 male/female bias in ASD diagnosis reported in the literature (Auyeung, Lombardo, Knickmeyer and Baron-Cohen, 2013) and a 4.62: 1 male/female bias reported for participation in autism spectrum research studies (Watkins, Zimmermann and Poling, 2014). In this study, we found a 1.7:1 male/female bias for those diagnosed with HFA/AS suggesting that females were more likely to volunteer to participate.
- In this study, carers of ASD+ID were found to be more likely to be female.
- The relatively lower number of ASD+ID participants and their Carers reflects the relative difficulties encountered in identifying and recruiting individuals within these categories to participate in research.

TABLE 2. TOTAL NUMBER OF PARTICIPANTS, BY PARTICIPANT CATEGORY, GENDER AND AGE

	MALE	FEMALE	GENDER UNSPECIFIED	TRANSGENDER	TOTAL PARTICIPANTS	AGE RANGE	MEAN AGE
HFA/AS	39	23	0	0	62	18 - 78	36
ASD+ID	13	2	0	0	15	18 - 58	25
CARERS	3	12	2	0	17	25 - 63	44
NT	22	35	15	1	73	19 - 62	32
TOTAL	77	72	17	1	167	18 - 78	34

Apart from age and gender, no demographic data were recorded for any other participant attributes such as ethnicity, employment status, socio-economic status or place of residence.

3.2.2 Recruitment

A range of methods were used to recruit participants into the study:

- Posting of information about the study on social media (Twitter, Facebook) via autism service providers, autism community networks and autism support groups; and other autism research groups, centres and networks
- Posters about the study displayed at sites of autism-related organisations (Appendix 1)
- Posting of information about the study on the websites of autism service providers, autism community networks, autism support groups; and other autism research groups, centres and networks
- Contact with individual potential participants via community- and university-based disability support services, autism-related social groups and carer networks
- Presentations given to autism and disability support groups, providing information about the study and how to participate
- Contact with individual potential participants by individual psychologists who specialise in autism-related services
- Promotion of the study via social media and personal approaches to individual potential participants by individuals already recruited to the study who were active, well-connected and well-known as advocates in the autism/Asperger's community
- Generic information about the study to individuals listed on the research participant registries held by the research study partner organisations
- Personal approaches to participants from previous autism-related research studies who had consented to being contacted for participation in futures studies.

Screening

On indicating their willingness to participate in the study, each participant was screened by the researchers for inclusion in the study. A screening questionnaire (Appendix 1) was used to qualify each participant based on:

- the participant's place of residence (Australia only)
- age (18+ years only)
- any self- or proxy-reported diagnosis for an autism spectrum disorder or neuro-typical status
- any self- or proxy-reported diagnosis for an intellectual disability
- any ASD+ID Carer responsibilities.

3.2.3 Data collection

The study employed a number of methods of data collection:

- Attendance at a focus group
- An individual or small group interview, conducted either face-to-face or by telephone
- An online survey.

Data collection was conducted from May to July 2014**.**

Focus groups and interviews

Seventeen focus groups sessions and 17 interviews were conducted from May to July 2014 in Sydney, Melbourne, Bendigo, Brisbane and Perth with a total of 129 participants.

TABLE 3. FOCUS GROUP AND INTERVIEW PARTICIPANTS, BY PARTICIPANT CATEGORY, GENDER AND AGE

CATEGORY	MALES	FEMALES	TRANSGENDEF	TOTAL NO. OF PARTICIPANTS	AGE RANGE	MEAN AGE
HFA/AS	34	19	0	53	18 -78	37
ASD+ID	13	1	0	14	18 - 38	23
CARERS	3	12	0	15	25 - 63	44
NT	22	24	1	47	19 - 62	30
TOTAL	72	56	1	129	18 - 78	33.5

TABLE 4. FOCUS GROUP AND INTERVIEW PARTICIPANTS, BY STATE

STATE	FOCUS GROUPS	INTERVIEWS	TOTAL NO. OF PARTICIPANTS
New South Wales	34	0	34
Victoria	34	4	38
Queensland	21	6	27
Western Australia	21	11	33
TOTAL	110	21	131

The focus groups, involving a total of 110 participants, ranged in size from three to 12 participants, with a median size of six.

Interviews, either individual or small group, were conducted with 21 participants where:

- the participant indicated that they were unable to or did not wish to attend a focus group with a larger number of people; or
- it was judged by the researcher that based on the communication style and cognitive abilities of the participant, an individual or small group interview would be more effective than participation in a focus group.

In focus group sessions and interviews, researchers collected data via three activities:

1. A card sort exercise (Appendix 3), which was completed by each participant as an individual activity. This yielded quantitative data on the likelihood of certain factors and possible incentives motivating, enabling or inhibiting the participant’s taking part in a future longitudinal autism spectrum research study.
2. A questionnaire (Appendix 3), completed by each participant as an individual activity. This yielded quantitative data on the participants’ attitudes to research and preferences for modes of participating in research.
3. A discussion facilitated by the researcher, based on the participants’ responses given in the card sort exercise and the questionnaire (Appendix 3). This yielded qualitative data on the participants’ attitudes, reasoning, motivations and preferences about a range of possible factors that were likely to motivate, enable or inhibit them to take part in a future longitudinal autism spectrum research study.

Research instruments

Copies of the research instruments used in the focus group sessions and interviews (card sort exercise procedure and materials, questionnaire and discussion points) are in Appendix 3.

The questions and discussion points included in these instruments were generated from the listing of commonly-identified incentives and disincentives for participation in longitudinal research (see Table 1) developed from the literature review conducted for this study (see Section 2 of this report).

All focus group sessions and interviews were audio-recorded with the exception of three cases where interviewed participants did not consent to audio-recording or it was not technically possible to make an audio-recording. In these cases, researchers made written notes of any extended responses provided by the participant.

Online survey

Approximately six weeks after the start of recruitment, it was decided to incorporate an online survey into the study.

This decision was based on feedback from potential participants during the initial stages of the recruitment process. This feedback indicated that by initially limiting recruitment to people willing or able to participate in either a focus groups or an interview, the study was potentially only appealing to those people who were either willing to engage in or actively seeking social engagement with other similar people or the researchers. Thus, the study was possibly excluding those people who did not want to engage within a social setting.

This was evidenced by numerous responses from potential participants who were willing to contribute but who asked to do so in an online format rather than by attending a focus group. It is also supported by the literature on the autism spectrum and social interaction, which has established that significant numbers of people on the autism spectrum prefer a low level of social engagement in groups, particularly with people with whom they are not familiar, and also demonstrate a high level of comfort with communication in an online environment.

The online survey incorporated the questionnaire used in the focus groups and interviews and also replicated the card sort exercise in a questionnaire format, with prompts provided within the survey for the participants to write additional open-ended comments or explanations about their responses.

The survey was available online for a period of two weeks in June 2014 and was completed by a total of 38 participants across all categories.

TABLE 5. ONLINE SURVEY PARTICIPANTS, BY PARTICIPANT CATEGORY, GENDER AND AGE

CATEGORY	MALES	FEMALES	GENDER NOT SPECIFIED	TOTAL NO. OF PARTICIPANTS	AGE RANGE	MEAN AGE
HFA/AS	5	4	0	9	22 - 51	32
ASD+ID	0	1	0	1	58	58
CARERS*	0	0	2	2	*	*
NT	0	11	15	26	24 - 60	41
TOTAL	5	16	17	38	22 - 60	43

* No data on age or gender

3.2.4 Data analysis

Quantitative data collected via participants' responses in the card sort exercise, questionnaire and online survey were collated and tabulated, and a frequency analysis produced for each question asked of participants, cross tabulated by participant category, and mode of participation (i.e., focus group/interview or online survey).

Commentary provided by participants in focus group discussions, interviews and via the online survey extended responses was transcribed from the audio recordings and transposed from the online survey data, and then coded for thematic analysis.

3.3 ETHICAL CONSIDERATIONS

3.3.1 Ethics approvals

Ethics approval to conduct this study as outlined in this report was initially obtained from La Trobe University, after which approval was obtained from other participating organisations:

- La Trobe University (Approval 14-005)
- Autism Spectrum Australia (Approval 1141)
- The University of Queensland (Approval 201400500)
- Curtin University (Approval HR 73/2014).

3.3.2 Inclusion

The researchers sought participation from the broadest possible spectrum of the sample populations by a number of methods:

- Identifying people on the autism spectrum with an intellectual disability as a separate category
- Allowing and encouraging guardians/carers of people with autism and an intellectual disability to facilitate the ASD+ID participants' engagement and involvement in the study
- Offering a range of methods for participation, including focus groups, one-on-one or small group interviews, and an online survey
- Using language in project communications that was inclusive and non-stereotyping
- Incorporating visual aids into materials used for data collection in focus groups and interviews, to facilitate dialogue for participants with differing communication preferences and/or abilities, such as those on the autism spectrum with an intellectual disability
- Limiting focus group size, to provide environments that were inclusive and comfortable for participants preferring lower levels of sensory stimulation and social interaction
- Selecting locations that minimised the amount of travel required for the majority of participants.

3.3.3 Consent

Individuals identified through the recruitment process received a Participant Information Statement (Appendix 2) and a Consent form (Appendix 2).

A completed consent form was required from all participants prior to participating in a focus group, interview or online survey. Guardian/carer written consent (Appendix 2) was also required for participants with an intellectual disability, and from those guardians/carers who accompanied any HFA/AS participants to a focus group or interview.

Participants taking part in focus groups or interviews were informed in writing of their right to withdraw from active participation in the project at any time, and to request that individually identifiable data arising from their participation not be used in the research project, provided that this right was exercised within four weeks of the completion of their participation in the project. To facilitate this they were provided with a Withdrawal of Consent form (Appendix 2). Participants in the online survey were not identified thus there was no provision for their data to be withdrawn. No participants withdrew from the study.

3.3.3 Incentives

All focus group and interview participants were provided with a $20 or $25 shopping voucher at the end of each session. Participants at these sessions also received free refreshments. Some participants were also reimbursed for travel expenses.

3.3.4 Privacy and confidentiality of personal data

Prior to their participation, participants were informed in writing about the methods of data collection and storage. Researchers also obtained verbal consent at each focus group and interview for any audio-recording made during the session and advised participants when the audio-recording was stopped. No individuals are named in this research report and findings are reported at a group level only. All paperwork, electronic files and audio recordings will be kept in a lockable filing cabinet or on a password-protected computer at the participating institution associated with the data collection. Only the research team will have access to this information. Data will be retained for at least five years following completion of the project or five years after the publication of any journal article, after which it will be destroyed (shredded or deleted).

4. Findings

A key finding of this study is that the motivators, inhibitors and enablers of participation differ distinctly and significantly between each category of participants examined in this study.

To provide an overview across all participant categories, assist with comparisons between participant categories and enable insight into specific key motivators, inhibitors and enablers across all participant categories, this section initially provides an overview of the findings in:

Section 4.1	Summary of findings and in five summary tables
Table 6	Summary of motivators, inhibitors and enablers common to all participant categories
Table 7	Summary of motivators, inhibitors and enablers for HFA/AS participants
Table 8	Summary of motivators, inhibitors and enablers ASD+ID participants
Table 9	Summary of motivators, inhibitors and enablers for Carers
Table 10	Summary of motivators, inhibitors and enablers for NT participants.

The initial summary is followed by a detailed analysis of findings for each of the four participant categories:

Section 4.2	HFA/AS participants
Section 4.3	ASD+ID participants
Section 4.4	Carers of ASD+ID participants
Section 4.5	NT participants.

Key lessons learned from the recruitment process employed in this study are also applicable to optimising recruitment for future autism spectrum research studies:

Section 4.6	Recruitment methods.

Extrinsic rewards

A topic of particular interest to researchers seeking to recruit and retain participants for their research studies is the use of extrinsic rewards. Appendix 4 provides a summary of participant responses across all categories to a number of specific questions in this study about extrinsic rewards (such as gifts, cash and vouchers).

4.1 SUMMARY OF KEY FINDINGS

The results showed that the factors influencing participation in longitudinal autism spectrum research can be categorised as:

- Motivators - *the reasons why I participate; the outcomes I am seeking from my participation*
- Inhibitors - *factors that discourage or prevent me from taking part*
- Enablers - *factors that make it easier for me to take part.*

One size does not fit all

The results indicate that the motivators, inhibitors and enablers of participation differ markedly between (and in some cases within) each participant category. Some factors identified as motivators for certain participants were found to be either inhibitors or enablers for others. The most noticeable example of this was participants' divergent attitudes about any social interaction. For some participants, the opportunity for social interaction was a motivator. For others, any requirement to mix with other people was found to lessen their propensity to participate.

Motivators

While helping others was found to be a key motivator across all participant categories, it was clear that participants also sought 'personal benefit' from their participation.

What participants considered to be a 'personal benefit' differed markedly between participant categories. For adults on the autism spectrum, 'personal benefit' was viewed through the lens of their individual preferences and needs, and their desire for improved opportunities to engage in all aspects of life in meaningful and rewarding ways. Carers of adults on the autism spectrum interpreted 'personal benefit' in terms of a benefit to their child rather than to themselves.

The results provided evidence that most participants were keen to contribute to and engage with autism spectrum research projects that will lead to practical programs and initiatives to enable people on the spectrum to enjoy a greater degree of acceptance, involvement and opportunities to lead fulfilled lives in the wider community.

Participants indicated a desire, in varying degrees and various ways, to draw comfort, a sense of worth, and inspiration from belonging to a research project community. Being kept up-to-date with the progress of the research project and how the participant's input had contributed to the research outcomes was found to be an important part of engendering this sense of belonging.

Inhibitors

Key inhibitors to participation were found to be the inconvenience of time and travel required; and any insensitivity shown in the research process to an individual's personal needs and preferences for engaging with the world and others.

Enablers

Findings showed that maximising choice for all aspects of participant involvement can act as a vital enabler of participation, as this choice allows for the breadth and idiosyncratic nature of the personal preferences and needs of individuals across the autism spectrum.

Participants also indicated that the reimbursement of any out-of-pocket expenses they incurred as part of their participation (such as travel costs) is an effective and valued enabler of their participation.

Extrinsic rewards

While participants were welcoming of any acknowledgement of the time and effort that they may contribute to a research project, the study found that the use of financial and other extrinsic rewards is likely to be problematic as a means of encouraging people to participate in longitudinal autism research studies.

While extrinsic rewards were an enabler to taking part for some participants, others participants considered that extrinsic rewards would act as an inhibitor to their participation. Thus, in seeking to optimise participation, the use of financial and other extrinsic rewards needs to be approached with care and sensitivity.

TABLE 6. SUMMARY OF IDENTIFIED MOTIVATORS, INHIBITORS AND ENABLERS COMMON TO ALL PARTICIPANT CATEGORIES

Motivators – WHY WE WILL PARTICIPATE	Inhibitors – WHAT WILL DISCOURAGE US	Enablers – WHAT WILL MAKE IT EASIER FOR US	Motivator/Enabler for some but Inhibitor for others
Opportunities to contribute to research that will effectively advance the world's understanding of autism and acceptance of people with autism, and will provide more opportunities for people with autism Being kept up-to-date with the research project, to know progress and outcomes Belonging to a project/community/sense of connection to the project	Travel- time. distance, cost, hassle Sensitivity re psychological/mental health issues	Choice and flexibility for all aspects of my involvement, e.g.: – how, when and where to participate – involvement in social interactions – opt-in for communications – options for mode of communication, i.e. digital/print – opt in for rewards/incentives, publicity, disclosure – options for any rewards/incentives Extrinsic rewards as acknowledgement and show of appreciation for my contribution and my time given Monetary reimbursement for the costs of participation, e.g.: travel, child-minding expenses Reminders for research project activities	Any requirement for social interaction Extrinsic gifts, e.g., branded gifts, payment for enlisting friends, birthday cards – *Inhibitor for some:* perceived as a waste of research resources and/or tokenism; – *Enabler for some:* perceived as a thoughtful and kind personal touch

TABLE 7. SUMMARY OF IDENTIFIED MOTIVATORS, INHIBITORS AND ENABLERS FOR PARTICIPANTS WITH HIGH FUNCTIONING AUTISM/ASPERGER'S SYNDROME

Motivators – WHY I WILL PARTICIPATE	Inhibitors – WHAT WILL DISCOURAGE ME	Enablers – WHAT WILL MAKE IT EASIER FOR ME	Motivator/Enabler for some but Inhibitor for others
Engaging with and contributing to research that will effectively advance the world's understanding of autism so as to improve the opportunities for adults living with autism to engage in all aspects of life in meaningful and rewarding ways and be adequately recognised for their abilities and contributions Opportunities to have my say, to have my voice heard, to explain myself fully, to be understood Opportunities to participate as an equal, skilled and valued partner in the research Opportunities to interact and communicate with the research team, about autism spectrum research and the research project Being kept up-to-date with the research project, to know progress and outcomes, and to see and compare others' responses in the research study with my own Opportunities to engage and exchange views and information within an autism spectrum community: e.g. via project website	"One size fits all" Insensitivity to autism spectrum issues unsuitable venues (noise, light, sensory issues) events with large numbers of people neuro-typical misinterpretation or misunderstanding of autism spectrum viewpoints modes of data collection that do not allow for autism spectrum concerns, AD cognition, autism spectrum communication styles, autism spectrum social preferences e.g. labelling of people on spectrum as having a disorder Tokenism, e.g.: – birthday cards – (for some) menial tasks – gifts, esp branded items – payment for enlisting friends (Perceived) waste of research resources, e.g.: – gifts, esp. branded gifts – payment for enlisting friends Travel – distance and time – cost – mode – anxiety	Choice in all aspects of my involvement to cater for my individual preferences, e.g.: – how, when, where to participate – involvement requiring social interactions – opt in for communications – options for mode of communication, i.e. digital/print – opt in for rewards/incentives – options for any rewards/incentives. In all aspects of my engagement with the research process, respect is accorded to my viewpoints, individual needs, concerns, ways of being; and my capacity to contribute as a valued and active partner in the research Extrinsic rewards as acknowledgement and show of appreciation for my contribution and time Monetary reimbursement for the costs of participation, e.g. travel, child-minding expenses Access to research team, to clarify my responses to research questions and methods Reminders for activities Venues cater for autism spectrum sensitivities Modes of data collection are sensitive to autism spectrum cognition, communication styles, social interaction preferences, e.g. researchers trained in autism spectrum interactions and issues	MOTIVATES SOME, INHIBITS OTHERS Any requirement for social interaction Social interaction in large groups FOR SOME ONLY, not an issue for others – Disclosure – Publicity – Mental health – Physical health

TABLE 8. SUMMARY OF IDENTIFIED MOTIVATORS, INHIBITORS AND ENABLERS FOR PARTICIPANTS WITH AUTISM AND AN INTELLECTUAL DISABILITY

Motivators – WHY I WILL PARTICIPATE	Inhibitors – WHAT WILL DISCOURAGE ME	Enablers – WHAT WILL MAKE IT EASIER FOR ME	Motivator/Enabler for some but Inhibitor for others
Explicit acknowledgement of and recognition for me (that I am important and valued), e.g.: – birthday card/gift – gifts, rewards, incentives that are specific to my personal interests – newsletter article and photo about me Knowing and finding out what is happening (now and next) and who is doing what Opportunities to make friendships Participation with/by a friend or family member Research will lead to a greater acceptance and understanding by the general public of ASD+ID people and my needs (Carer): Opportunities for my ASD+ID children to learn more about themselves (Carer): Opportunities for my ASD+ID children to acquire work-related skills and experience	The project does not allow or enable my carer to participate with/for me Research does not cater for participation that fits my routine, cognition or communication skills No established relationships of trust with research team (Carer) Any potential for harm to self-esteem or sense of safety for ASD+ID child Mental health Travel and travel costs (a carer issue, not my issue) Research activities disrupt my regular routine	ESSENTIAL Support and participation of my Carer Research is designed and conducted with sensitivity to my particular needs: – Flexibility in how, when and where I participate – Researchers have established relationships of trust with me – Project offers the capacity to fit the research activities into the participant's normal daily routine and environment where a sense of security, safety and calm for me is assured. – Research is conducted in my own environment Carer can contact research team for: project liaison, project information, explanations about my needs Adequate time to complete activities and provide responses	FOR SOME ONLY, not of interest for others – Social interaction with others similar to me

TABLE 9. SUMMARY OF IDENTIFIED MOTIVATORS, INHIBITORS AND ENABLERS FOR CARERS OF ASD+ID ADULTS

Motivators – WHY I WILL PARTICIPATE	Inhibitors – WHAT WILL DISCOURAGE ME	Enablers – WHAT WILL MAKE IT EASIER FOR ME	Motivator/Enabler for some but Inhibitor for others
Finding knowledge and practical solutions that will improve the well-being of and life choices for my ASD+ID child and for other people Being kept up-to-date with Information about: – autism spectrum knowledge and ASD+ID services – the research project Opportunities to share information and experiences with others in a similar situation: e.g.: – drinks function – project website	Carer responsibilities – time and routine Travel – carer responsibilities My sensitivity re my child's psychological/mental health issues and the potential for my child to be upset by the research process	Choice of how, where and when to participate, to fit in with carer responsibilities and routine Reimbursement of costs of participation, e.g.: – travel – child-minding expenses Cash payments and/ vouchers Communication, liaison, reminders organised by the research team	FOR SOME ONLY – Negative discussions about ASD+ID – Lack of regular access to telephone or internet

TABLE 10. SUMMARY OF IDENTIFIED MOTIVATORS, INHIBITORS AND ENABLERS FOR NEURO-TYPICAL PARTICIPANTS

Motivators – WHY I WILL PARTICIPATE	**Inhibitors – WHAT WILL DISCOURAGE ME**	**Enablers – WHAT WILL MAKE IT EASIER FOR ME**	**Motivator/Enabler for some but Inhibitor for others**
An easy way to do something to help others, esp. my family members living with autism Opportunities to learn more about the autism spectrum, especially how to understand, help and interact with my family members living with autism Opportunities for learning for self-awareness and personal development Seeing the outcomes of their own contributions and comparing these to others Belonging to a project/community/sense of connection to the project Acknowledgement and appreciation of my contributions	Inconvenience: e.g.: – time for participation – travel time, distance, hassle – requirement to participate in a particular way Travel – distance – time – cost – mode – inconvenience Publicity for self	Choice for how, when and where to participate Reimbursement of travel costs Choice for project communications – format and opt-in/out Single hub for all information and liaison for the project e.g. project website	MOTIVATOR OR ENABLER FOR SOME ONLY Extrinsic rewards and incentives as acknowledgement and appreciation of my contributions, e.g.: – gift vouchers – gifts - consumables ENABLER FOR SOME, INHIBITOR FOR SOME Branded gifts, payment for enlisting friends, birthday cards – *Inhibitor for some:* perceived as a waste of research resources and/or tokenism; – *Enabler for some:* perceived as a thoughtful and kind personal touch FOR SOME ONLY Opportunities to participate with a friend or relative Opportunities to be involved with the project behind the scenes Sharing information and experiences wrt my autism spectrum child/relative

4.2 PARTICIPANTS WITH HIGH FUNCTIONING AUTISM/ASPERGER'S SYNDROME (HFA/AS)

4.2.1 Engagement with autism spectrum research

As shown in Table 11, the factor for which HFA/AS participants expressed the strongest level of support as a motivator for their participation was their desire to engage with and contribute to research that will effectively advance the world's understanding of people on the autism spectrum.

TABLE 11. ENGAGEMENT WITH AUTISM SPECTRUM RESEARCH
HFA/AS participants

STATEMENT	MORE or MUCH MORE LIKELY TO PARTICIPATE
When this research is completed, it is likely to benefit other people, especially those with autism spectrum.	85.5%
We will send you a copy of the final research report when the project is complete.	80.3%
It is likely that this research will help you learn more about autism spectrum.	77.4%
It is likely that this research will help you learn more about yourself.	74.2%
There will be a special website for the research project, where you will be able to ask questions, leave feedback, and engage in online discussions with the research team and other participants.	66.2%
You will receive a printed newsletter from the project team twice a year, letting you know how the research is going.	59.6%

This was also evident in their commentary, which emphasised their strongly held opinion that the purpose of autism spectrum research should be to improve the opportunities for adults living with autism to engage in all aspects of life in meaningful and rewarding ways and be adequately recognised for their abilities and contributions. The participants voiced their strong support for research that is focused on producing practical programs of support and enablement of people on the autism spectrum.

Thus, their discussions spoke of how research about the autism spectrum could benefit other people, particularly those on the autism spectrum, by developing an evidence-based knowledge base that will:

- enable greater acceptance and understanding of the strengths, capabilities and issues facing people with autism;
- address misperceptions and stereotypes of what it is to live with autism; and
- make it easier for future generations living with autism (including their own children).

"There is lack of public understanding about what it is to be an Aspie, and it would be good if after this research, we can get that message (to the general public)."

"To help to dispel myths about people living on the autism spectrum, for example, being like Rainman, having genius powers; those stereotypes about the memory and mathematical abilities of autism spectrum people."

"There is a gap in public policy and debate in that adults with Aspergers are just not on the radar."

"There needs to be more support for adults and my goal in being involved would be to see programs put in place to provide a lot more support for adults with autism."

"I think that most of us are motivated on that one (i.e., because we want people to know what our lived experience is) because we have to struggle in a world where we don't fit."

These participants expressed a vital concern that in all aspects of their engagement with the process of autism spectrum research, due respect should be accorded to their viewpoints; to their particular individual needs, concerns and ways of being; and to their capacity to contribute as valued and active partners in the research.

For example, in a number of the focus groups, HFA/AS participants advocated for mechanisms and processes whereby people with autism could participate as key decision-makers and implementers of autism spectrum research studies. This was based on their concern that their views are commonly misrepresented, misinterpreted and misused by a neuro-typical world and specifically neuro-typical researchers. Associated with this topic, a number of these participants indicated they were skilled, qualified or interested in undertaking formal academic research.

“I think the only way to do this successfully is to use the methodology of participatory action research, and the reason for that is that this theory of mind thing goes both ways. Neuro-typical people think we don't understand you, but … you don't understand us either, and so we tend to get misrepresented a lot. So I think that the only way that this can be done successfully is if you have the community involved in building the questionnaires and building the focus groups and everything, not just like this (i.e., only responding to questions put by the research team). And having the right of veto, analysing the data, and having feedback, being really involved in it. We're not dumb, in fact a lot of us are researchers ourselves, it would be much better if it was Aspie run. It's our voice.”

“If you (neuro-typical researchers) do the abstracting out of the information we give, and it gets misinterpreted. So if we (autism spectrum research participants) did it, and extracted the information properly, then instead of misunderstanding us, it would be (in our voice).”

“The CRC is critical to that (influencing public debate and changing public attitudes and policy). If it (the CRC research) goes wrong and it misrepresents us, there are going to be a whole lot of Aspies with sharp tails (and sharp tongues) so for goodness sake, let's get it right.”

"If research really is a two-way business, if it is involving input, I would like to see some consumer input. (in that, in the area of mental health, we are the consumers of the govt programs and services). There is a lot of lip service paid to consumer input, I don't know how much of it goes on in research ... I would like to see consumer input (in research) from the people who have a label ..."

“There is a need for people on the spectrum to be consulted about the research before the research starts. Some research that I have taken part in has been good and you don't feel like a lab rat. Getting a say in some of the processes and how policies are set up is good.”

“This relates to guidelines into research in autism put out by ASAN (Autistic Self Advocacy Network) advocating for an holistic approach to involvement from people on the spectrum ...in all aspects of the research. It is generally considered by people on the spectrum that a lot of research into the so-called "cure" (for autism)" is somewhere between pointless to offensive, whereas things that we consider to be important, such as lowering barriers to employment for us in the general community don't get a look in, even though they are probably a lot cheaper to implement ..."

“A certain percentage of researchers and decision-makers in the project should be people on the spectrum.”

“I have knowledge in research and in biomedical science and population health, plus the knowledge of being as Aspie, so I would like the opportunity to contribute that knowledge.”

Concern for being treated with tokenism rather than as equal and skilled partners in any research project was also reflected in the commentary of some HFA/AS participants about the opportunity to be involved with a research project ‘behind the scenes’.

“I don’t want token involvement.”

“We want to be at the frontline of the project.”

“I am not interested in admin jobs; this is relegating us to a position that is not central to the project.”

“I do not want menial boring admin tasks - left over, that no-one else wants to do.”

“It needs to be clear upfront about what is being offered and what’s in it for the participant.”

“I don't want to be cheap labour.”

“I don’t want to be taken advantage of.”

However, other HFA/AS participants were keen for any opportunity and some were specifically attracted by the ‘behind the scenes’ nature of any work with the project.

“Being involved would be a way that we could show our appreciation for the research.”

“Any chance I get to use my knowledge, skills, capabilities and experience is a chance to improve my skills.”

“If I'm still job seeking at the time, I may entertain the idea of doing volunteer work if offered.”

“Happy to do the monotonous and boring tasks, work through them and tick them off when completed.”

“Some like admin tasks, so as not to be in the limelight.”

For most HFA/AS participants, participation in research is an individual, personal engagement. Thus, as shown in Table 12, participation by a friend or family member was likely to motivate some HFA/AS participants to take part in a research project but most did not consider it would make them more likely to participate.

TABLE 12. PARTICIPATION OF FAMILY AND FRIENDS
HFA/AS participants

STATEMENT	AGREE	NEITHER	DISAGREE
I would be more likely to take part in a research project if my friends or family members were also taking part.	31.1%	16.4%	52.4%

Amongst HFA/AS participants, their desire to support autism spectrum research was tempered by a degree of suspicion regarding large-scale research projects.

TABLE 13. SUSPICION ABOUT LARGE RESEARCH PROJECTS
HFA/AS participants

STATEMENT	AGREE	NEITHER	DISAGREE
I tend to feel suspicious about the motives behind large research projects.	26.2%	19.7%	54.1%

While 47.5% of HFA/AS participants expressed a concern about their privacy when taking part in research (Table 14), only 14.5% indicated that the requirement to provide personal, confidential information would make then less likely to participate in research, though their level of concern was not widely disparate from that of all participants in this study.

TABLE 14. CONCERNS ABOUT PRIVACY
HFA/AS participants

STATEMENT	AGREE	NEITHER	DISAGREE
I tend to feel concerned about my privacy when taking part in research.	47.5%	8.2%	44.3%
STATEMENT	MORE or MUCH MORE	NO DIFFERENCE	LESS or MUCH LESS
As part of the research, we may ask you for information that is private or sensitive (e.g., about your health or your personal relationships). This information will stay confidential and will not be shared.	37.1%	48.4%	14.5%

The chance to have their photograph and a brief article about themselves printed in our project newsletter (Table 15) was not considered as a motivator for participation for most HFA/AS participants. The main reasons were their desire for privacy, issues regarding public disclosure of their diagnosis, the specific request for no photographs, and a concern that their personal stories would be misinterpreted or misrepresented by neuro-typical writers who did not understand them, or misused by others to hurt them in some way. Others saw the benefits it would bring for autism spectrum research and the autism spectrum community.

TABLE 15. RECOGNITI0N
HFA/AS participants

STATEMENT	MORE or MUCH MORE	NO DIFFERENCE	LESS or MUCH LESS
You will be given the chance to have your photograph and a brief article about yourself printed in our project newsletter.	27.4%	32.3%	40.4%

"You would not even get me to smile at the camera."

"I'm not keen for any kind of fame unless I get rich first and can defend myself properly from the backlashes that it brings. I work extremely hard to ensure that people who have reacted negatively to me will never see or hear from me again and it would be a shame to ruin that work if I was not in a position to keep those bridges of influence closed at my end."

"I don't like photographs. Personal information once given out can't be taken back and has been used against me before."

"I don't want the disclosure, this is all very private for me, I'm just not ready for the disclosure."

"The person writing the article would need to be aware and sensitive to autism spectrum issues."

"It puts a human face to the research, acknowledges us as people, put a face to it, not just being a number."

"It is good to have stories of real, normal people, as this is what changes attitudes and helps to dissipate stereotypes of what autism spectrum people are like."

"My workplace and my friends already know about my Aspergers, It's not a secret, it's public knowledge, so this would not impinge on my privacy, and I am happy to share my story if that helps get other people involved in the research."

The offer to provide a referral to a psychologist in the event that the participant experienced distress or anxiety as a result of taking part in the research (Table 16) produced divergent views amongst HFA/AS participants. Some expressed support and gratitude for this service; some said they had no need for this, while others expressed antagonism and suspicion.

TABLE 16. STRESS AND ANXIETY FROM PARTICIPATION
HFA/AS participants

STATEMENT	MORE or MUCH MORE	NO DIFFERENCE	LESS or MUCH LESS
In the unlikely event that you experienced distress or anxiety as a result of taking part in the research, we would refer you to a psychologist for advice and support.	37.1%	33.9%	29.0%

"This shows that you care, and is respectful to the participants."

"It's good to have someone available who knows how to handle things professionally in the right way, who knows what to do."

"It is unlikely I would not experience some level of anxiety, but I am quite used to coping with it."

"I have no need for this, I have my own psych I see regularly and tell everything to two close friends."

"I really don't like being told how I think and behave by someone who is wired differently to me and doesn't understand me, so I would be not interested unless it was an Aspie psych."

"I dislike the idea that if there was an issue that arose from the research participation, the problem was with the autism spectrum person."

"The only thing that might stress me out is if I find the research to be stupid."

4.2.2 Extrinsic rewards

In line with their views about participation in autism spectrum research, HFA/AS participants generally considered any extrinsic rewards to be less meaningful and relevant as motivators of their participation than the intrinsic benefits they may gain. With the exception of reimbursement for travel costs, HFA/AS participants expressed stronger support for all intrinsic benefits as motivators for participation than for any extrinsic reward that was suggested to the participants (Table 17).

TABLE 17. EXTRINSIC REWARDS AS MOTIVATORS FOR PARTICIPATION
HFA/AS participants

STATEMENT	MORE or MUCH MORE	NO DIFFERENCE	LESS or MUCH LESS
You will receive a cash payment each time you contribute to the research (i.e. once a year).	54.8%	33.9%	11.3%
You will receive a gift voucher every time you contribute to the research (i.e. once a year).	53.2%	35.5%	11.3%
Three times a year, we will send you a small gift (e.g. a pen, cap or drink bottle) to thank you for participating in our research.	37.1%	43.6%	19.4%
If you tell one of your friends about the research project and they then sign up to take part, we will send you a gift voucher as a 'thank you'.	30.7%	50.0%	19.4%
You will receive a card from the research team on your birthday.	19.4%	53.2%	27.4%
STATEMENT	AGREE	NEITHER	DISAGREE
If I am going to take part in a research project, I want to know that I will personally benefit from the research.	59.0%	11.5%	29.5%

Some HFA/AS participants expressed distaste for, or disapproval of, extrinsic rewards for participation in research. Others emphasised that although they would willingly accept extrinsic rewards, these were not the key motivation for their participation.

"It denigrates the importance of this research. If we're going to be fair dinkum about this, people have to be motivated because they want people to know what our lived experience is, that's got to be why you come along and do this."

"For me, being part of the research is enough for me, having the ability to be heard."

"I felt that the list of things on offer showed that whoever wrote them did not understand me because for me I am much more motivated by justice and by what I can contribute to the world, rather than what the world needs to do to accommodate me, and there is none of that in there, those things would be great motivators for me - how can the world value the work that we can bring, how can civil society be improved by a group of people who don't lie."

"Having the ability to meet other people who are similar to yourself is reward (for me)."

"Research advancement is of greater importance than getting money."

"For me, (participating) depends on the topic, and if it is worthwhile."

"Gifts, like touching another person, make me incredibly uncomfortable. I've become very proud of supporting myself since leaving home at 16, the only charity I cherish is the gift of understanding from those I deal with."

"I won't say no, but it is not the main motivator."

Extrinsic rewards were instead viewed as being both an acknowledgement of appreciation for the participant's contribution, and as providing some recompense for the cost of participation, such as travel and child-minding expenses, and time.

"I accept the gifts under pains. It's not the reason I do any of this. But being a practical sort of guy, who knows - it may come in handy at some point, if not I might give it to someone else … It's nice that you have offered and whether I take it or not is an option for me."

"I am just dedicated to research, but I appreciate a bit of money, it goes towards your travel costs more than anything else, something as a bonus to say thank you."

"I am unemployed and not well-off, I will take any money I can get."

"It's not about the dollar sum, I don't come in to do research because I am going to get a monetary reward, it's not about the amount, it's about the acknowledgement, such as the gift card today, it's amazing, even the fact that you were not handing out the generic ones, but thought about and asked and made the effort to go and get one that I would use, meant more that the monetary value, it's an acknowledgement of the time and effort (that we are contributing) because for me this is an effort, so knowing that there is acknowledgement is nice. It's a token of appreciation."

4.2.3 Choice

As with all of the options presented to HFA/AS participants about their participation in future research studies, there was no general category preference for certain types or modes of extrinsic rewards. Instead, HFA/AS participants indicated that what was most important to them was being offered the flexibility to choose. This would enable them to tailor all aspects of their participation according to their very individual, personal preferences, interests and needs. They expressed that they did not want to be "boxed in" to any pre-set conceptions of what may or may not appeal to them.

"It is well-meaning, but the difference for me between reward and punishment is a very fine line. Just because you think I will appreciate something, if it is something that I do not enjoy, you are punishing me, you are not rewarding me. So for me, being unemployed and on Newstart, to buy DVDS or whatever it is that suits me is a strain on my allowance, so a voucher for x amount of dollars for something I enjoy that I need financial assistance with is appreciated, and as long as it is tailored to the person so that they see it as a reward rather than you just assuming so therefore it becomes a punishment - then it is really greatly appreciated and the amount does not matter … Because I have I have an ASD, my world focuses around me, my needs focus around me and satisfying my needs focuses around me, and only I know how to satisfy to the best I can and anything that you contribute that makes that easier, I appreciate."

Some examples of this desire for maximum choice are:

- It was common for HFA/AS participants to indicate that they would appreciate being given the explicit choice to accept or decline anything that was being offered to them, whether it be an extrinsic reward (such as a gift, voucher, cash payment), a communication from the project team (such as newsletters, reports or reminders), or an invitation to an event.
- For HFA/AS participants, cash payment was generally preferred to a voucher for the reason that it offered these participants the most flexibility as to how they then used the reward.

- When asked for preferences for types of gift vouchers, while some HFA/AS participants suggested generic shopping/groceries vouchers that could be used at a range of different stores, so as to suit a spectrum of different interests and needs, others then expressed that this would not suit them.

“My interests are narrow and deep; vouchers for big stores don’t satisfy this, they are for interests that are broad and shallow, so that sort of voucher is not wow at all for me.”

“It needs to be tailored to the individual.”

“Vouchers are fine, but it needs to be something I am guaranteed to use. Prepaid Visa cards are great, then the person can use them anywhere, including online.”

4.2.4 Tokenism

In general, HFA/AS participants rejected and expressed cynicism about any engagement that suggested tokenism to them. Thus, while a segment of HFA/AS participants considered receiving a birthday card from the research team was a welcome gesture (Table 17), over half of these participants indicated that such a gesture would make no difference to their participation, while some indicated it would discourage their participation.

“I like to be acknowledged as human”; “Nice recognition and acknowledgement”; “Makes you feel warm inside.”

“If the research team have formed a relationship with me and send me a card on my birthday that is meaningful. Receiving a generic birthday greeting from people I have not met that is not meaningful.”

“I don't understand the point of doing that.”

“Is this question for real?”

“I have little to no concept of birthdays or any other 'special' days. Such a thing might elicit a positive response in my mind rarely, more likely it will be lost on me.”

Similarly, while a minority of HFA/AS participants (expressed an interest in receiving a small gift three times a year as a ‘thank-you’ for their participation (Table 17), a larger proportion indicated that it would make no difference, while some indicated that it would make them less likely to participate.

“It is practical and a small positive reminder that I participated in something.”

“This is not my reason for participating; I'm not going to do it because I get a gift.”

“It would mean less money for the research.”

“Just getting a result from the research is enough for me.”

“It is only just clutter.”

“I don't really need it.”

“Sending a pen in the mail, etc it's a waste of money.”

“Please don’t, I have particular tastes, simplistic and cubist, I have even painted and have written scores of poetry, I can’t abide gimcrackery or clutter.”

“It would be better to be reimbursed for costs of participating, such as travel expenses and babysitter.”

4.2.5 Communication and modes of participation

When considering the possible modes of engagement and formats for communications between them and the research team, HFA/AS participants expressed their interest in research, their desire for choice so as to tailor their engagement to match their individuality, and their distaste for tokenism.

Modes of participation

As with other options canvassed with HFA/AS participants, there was no general group preference for certain modes of participation. Instead, HFA/AS participants indicated that what mattered most to them was being offered the flexibility to choose (Table 18), so as to fit with their very individual, personal preferences, interests and needs. They also expressed that they did not want to be "boxed-in" to any pre-set conceptions of what may or may not appeal to them.

TABLE 18. CHOICE IN MODE OF PARTICIPATION
HFA/AS participants

STATEMENT	MORE or MUCH MORE	NO DIFFERENCE	LESS or MUCH LESS
When we ask you for information for the research, you can choose if you want to do this in person, over the phone, online, or via a questionnaire that we will post to you.	75.8%	16.1%	8.1%

"I suggest that you offer participation in multiple formats, then you will get a broader spectrum of people to participate."

Responses provided by these participants to the questions about "*How do you feel about this way of collecting information from you?*" (Table 19) and the length of time for responding to a questionnaire(Table 20*)* reflected the wide range of preferences within this participant category for engaging in research in different ways.

TABLE 19. HOW DO YOU FEEL ABOUT THIS WAY OF COLLECTING INFORMATION FROM YOU?
HFA/AS participants

	WOULD ENJOY	NOT SURE	WOULD NOT ENJOY
Face-to-face interview	76.7%	18.3%	5.0%
Focus group	68.9%	21.3%	9.8%
Online survey	70.5%	21.3%	8.2%
Paper survey	45.9%	31.1%	23.0%
Telephone interview	32.8%	41.0%	26.2%
Telephone survey	26.2%	27.9%	45.9%

TABLE 20. COMPLETING QUESTIONNAIRES
HFA/AS participants

STATEMENT	MORE or MUCH MORE	NO DIFFERENCE	LESS or MUCH LESS
If we asked you to fill in a questionnaire as part of the research, we would give you up to one month to complete the questionnaire and send it back to us.	60%	20%	20%

This divergence was based on each individual's particular needs, situation, communication and social skills, as shown in the following selection of comments from focus group discussions.

"I hate telephone calls, telephone interviews and one-on-one interviews or one-on-one meetings – it makes me nervous, I can't say much, I almost freeze; I am much better in a group with similar people, such as this focus group, it is calming; it provides support I need to be able to make contributions."

"I prefer in person because it is easier to hear people, and in face-to-face you communicate with means other than words, so it's better communication."

“I prefer online, as I am most comfortable in my own home. I am tired of trying to fit ticks inside boxes (on paper) and I make a mistake and it looks messy when I cross it out. Online I can take my time, search for definitions, and do all that at home, whereas on telephone, it is too quick and don’t have time to ponder a particular aspect of a question. But the good thing about telephone is that you can clarify, so what works best for me is for the survey to be is online plus being able to contact the researcher by telephone to clarify things. Postage and pens and things - I live in the 21st century - it's a nice place to be, join me there.

“For me, face-to-face in this context can be over overwhelming, with all the body language and eye contact that goes on it is too distracting; I prefer not to look at people when I am trying to articulate something that is complex, the distraction and the noise is too much.”

“It would be less effort for me if I could call someone (on the research team) and they had the chore to take notes and transcribe and write it up for the research.”

Some HFA/AS participants advocated for autism spectrum researchers to be mindful to use methods of data collection that enable meaningful contributions from HFA/AS participants and are sensitive to these participants’ particular and individual cognitive styles.

“I am concerned that in the card sort exercise, the way that the questions are structured, you will miss valuable information, because it is unappealing, and what might motivate us, you haven't even touched or covered. If there was an opportunity where you gave us a blank sheet of paper and asked us the question and we will tell you the answer, you might get more valuable information. I think you need to have someone with Asperger’s helping you write your questionnaires and your research material, because the way that this is structured doesn't appeal to my way of thought whatsoever, some of it I am thinking this is stupid what are you even asking me this for, I would even word things much more differently, I think that someone with a bit more insight would generally give you much better results with the way your structure the questionnaires and do your card game.”

“I feel like it is another meaningless conversation with you trying to get something from me that I'm trying to give you, and we're just missing the mark. I think that these activities and materials are designed for the general population. The structure of it being on a continuum, rather than being black and white choices, is bad.”

“Some people are very good at giving answers, I am not. I am very good at improving things, you can give me anything and I can improve it or look at it and say yes or not, or I prefer to do this, but if you give me no starting point then I tend to not do as well.”

“Sometimes well-meaning researchers put up questions that do not make any sense, for example, if I cannot experience a feeling of something, I cannot answer a question about this, so I need to be able to skip over these questions that do not apply for me.”

“If you give me the option to write, I will write up to the word limit. If you do not give a word limit, I will write 20-30 pages. You need to clearly specify how much you want.”

“You need to be clear with words and phrasing so that questions cannot be construed in different ways, you need to be careful with the use of words and phrasing in questions for autism spectrum people.”

Access to either a telephone or to the internet (Table21) was not identified as a significant barrier to participation for HFA/AS participants.

TABLE 21. REGULAR ACCESS TO INTERNET AND TELEPHONE
HFA/AS participants

STATEMENT	AGREE	UNSURE	DISAGREE
I have regular access to a telephone (landline or mobile).	91.7%	5.0%	3.3%
I have regular access to the internet.	93.4%	3.3%	3.3%

Interaction with the research team

As shown in Table 22, most HFA/AS participants placed considerable value and importance on opportunities for communication between the individual and the researchers.

TABLE 22. INTERACTION WITH THE RESEARCH TEAM
HFA/AS participants

STATEMENT	MORE or MUCH MORE	NO DIFFERENCE	LESS or MUCH LESS
We will give you the telephone number and email address of one of the researchers. You can contact this researcher at any time if you have a question or comment about the research.	62.9%	24.2%	12.9%
One of the researchers will contact you by phone or email at least once a year, to check we have your correct contact details and tell you what we would like you to do next as part of the research.	61.2%	33.9%	4.9%
There will be a special website for the research project, where you will be able to ask questions, leave feedback, and engage in online discussions with the research team and other participants.	66.2%	16.1%	17.7%
You will receive a printed newsletter from the project team twice a year, letting you know how the research is going.	59.6%	32.3%	8.1%
We will send you a copy of the final research report when the project is complete.	80.3%	18.1%	1.6%

A common reason why HFA/AS participants appreciated being able to contact the research team directly at any time by telephone or email was the opportunity to either clarify a question in a survey or to provide an explanation to the research team about the participant’s response to a survey question. This reflected their concern that they are commonly misrepresented, misinterpreted or misunderstood in autism spectrum research, particularly in research conducted by neuro-typical people.

“Since you don't know what is going on in our minds, you can only make a guess, and so there has to be a way to get clarification, how else are you going to make sure that you are using language that everyone is interpreting in the same way.”

“It is common that surveys, especially in field of autism, have loaded questions based on pre-conceptions and misperceptions, so participants need to be able to put our concerns forward (to the researcher) and not be bundled off and never be seen again.”

“Sometimes you might recognise a pattern in your own behaviour and this may be a clue or useful information for the researchers. It’sbest to get it out quickly rather than to procrastinate and you might forget it.”

However, a lesser number of HFA/AS participants expressed a concern that in their particular circumstances, having such access was not a good idea, with the suggestion that participants are given the option.

“This may not be good for me, because if I have the researcher's contact details I will tell the researcher where the research is wrong to start with, what is wrong with the methodology, and it will consume me, so it is better if they can contact me but I don’t want their contact details.”

“I have little to no concept of appropriate times and frequency of communication.”

Additionally, a number of HFA/AS participants noted that they would need reminders to prompt them to complete or engage in any activities.

“I am adaptable, but preoccupied, an approach that might seem berating could be required.”

“You will need to contact me just in time when you want me to do something, not months in advance, because I will not remember or re-read it again.”

Project communications

Most HFA/AS participants valued communications that provided ongoing and updated information about the project and its progress, such as via a website, newsletter and final report (Table 22).

Knowing the results of the research and being able to see and compare others' responses and contributions were common reasons for wanting to see the final report. Others felt that they would be able to use the report itself or the information about the results for their personal learning and development.

To some extent, some of the lack of enthusiasm indicated by HFA/AS participants for receiving a newsletter (Table 22) was that the option given in the questionnaire specified a print newsletter. However, many HFA/AS participants explained that they would opt for a digital version, to be received either by email or by download from a website. Once again, in focus group discussions, HFA/AS participants suggested being given an option as to whether they wished to receive a particular communication piece (such as a newsletter or report) and a choice of the preferred format for that communication. It was also suggested that options be given to receive a summary or a ‘plain language’ version of any report, or attend a session to receive a ‘face-to-face’ explanation of the final outcomes of the project.

“*I would like everyone to be given the option to get full report, a summary or plain language report or no report, because everyone is different.”*

“It depends how technical it is, it will be an issue for me; face-to-face explanation would be good; it will help me to understand.”

Over 66% of HFA/AS participants indicated they would make use of a project website where they would be able to ask questions, leave feedback, and engage in online discussions with the research team and other participants (Table 22). The flexibility to engage as it suits the individual and the interactive nature were attractive. The opportunity to make and engage in relationships online and the reassuring support of sharing and communicating with a community of people with similar interests being common reasons why HFA/AS participants valued such a website.

“I am very comfortable on the web. It's an effective means of retaining connections especially with a program. It's on my terms, I can choose when I decide to go online and check things out, rather than taking a phone call when it’s not appropriate or having to pick up and open up a letter, but if you provide the information and the interface, I can choose how much or how little I want to do online, I like to have that choice because I can plan.”

“I was diagnosed about 15 years ago, and I learn something every day about myself in regards to certain things, so I don’t think you really stop learning and I think that working with others you might understand things better and relate better, so that it's not just you. A website is good because it gives you the chance to communicate about things that you might not be comfortable talking about face-to-face.”

“A website is a chance to be communicating and to be involved, to understand what is going on, to be learning more about ASD. I was only diagnosed recently so I have a lot to learn.”

“Seeing different people's perspectives, engaging in conversation with other people, sharing stories, challenges, bouncing ideas, sharing with people who have an understanding, having an avenue to communicate with similar people.”

However, again there was no consensus across this group, with some indicating this would make them less likely to participate and others indicating it would make no difference (Table 22).

“*I can already contact the researchers directly by email or phone.”*

“My communication style is best suited to one on one communication. Forums increase the chance for miscommunication and decrease the chance for resolution. I tend to offend too many people by averages.”

“I am trying to get past my fears and issues about interactions.”

4.2.6 Social interaction

As shown in Table 23, the desire for or level of comfort with social interaction was an issue that produced divergent responses about activities that required HFA/AS participants to be with other people.

TABLE 23. SOCIAL INTERACTION
HFA/AS participants, by mode of participation

STATEMENT	MODE OF PARTICIPATION	MORE or MUCH MORE	NO DIFFERENCE	LESS or MUCH LESS
Once a year, we will invite you to come to a discussion group where you can meet other people who are also taking part in the research.	ALL HFA/AS participants	67.8%	14.5%	17.7%
	FOCUS GROUP/IV	71.7%	15.1%	13.2%
	ONLINE SURVEY	44.4%	11.21%	44.4%
Once a year, we will invite you to a drinks reception hosted by the research team. We will update you on how the research is going and you can meet other people taking part in the research.	ALL HFA/AS participants	58.1%	24.2%	17.7%
	FOCUS GROUP/IV	58.5%	26.4%	15.1%
	ONLINE SURVEY	55.6%	11.1%	33.3%

A number of participants in this category were concerned about mixing in large groups and preferred engaging within smaller groups.

“No more that 8-10 people in a group.”

“How large will the group be? I prefer small groups.”

“I am happy to get together and share information …in a small group - the smaller the group, the better.”

“I am … terrified of large groups of strangers or the attention of more than 1 or 2 people where I am not in a teacher-student peer relationship situation.”

Of those HFA/AS participants who attended focus group discussions, the opportunity for interaction with others who were similar to them was highly valued, and as evidenced in the group settings, enthusiastically engaged in.

Of prime importance for these participants was the lively and free exchange of views, and in an environment with a level of mutual understanding where much that was particular to them did not need to be said or explained. This sharing of both opinion and experiences was valued both for the supportive contact and the learning and self-development it afforded. Others also expressed a preference for face-to-face communication as it lessened the chance for ambiguity and misunderstandings and provided prompts for contributions. A number also viewed such events as an opportunity to meet researchers, either for exchange of views, to learn more about the autism spectrum or to query the researcher’s approach to autism spectrum research.

“To learn from each other, it's very interesting. It’s a good reminder to me that Aspies have as many differences between each other as between other people.”

“I like the idea of the discussion, not so much for the social angle, but because I might be thinking one way, but hearing other people, they will bring something else up, so it is more layered and will prompt me to think about other things, and more chance that I won't forget things.”

“I would like to come to a discussion group because I do not do surveys (in any format) so I will not participate unless there is a face-to-face (element in the research). In a focus group, at least I have a chance to listen to other people's thoughts, and that can expand my knowledge base about how I can manage about what I can do, I am open to hear what they have to say whether I agree or disagree with it is immaterial, it is a chance to hear what they have to say, it might be the only contact I have with other people with this condition.”

“The opportunity to meet and interact with other Asperger’s people would be the only thing that motivates me to continue coming to something like this, because I spend every day thinking that I am not being heard, and today with you, I am not being offensive, but it is no different.”

“To meet new people, network, connect, find other people on the spectrum, we are social in our own way.”

“We (Aspies) can engage with each other better than neuro-typical people can with us; we can put things in a way that Aspies understand, whereas neuro-typical people may not be able to get across to them. For example, we would not describe Aspies as having a disorder, or give them a label.”

“I want to see why people justify the autism spectrum research they're using."

“To understand about the people behind the research and get to learn about them more.”

For other HFA/AS participants at the focus groups, the social aspect was either less important or not relevant to them. Instead, it was the opportunity to contribute and exchange opinions around a specified topic of interest to them while undertaking a purposeful task (and this in part ameliorated their distaste for or anxiety about the social setting.

“Sharing experience is rewarding and also a discussion group that has a theme/topic with a directed aim and is around a common interest, with an aim of why the group is meeting and a structure. So combined with a sharing experience, this makes a discussion group format more rewarding and enjoyable. I do not enjoy a social gathering - it is all over the place and I'm no good at (it).”

“I am completely not interested in any social interactions of any form … Socialising - absolutely no. Send me a bottle of wine in the post and I will happily socialise with myself at home."

“It needs an agenda and independent chair (Neuro-typical person) for direction and control, and a system for turn-taking.”

By contrast, of those HFA/AS participants who responded via online survey, equal numbers were either enthusiastic or hesitant about a focus group discussion.

“Yes, it'll be nice to meet other autism spectrum people out of personal curiosity and for potential social connections.”

“(I like the idea) to meet other people who might be facing the same things.”

“I can honestly say that meeting other Aspergers as well as intellectuals who can understand my thinking has always been one of my favourite things to do. I have this tendency to 'absorb' people and receptive people are the easiest. The knowledge I gain is used to improve ... and help me fly even further under the radar.”

“I am somewhat apprehensive about performing in a group. But I am Interested in meeting others like me. It would need to be facilitated well to obtain the best from me.”

“Due to my autism I do not cope in groups, I struggle to follow group conversations, etc.”

“Not too interested in discussion groups.”

"Too anxious and scared to meet with new people in a new place. An online forum/discussion board would be a great alternative."

"My communication is context and meaning based, using phrases I know by rote. I am limited by what I know and can absorb. My frustration often allows emotional corruption of the intended message leading to an occasional appearance of naivety and immaturity. I fear the contempt and derision I have faced all my life from the occasional individual. It has made me paranoid, defensive and occasionally delusional to what is actually going on."

HFA/AS participants made numerous suggestions about the need to carefully choose venues for social events to ensure it was a rewarding and enjoyable experience for them. Issues highlighted included the need for a convenient location, quiet acoustics, a private venue, and a relaxed, informal setting.

"It's important to ask about and consider the sensory issues, especially for venues for meetings; think about noises and smells. It will be insulting to us if a group that is all about people on the spectrum does not take sensory issues into account, it's the same as asking other people about allergies."

4.2.7 Travel

HFA/AS participants indicated that the cost, inconvenience and anxiety associated with travel were likely to form a major barrier to their participation (Table 24).

They also indicated a strong preference that any payments to them were made as recompense, at least in part, for their costs of participation, and for travel costs in particular. These sentiments about travel were strongest amongst those HFA/AS participants who participated via online survey.

TABLE 24. TRAVEL
HFA/AS participants

STATEMENT	MODE OF PARTICIPATION	MORE or MUCH MORE	NO DIFFERENCE	LESS or MUCH LESS
As part of your participation in the research, you may be asked to make a round trip of up to 50km no more than once a year (e.g. to take part in a discussion group.	ALL HFA/AS participants	29.0%	37.1%	33.9%
	FOCUS GROUP	30.2%	39.6%	30.2%
	ONLINE SURVEY	22.2%	22.2%	55.6%
If you have to travel somewhere as part of your involvement in the research (e.g. to attend a discussion group), we will reimburse your travel costs.	ALL HFA/AS participants	75.8%	17.7%	6.5%
	FOCUS GROUP	75.5%	17.0%	7.5%
	ONLINE SURVEY	77.8%	22.2%	0%

"Anxiety of traveling somewhere new might be too much for me."

"It's the convenience of getting to the location, not about the distance."

"Mainly related to the time commitment and trouble of traffic than cost."

"Although I have a driver's licence, I don't like travelling to places that aren't easily accessible by public transport. If you paid the travel costs (for taxi etc), then I would tolerate it."

"More likely to travel if I am reimbursed for travel."

"Reimbursement for travel would still not work to motivate me to travel because my family commitments make it difficult for me to travel."

"If you really want to do it you will get there."

4.2.8 Physical and mental health

Some HFA/AS participants considered that their physical health and mental health would be potential barriers to participation (Table 25). Concern about their mental health was more noticeable in those HFA/AS participants who participated via online survey than amongst those who attended a focus group in this study. Concern about their physical health being a potential barrier was higher in those HFA/AS participants who participated in focus groups.

TABLE 25. PHYSICAL AND MENTAL HEALTH
HFA/AS participants

STATEMENT: My physical health might be a barrier to me taking part in a long-term research project.

PARTICIPANTS	AGREE	UNSURE	DISAGREE
All HFA/AS participants	31.1%	18.0%	68.9%
HFA/AS participants via focus groups	15.4%	17.3%	67.3%
HFA/AS participants via online survey	0%	22.2%	77.8%
NT participants	0%	9.6%	90.4%

STATEMENT: My mental health might be a barrier to me taking part in a long-term research project.

PARTICIPANTS	AGREE	UNSURE	DISAGREE
All HFA/AS participants	16.4%	21.3%	62.3%
HFA/AS participants via focus groups	13.5%	21.1%	65.4%
HFA/AS participants via online survey	33.3%	22.2%	44.5%
NT participants	6.9%	13.7%	79.4%

4.3 PARTICIPANTS ON THE AUTISM SPECTRUM WITH INTELLECTUAL DISABILITIES (ASD+ID)

4.3.1 Requirements for flexibility and sensitivity

How the research was organised and conducted to allow for the particular individual needs of each ASD+ID participant was shown to be of most importance to involving these participants.

Thus, factors that ASD+ID participants indicated were vital to becoming and staying involved in any research study included: offering flexibility in the mode of participation (Table 26); having relationships of trust with those conducting the research; the capacity to fit the research activities into the participant’s normal daily routine; and an environment where a sense of security, safety and calm for these participants was assured.

TABLE 26. CHOICE IN MODE OF PARTICIPATION
ASD+ID participants

STATEMENT	MORE or MUCH MORE	NO DIFFERENCE	LESS or MUCH LESS
When we ask you for information for the research, you can choose if you want to do this in person, over the phone, online, or via a questionnaire that we will post to you.	78.6%	7.1%	14.3%

Of all modes of participation offered to ASD+ID participants (Table 27), telephone and paper surveys were considered to be unenjoyable to a majority of these participants, although some Carers indicated that paper or online surveys would be more manageable and effective for their child rather than a telephone survey or interview. In general, ASD+ID participants expressed a wide range of preferences for a mode of participating in autism spectrum research, in order to suit their individual needs and their communication style and skills.

TABLE 27. "HOW DO YOU FEEL ABOUT THIS WAY OF COLLECTING INFORMATION FROM YOU?"

ASD+ID participants

	WOULD ENJOY	NOT SURE	WOULD NOT ENJOY
Online survey	46.7%	26.7%	26.7%
Face-to-face interview	46.7%	26.7%	26.7%
Focus group	46.7%	26.7%	26.7%
Telephone interview	40.0%	33.3%	26.7%
Paper survey	13,3%	20.0%	66.7%
Telephone survey	6.7%	26.7%	66.7%

"Flexibility is important; preference would be face-to-face in a very supportive place, someone to come to talk with him in his own environment at home."

"He would not like an online survey. It often takes time to get a response from him and also often he can't sit still, so a paper survey that can be completed in bits over time would suit, or if face-to-face, it's best if someone could come to talk with him in his own environment at home, it's easier for me (carer) to manage him there and without distraction."

"I like to see this information online or to send or receive an email with information; I prefer to receive an email with information rather than talking on the phone; I don't really like talking on the phone; like to be contacted."

"It is easier to both receive and to give information verbally than doing it by a paper or online."

"I like to sit in a group and if I feel upset talk to my mum on the phone. For private questions, I prefer to do surveys by telling someone, I also like doing questions on the computer."

"The likelihood of participation in face-to-face is slim if the facilitator is someone who is not familiar to the participant. Theo participant has difficulties with comprehending language; so he will also not be able to understand a paper survey or online surveys; location means that it will be difficult to get to a focus group."

"His capacity to participate and contribute on a particular day will fluctuate widely due to his physical and mental health issues; it is not predictable ahead of time."

ASD+ID participants also indicated that they needed adequate time to complete any surveys (Table 28). Their comments highlight the need for such tasks to be broken into smaller tasks that can be gradually completed over a longer time period. When completing surveys, boredom and short concentration were also issues for ASD+ID participants.

TABLE 28. COMPLETING QUESTIONNAIRES

ASD+ID participants

STATEMENT	MORE or MUCH MORE	NO DIFFERENCE	LESS or MUCH LESS
If we asked you to fill in a questionnaire as part of the research, we would give you up to one month to complete the questionnaire and send it back to us.	60.0%	20.0%	20.0%
STATEMENT	AGREE	UNSURE	DISAGREE
I tend to get bored or lose concentration when filling in long questionnaires.	66.7%	13.3%	20.0%

"I don't like to sit and do something that takes a long time, it is boring, so I like enough time to do it in small bits."

"It often takes time to get a response from him and also often he can't sit still, so it's good to have time to compete a survey in parts over a longer period of time."

"One month gives me enough time to think about it, and write things down during the month, a bit at a time. When I have to do it all in one time and I lose concentration and try to rush through and not think about the answers properly, so prefer to do a bit at a time and then send it all at the end of the month."

Access to either a telephone or to the internet (Table 29) was not identified as a significant barrier to participation for ASD+ID participants.

TABLE 29. REGULAR ACCESS TO INTERNET AND TELEPHONE
ASD+ID participants

STATEMENT	AGREE	UNSURE	DISAGREE
I have regular access to a telephone (landline or mobile).	93.3%	0.0%	6.7%
I have regular access to the internet.	100%	0%	0%

ASD+ID participants did not indicate major concerns about travel distances or travel costs inhibiting their participation (Table 30) and provided no commentary about travel issues. This is possibly because their travel is organised and paid for by their carers.

TABLE 30. TRAVEL
ASD+ID participants

STATEMENT	MORE or MUCH MORE	NO DIFFERENCE	LESS or MUCH LESS
As part of your participation in the research, you may be asked to make a round trip of up to 50km no more than once a year (e.g. to take part in a discussion group).	26.7%	53.3%	20.0%
If you have to travel somewhere as part of your involvement in the research (e.g. to attend a discussion group), we will reimburse your travel costs.	33.3%	46.7%	20.0%

As was the experience of the researchers when conducting this study, the full support of the carers of ASD+ID participants was in almost all cases essential to organise, enable and facilitate the participant's contribution and expression of their views.

"We (the parents) would be the ones doing this, and/or there to guide our son."

Consequently, participation by a friend or family member (Table 31) was likely to motivate of most ASD+ID participants (60%) to take part in a research project.

TABLE 31. PARTICIPATION OF FAMILY AND FRIENDS
ASD+ID participants

STATEMENT	AGREE	NEITHER	DISAGREE
I would be more likely to take part in a research project if my friends or family members were also taking part.	60.0%	6.7%	33.3%

4.3.2 Desire for acceptance and understanding: The world and self of ASD+ID

In supporting autism spectrum research (Table 32), ASD+ID participants expressed their desire that such research would lead to a greater acceptance and understanding by the general world as to who they were. Carers considered that for their children, the opportunity to learn more about themselves and autism would be beneficial for their self-development and self-awareness.

TABLE 32. BENEFITS FROM RESEARCH OUTCOMES
ASD+ID participants

STATEMENT	MORE or MUCH MORE	NO DIFFERENCE	LESS or MUCH LESS
When this research is completed, it is likely to benefit other people, especially those living on the autism spectrum.	73.3%	13.4%	13.3%
It is likely that this research will help you learn more about ASD.	42.9%	35.7%	21.4%
It is likely that this research will help you learn more about yourself.	40.0%	40.0%	20.0%
STATEMENT	AGREE	NEITHER	DISAGREE
If I am going to take part in a research project, I want to know that I will personally benefit from the research.	60.0%	33.3%	6.7%

“We are not sure that he understood this concept, but we think it would be good for him (to learn more about himself).” (Carer)

“It would be good for him to be exposed to new experiences, and learn about himself in this way.”

“He is starting to realise that everyone is different. He would like to understand more about those differences.”

“It would be nice to help others.”

“To build understanding in the general public, so that there is greater acceptance of people with autism, and also educate people such as police, taxi drivers, so they understand and accept the behaviours of people with autism.”

Some carers of ASD+ID participants expressed an interest in their children having the opportunity to develop skills and experience through working ‘behind the scenes’ with the research project (Table 33). However, for a considerable proportion, this had no significance for their participation.

TABLE 33. ADDITIONAL PARTICIPATION
ASD+ID participants

STATEMENT	MORE or MUCH MORE	NO DIFFERENCE	LESS or MUCH LESS
You will have the opportunity to be involved with the project ‘behind the scenes’, if you would like: e.g. helping with administrative tasks or the project newsletter.	33.3%	46.7%	20.0%

“*He would like to opportunity to be part of a team working on the project, rather than being just a subject, he would be good at providing comments, feedback, input about what might work better in research for younger people with ASD+ID, he would love that sort of thing, he already does this sort of thing with xxx.”*

“He does already do work in supportive employment, and has done some administrative work, so as long as you make the task clear, use visuals and modify your language, and give him time to process, then he can do simple tasks, and he does get enjoyment out of that and he does feel good about this even though he may not say so, as he feels that he is contributing. Break the task up and give a reward for each step of the task. He is very competitive, that will drive him to completion. Make it very black and white with a specific simple task, a reward for the task and a visual timetable. He is very capable but he does not come across as capable, and people don't know how to tap into the resources he has.”

4.3.3 Desire for recognition

A considerable proportion of ASD+ID participants indicated that receiving acknowledgment and recognition, such as from an article about the participant in the project newsletter or a birthday card from the research team would encourage their participation (Table 34). For these participants, such recognition was more than a polite gesture; it would provide a much-appreciated boost to their self-esteem and was a means of projecting a public profile for themselves.

TABLE 34. RECOGNITION
ASD+ID participants

STATEMENT	MORE or MUCH MORE	NO DIFFERENCE	LESS or MUCH LESS
You will be given the chance to have your photograph and a brief article about yourself printed in our project newsletter.	53.3%	26.7%	20.0%
You will receive a card from the research team on your birthday.	46.7%	33.3%	20.0%

"He loves birthdays and Christmas, and reads all his cards back to front; he is very motivated by this."

"He would like the acknowledgement."

"He would like to get the recognition, in a positive way."

"To show other people how well I did."

"I like this (an article) because you can see who has taken part and to show the general community who is helping the research, so other people know that I am involved in the research."

"He wants to be 'out there'."

4.3.4 Extrinsic rewards

While indicating that their support for the altruistic benefits of autism spectrum research would make them more likely to participate in autism spectrum research, most ASD+ID participants were happy to receive any extrinsic rewards offered to them, such as vouchers, cash, gifts or cards (Table 35). However, no ASD+ID participants expressed that such rewards were an essential requirement for their participation; rather they were 'nice to have'.

While no strong preference were expressed by ASD+ID participants about the type of rewards, the most popular suggestions by ASD+ID participants for extrinsic rewards were for gift vouchers that could be used to satisfy the participant's particular personal interests or cash. ASD+ID participants did not express the negative comments about extrinsic rewards that were made by other participants (notably HFA/AS participants).

TABLE 35. EXTRINSIC REWARDS AS MOTIVATORS FOR PARTICIPATION
ASD+ID participants

STATEMENT	MORE or MUCH MORE	NO DIFFERENCE	LESS or MUCH LESS
You will receive a cash payment each time you contribute to the research (i.e. once a year).	66.7%	20.0%	13.3%
You will receive a gift voucher every time you contribute to the research (i.e. once a year).	66.7%	20.0%	13.3%
Three times a year, we will send you a small gift (e.g. a pen, cap or drink bottle) to thank you for participating in our research.	42.9%	42.9%	14.2%
If you tell one of your friends about the research project and they then sign up to take part, we will send you a gift voucher as a 'thank you'.	53.3%	20.0%	26.7%

“I don't worry much about money. I liked getting the voucher today.”

“A $20 voucher is plenty, more is okay, but we should be giving money to the researchers to help in research.”

“Money wouldn't matter for the boys.”

“He understands this concept; he knows about gift cards.”

“He understands the concept of money and the power associated with it.”

“I am not doing it for the money, I am happy to contribute to the research in any way.”

“They would prefer a general Coles or Woolworths voucher, so it's not restricted to just Westfield etc. Could you include their special interests? For example, the boys like the movies. Any amount is appropriate; it doesn't necessarily have to increase each year. Whether it was cash or voucher wouldn't matter to the boys.”

“They would be motivated by something like this. Not a trinket, something tailored to their interests, such as a book voucher or iTunes voucher. Not pens, caps, water bottles. It does not have anything large, but good to be personalised to them.”

“He would not understand this concept of referring a friend. He would not know how to refer a friend (to the study). He would love to get a gift, but would not understand that he had received it for that purpose.”

4.3.5 Keeping up-to-date

Wanting to know ‘what was happening’ next and to keep in touch with what other people were doing, especially people known to them were commonly-expressed interests in the commentary of ASD+ID participants. Thus, as shown in Table 36, newsletters, reports and other forms of communication from the research team were viewed by these participants as useful ways of keeping up-to-date and in-touch.

TABLE 36. KEEPING UP-TO-DATE
ASD+ID participants

STATEMENT	MORE or MUCH MORE	NO DIFFERENCE	LESS or MUCH LESS
You will receive a printed newsletter from the project team twice a year, letting you know how the research is going.	66.7%	20.0%	13.3%
One of the researchers will contact you by phone or email at least once a year, to check we have your correct contact details and tell you what we would like you to do next as part of the research.	66.7%	20.0%	13.3%
We will send you a copy of the final research report when the project is complete.	64.3%	21.4%	14.3%

“*To see if anyone I know is in the newsletter or in the study.”*

“To see the results of the research, how it is going, any further development planned for the future.”

“How is everyone with autism going and when is their birthday.”

“I like to know what is going on.”

“So I can talk directly with someone and find out what is going to happen next with the research.”

4.3.6 Safety and confidentiality

Common points in the commentary of ASD+ID participants were concerns to ensure that the confidentiality of their private information was assured and that the participants' communications with others in the project would be in a safe environment where they would be free from harassment (Table 37). Generally this concern was expressed by carers on behalf of their adult children, not directly by the participants.

TABLE 37. CONCERNS ABOUT PRIVACY
ASD+ID participants, and all participants

STATEMENT	AGREE	UNSURE	DISAGREE
I tend to feel concerned about my privacy when taking part in research	66.67%	13.33%	20.00%
STATEMENT	**MORE or MUCH MORE**	**NO DIFFERENCE**	**LESS or MUCH LESS**
As part of the research, we may ask you for information that is private or sensitive (e.g., about your health or your personal relationships). This information will stay confidential and will not be shared.	26.7%	46. 7%	26.6%

"He might be a bit concerned about where the information is going."

"He would not like to do certain types of tests that feel invasive of privacy, such as IQ tests."

"He would not care at all."

"I don't think that he has understood the concepts in this question." (Carer)

Thus, having the contact details of the research team and a dedicated project website were valued for the secure access that they would provide for sharing information with others in the project community.

TABLE 38. ACCESS TO THE RESEARCH COMMUNITY
ASD+ID participants

STATEMENT	MORE or MUCH MORE	NO DIFFERENCE	LESS or MUCH LESS
There will be a special website for the research project, where you will be able to ask questions, leave feedback, and engage in online discussions with the research team and other participants.	60.0%	26.7%	13.3%
We will give you the telephone number and email address of one of the researchers. You can contact this researcher at any time if you have a question or comment about the research.	46.7%	33.3%	20.0%

"So I can talk directly and so I can send and receive private and confidential information."

"It's a good way of communicating with other people, it feels like a safe and secure space where people from the general public would not leave bad comments, he likes that it is only for people who are part of the research study."

"You could have a secret Facebook page for the research study/community - researchers and participants."

4.3.7 Social interaction

ASD+ID participants divided into those who would enjoy activities that provided opportunities for social interaction, particularly interactions with others similar to them; and those who did not seek or enjoy social interactions.

TABLE 39. SOCIAL INTERACTION
ASD+ID participants

STATEMENT	MORE or MUCH MORE	NO DIFFERENCE	LESS or MUCH LESS
Once a year, we will invite you to come to a discussion group where you can meet other people who are also taking part in the research.	60.0%	0.0%	40.0%
Once a year, we will invite you to a drinks reception hosted by the research team. We will update you on how the research is going and you can meet other people taking part in the research.	46.7%	33.3%	20.0%

"To get to know other people well, knowing about other people, when their birthday is, what team they follow in footy, what music they like."

"To see whoever is there, I would like to see people I have not seen for ages."

"It's good to meet other people with Asperger's or autism, and then you can discuss how they have got through their life to this point, see where they want to go in their life, what they want to do to improve their life, and help each other to discuss your disabilities."

"It is a good opportunity to meet other new people, get to know other peoples disabilities, so you can talk amongst each other and help each other, meet the research team and help them if they need more research done."

"He would like meeting people like himself, with whom he shares common interests."

"It's good for him to be exposed to others who have similar issues and concerns, good to be out there and seen."

"When you get out of school, you need new ways to connect in to networks for young adults with autism and an intellectual disability. We start to see it around hobbies, so you need to be able to access those groups, but there are not so many social groups for adults. They no longer have the routine of going to school, and they can get depressed, so you need to get them out and socialising, especially if they are not in the workplace, so a research project may give opportunities to connect people autism and an intellectual disability through their interests, especially through social media. This would be more attractive for them and for parents than these participants coming to a discussion group or a drinks event."

"If there is something serious to discuss, then this will be a more motivating for him, but won't get much from him socially at such an event, he not motivated by just getting together with people (he is not verbal)."

"He does not like socialising."

"The attraction for him would be the right type of food for him (both sweet and savoury junk food, nothing healthy)."

4.3.8 Physical and mental health

A notable proportion of ASD+ID participants considered that their mental health may be a potential barrier to participation (Table 40) compared to fewer who considered that their physical health might be a potential barrier.

TABLE 40. PHYSICAL AND MENTAL HEALTH
ASD+ID participants, HFA/AS participants and NT participants

STATEMENT: My mental health might be a barrier to me taking part in a long-term research project.

PARTICIPANTS	AGREE	UNSURE	DISAGREE
ASD+ID participants	33.3%	13.4%	53.3%
HFA/AS participants	16.4%	21.3%	62.3%
NT participants	6.9%	13.7%	79.4%

STATEMENT: My physical health might be a barrier to me taking part in a long-term research project.

PARTICIPANTS	AGREE	UNSURE	DISAGREE
ASD+ID participants	13.3%	13.4%	73.3%
HFA/AS participants	31.1%	18.0%	68.9%
NT participants	0%	9.6%	90.4%

For the majority of ASD+ID participants, the offer to provide a referral to a psychologist in the event that the participant experienced distress or anxiety as a result of taking part in the research (Table 41) was considered as being likely to discourage or make no difference to participation. Issues of trust and communication styles were cited as concerns.

TABLE 41. STRESS AND ANXIETY FROM PARTICIPATION
ASD+ID participants

STATEMENT	MORE or MUCH MORE	NO DIFFERENCE	LESS or MUCH LESS
In the unlikely event that you experienced distress or anxiety as a result of taking part in the research, we would refer you to a psychologist for advice and support.	13.3%	53.4%	33.3%

"He is not keen on verbal discussion, or dealing with new people. A counselling service may be effective and helpful if there was a trained professional who is skilled in using visual cues."

4.4 CARERS OF ASD+ID PARTICIPANTS

As experienced in conducting this study, the full support of the carers of ASD+ID participants is in almost all cases essential to organising, enabling and facilitating the contributions and the expression of their views of ASD+ID participants.

4.4.1 Altruism: First and foremost a carer

As shown in Table 42, central to the motivations of the Carers who participated in this study were altruism and the desire to make life better for others. These carers interpreted 'others' as being people on the with autism spectrum and in particular, their ASD+ID child.

TABLE 42. ALTRUISM
Carers

STATEMENT	MORE or MUCH MORE	NO DIFFERENCE	LESS or MUCH LESS
When this research is completed, it is likely to benefit other people, especially those with an autism spectrum disorder (ASD).	94.1%	5.9%	0.0%
It is likely that this research will help you learn more about autism spectrum disorders (ASD).	88.2%	11.8%	0.0%
It is likely that this research will help you learn more about yourself.	70.6%	29.4%	0.0%

“We would like to be able to share information about our experiences with others so as to help them.”

“We have always been happy to participate in research.”

“A lot of research needs to go into employment, workplaces and workplace environments, and how to lift the workforce participation rate for people on the spectrum, and everyone is so different, everyone is capable of doing something worthwhile; research into this would help everyone (on the spectrum) from late teens onwards.”

“We feel we know all about our child and so it is a little late for this.”

While willingly offering their time to help others, Carers were not unconcerned about obtaining a ‘personal’ benefit from their participation in, and contribution to autism spectrum research (Table 43). It is important to note, however that ‘I, ‘you’ and ‘yourself’ were interpreted from the point of view of their role as a carer. Personal benefits were considered solely in terms of helping their ASD+ID child. Thus, their focus for autism spectrum research and their participation in it was the development of practical knowledge and solutions that will improve the well-being and life choices of their child.

TABLE 43. PERSONAL BENEFITS
Carers

STATEMENT	AGREE	NEITHER	DISAGREE
If I am going to take part in a research project, I want to know that I will personally benefit from the research.	58.8%	11.8%	29.4%

“*This is for me as a carer; there is so much to be learnt.”*

“The real thing is that it would be good for us as his parents to learn more about him, to make his life easier.”

“For me, as a parent and carer (of an adult on the spectrum) to see my son involved in research about autism is really a good thing because it means that hopefully the outcome would mean that we would have a better understanding of what people like my son need and require and how they feel about things, it will give us a better idea of how to help as a parent and carer.”

“The main motivation for us in participating is to learn more about how we can help them.”

Consistent with their primary focus on others and their children, Carers showed little or no interest in receiving any exposure or recognition for themselves (Table 44). A further indication of this was the lack of commentary from Carers on such options for themselves.

TABLE 44. RECOGNITION
Carers

STATEMENT	MORE or MUCH MORE	NO DIFFERENCE	LESS or MUCH LESS
You will receive a card from the research team on your birthday.	23.5%	47.1%	29.4%
You will be given the chance to have your photograph and a brief article about yourself printed in our project newsletter.	35.3%	29.4%	35.3%

4.4.2 Being engaged with and informed about autism spectrum research

In line with these concerns, Carers indicated an interest in engaging with the research project and being kept up-to-date with information about the project and most trusted the motives behind large research projects (Table 45). The desire, willingness and capacity of Carers to contribute to research that will help their ASD+ID children and others was balanced by their pragmatic need to deal with the practicalities of a demanding everyday life as the carer of an adult with a disability. It is these practicalities that were seen by them as the inhibitors and enablers to their participation in longitudinal autism spectrum research.

TABLE 45. PROJECT COMMUNICATIONS AND ENGAGEMENT
Carers

STATEMENT	MORE or MUCH MORE	NO DIFFERENCE	LESS or MUCH LESS
We will send you a copy of the final research report when the project is complete.	88.2%	11.8%	0.0%
You will receive a printed newsletter from the project team twice a year, letting you know how the research is going.	82.4%	17.6%	0.0%
There will be a special website for the research project, where you will be able to ask questions, leave feedback, and engage in online discussions with the research team and other participants.	70.6%	23.5%	5.9%
STATEMENT	**AGREE**	**NEITHER**	**DISAGREE**
I tend to feel suspicious about the motives behind large research projects.	26.7%	20.0%	53.3%

”We are very keen on research.”

“Yes, we would be interested in learning how our time was then translated into research.”

“We would appreciate being kept informed and up-to-date. So many times you participate in research and then never hear anything about it again, which is very disappointing.”

“This would be interesting to us, and we would share it with (our child).”

Thus, for Carers, having the contact details of the research team and receiving regular contact from the research team to check on details (Table 46) were both seen as convenient and practical ways to enable their child’s participation in the research.

TABLE 46. ACCESS TO AND CONTACT WITH THE RESEARCH TEAM
Carers

STATEMENT	MORE or MUCH MORE	NO DIFFERENCE	LESS or MUCH LESS
We will give you the telephone number and email address of one of the researchers. You can contact this researcher at any time if you have a question or comment about the research.	70.6%	23.5%	5.9%
One of the researchers will contact you by phone or email at least once a year, to check we have your correct contact details and tell you what we would like you to do next as part of the research.	52.9%	41.2%	5.9%

Most Carers expressed no concern regarding sharing private personal information about themselves with the research team (Table 47), subject to confidentiality, and again, any commentary they provided on this topic was with regards to their child, not themselves.

TABLE 47. CONCERNS ABOUT PRIVACY
Carers

STATEMENT	MORE or MUCH MORE	NO DIFFERENCE	LESS or MUCH LESS
As part of the research, we may ask you for information that is private or sensitive (e.g., about your health or your personal relationships). This information will stay confidential and will not be shared.	35.3%	58.8%	5.9%
STATEMENT	**AGREE**	**NEITHER**	**DISAGREE**
I tend to feel concerned about my privacy when taking part in research.	35.3%	17.7%	47.1%

4.4.3 Extrinsic rewards

This balance of altruism and pragmatism was reflected in Carers' attitudes to the extrinsic rewards canvassed in this study (Table 48). Of greater concern to Carers were the practicalities of how they would enable their child's participation in research, such as travel and travel costs, communication with the research team and modes of participation.

TABLE 48. EXTRINSIC REWARDS AS MOTIVATORS FOR PARTICIPATION
Carers

STATEMENT	MORE or MUCH MORE	NO DIFFERENCE	LESS or MUCH LESS
You will receive a cash payment each time you contribute to the research (i.e. once a year).	64.7%	29.4%	5.9%
You will receive a gift voucher every time you contribute to the research (i.e. once a year).	58.8%	29.4%	11.8%
If you tell one of your friends about the research project and they then sign up to take part, we will send you a gift voucher as a 'thank you'.	58.8%	29.4%	11.8%
Three times a year, we will send you a small gift (e.g. a pen, cap or drink bottle) to thank you for participating in our research.	47.1%	35.3%	17.6%

The greatest proportion of Carers indicated support for receiving a cash payment, while gifts such as pens, bottles and caps received the lowest level of support, as most Carers indicated that such gifts were no motivation for their participation. As with most questions canvassed with Carers in this study, most comments provided by Carers about any extrinsic rewards focussed on what their child would receive, not themselves.

"We appreciate that our time is being valued."

"This isn't the main reason to do the research but we are happy to receive payment."

"The voucher was appreciated."

"This would help to cover costs, and would go into their bank accounts, so it would be something to help them (financially). It would not be an incentive to participate, but it would be a nice gesture."

4.4.4 Travel

While any travel required to participate in research was considered a barrier for some Carers and not for others (Table 49), the majority considered that reimbursement for their travel costs would encourage their participation.

TABLE 49. TRAVEL
Carers

STATEMENT	MORE or MUCH MORE	NO DIFFERENCE	LESS or MUCH LESS
As part of your participation in the research, you may be asked to make a round trip of up to 50 km no more than once a year (e.g. to take part in a discussion group).	29.4%	29.4%	41.2%
If you have to travel somewhere as part of your involvement in the research (e.g. to attend a discussion group), we will reimburse your travel costs.	88.2%	11.8%	0.0%

4.4.5 Modes of participation

In general, Carers expressed a wide range of preferences for a mode of participating in autism spectrum research so as to suit their individual circumstances (Table 51). The majority of Carers indicated that a choice of modes of participation and adequate time to provide responses to questionnaires would enable their participation (Table 50).

TABLE 50. CHOICE IN MODE OF PARTICIPATION; COMPLETING QUESTIONNAIRES
Carers

STATEMENT	MORE or MUCH MORE	NO DIFFERENCE	LESS or MUCH LESS
When we ask you for information for the research, you can choose if you want to do this in person, over the phone, online, or via a questionnaire that we will post to you.	82.3%	11.8%	5.9%
If we asked you to fill in a questionnaire as part of the research, we would give you up to one month to complete the questionnaire and send it back to us.	64.7%	17.7%	17.6%

TABLE 51. HOW DO YOU FEEL ABOUT THIS WAY OF COLLECTING INFORMATION FROM YOU?
Carers

	WOULD ENJOY	NOT SURE	WOULD NOT ENJOY
Face-to-face interview	76.5%	17.6%	5.9%
Focus group	76.5%	23.5%	0.0%
Online survey	64.7%	5.9%	29.4%
Paper survey	52.9%	35.3%	11.8%
Telephone interview	58.8%	5.9%	35.3%
Telephone survey	52.9%	0.0%	47.1%

“Prefer online.”

“Choice is good.”

“For me email is best.”

“For me paper is best.”

A notable proportion of Carers indicated that they did not have regular access to a telephone or to the internet.

TABLE 52. REGULAR ACCESS TO INTERNET AND TELEPHONE
Carers

STATEMENT	AGREE	UNSURE	DISAGREE
I have regular access to a telephone (landline or mobile).	88.2%	0.00%	11.8%
I have regular access to the internet.	82.4%	11.8%	5.9%

4.4.6 Social Interaction

Most Carers considered that meeting and sharing experiences with others Carers at events such as a discussion group or a drinks reception would increase the likelihood of their participation (Table 53). However, some were reticent to be in a forum where the negative aspects of caring for an ASD+ID child may dominate the discussion. A notably greater proportion of Carers were positive about attending a drinks reception rather than a discussion group.

TABLE 53. SOCIAL INTERACTION
Carers

STATEMENT	MORE or MUCH MORE	NO DIFFERENCE	LESS or MUCH LESS
Once a year, we will invite you to come to a discussion group where you can meet other people who are also taking part in the research.	52.9%	41.2%	5.9%
Once a year, we will invite you to a drinks reception hosted by the research team. We will update you on how the research is going and you can meet other people taking part in the research.	70.6%	23.5%	5.9%

“To meet other people so we can hear different opinions and learn from them.”

“It would be good to bring like-minded people together with a common interest.”

“We would enjoy the insight into the project and feeling like we were a part of the bigger picture.”

“My only concern would be that provision was made for people living on the autism spectrum.”

”We’re not sure if we would have the time to participate; it would depend on our schedule.”

“This sounds like a nice experience if it wasn't too far away.”

“I’m not interested in meeting other carers.”

“We're not big on this, to meet up with other parents (in the same situation), we have done it in the past and everybody is down in the dumps, and that worries me, when you live with people with autism, you don’t need to socialise with people like that so we don't as couple do any of that, you just come out and it's depressing;. It would be okay if it was upbeat and positive, with just being social, or there would need to be agenda or strategy to avoid the depression-driven discussion. A lot of people are still not in acceptance and are not upbeat. We don't dwell, we just accept life and move on.”

4.4.7 Physical and mental health

A small proportion of Carers indicated that their mental health may be a potential barrier to participation (Table 54). None considered that the physical health would inhibit their participation, though some were unsure about this.

TABLE 54. PHYSICAL AND MENTAL HEALTH
Carers

STATEMENT	AGREE	UNSURE	DISAGREE
My mental health might be a barrier to me taking part in a long-term research project.	11.8%	17.6%	70.6%
My physical health might be a barrier to me taking part in a long-term research project.	0.0%	17.6%	82.4%

The offer to provide a referral to a psychologist in the event that the Carer experienced distress or anxiety as a result of taking part in the research produced divergent views amongst Carers (Table 55). While the majority of Carers indicated that this would either discourage their participation or make no difference to them, some Carers indicated that it would make their participation more likely. Carers provided no commentary on this topic. However, it may be viable to infer that their views on this would broadly reflect those of the NT participants, some of whom expressed that such an offer caused them to be concerned as to why this would be necessary, and what the research may involve that would possibly cause them to suffer any anxiety or distress.

TABLE 55. STRESS AND ANXIETY FROM PARTICIPATION
Carers

STATEMENT	MORE or MUCH MORE	NO DIFFERENCE	LESS or MUCH LESS
In the unlikely event that you experienced distress or anxiety as a result of taking part in the research, we would refer you to a psychologist for advice and support.	37.1%	33.9%	29.0%

4.5 NEURO-TYPICAL PARTICIPANTS (NT)

4.5.1 Altruism

NT participants who were willing to participate in autism spectrum research viewed their contribution as an easy way in which they can help others, and this was the primary motivation for their participation.

TABLE 56. ALTRUISM
NT participants

STATEMENT	MORE or MUCH MORE	NO DIFFERENCE	LESS or MUCH LESS
When this research is completed, it is likely to benefit other people, especially those with an autism spectrum disorder (ASD).	98.6%	1.4%	0.0%

“This is my main reason for being involved.”

“I don't care about commercial surveys when people call me up. Here, you feel like you are doing something that will ultimately help someone.”

“I am more likely to participate if it's going to help someone else who needs it, rather than just doing it for getting a gift voucher.”

“It doesn't take that much effort and it's going to help someone.”

“It's a feel good thing, A lot of the time that is what volunteering your time is about - you get something out of it, it does give you a bit of a positive power trip, you think - I'm getting something about it while doing something good for someone else, and if you're talking to someone about it, it’s like “wow" and that lifts you up.”

“The research is results-oriented, so I know that I am not wasting my time, I know that something is going to come out of it.”

“I know there is a lot of research into the genetics of autism, and (as a parent of autism spectrum children) I want to learn more about this, and if my partner has passed it on or have I passed this on and how you come to this conclusion, understanding if it is genetic, or what else is it.”

Reflecting this faith in the good that research could produce, by far the majority of NT participants trusted the motives behind large research projects.

TABLE 57. SUSPICION ABOUT LARGE RESEARCH PROJECTS
NT participants

STATEMENT	AGREE	NEITHER	DISAGREE
I tend to feel suspicious about the motives behind large research projects.	2.7%	15.1%	82.2%

4.5.2 Developing understandings

NT participants commonly viewed their engagement in autism spectrum research as an opportunity to improve their personal understanding of the autism spectrum and the lived experience of a person with autism (Table 58). Of particular interest to them was that this knowledge would then enable them to be effective in promoting greater understanding and acceptance by others of people living on the autism spectrum, and would better equip them to interact and help people living on the autism spectrum, including those whom they already knew through family and friends. NT participants who were related to people living on the autism spectrum commonly expressed an interest in learning about the genetics of the autism spectrum.

TABLE 58. PERSONAL BENEFITS: LEARNING ABOUT ASD
NT participants

STATEMENT	MORE or MUCH MORE	NO DIFFERENCE	LESS or MUCH LESS
It is likely that this research will help you learn more about autism spectrum disorders (ASD).	84.9%	13.7%	1.4%

“To educate people beyond the stereo-typical view of autism, to educate people about all the different levels of autism and many different ways of functioning with autism; to understand how wide the spectrum is.”

“There is probably so much in the media about autism and about people with autism that is probably not true and is twisted to make a story, so we want to know what is actually true about people with autism.”

“To get a general knowledge and understanding of the autism spectrum, as I haves not had exposure to people on the spectrum.”

“To help me to be more understanding and tolerant of people who are different.”

“What are the causes and what can be done to help once you know that.”

“I want to learn as much as I can, as I have a brother who is on the spectrum, why he acts as he does, how we can communicate better with him, how we can understand each other.”

“I would like to learn more about Asperger's and potential treatments for my son.”

“I would like to learn more about the genetics of autism. My family is a mix of ADD, OCD, learning disabilities, anxiety, autism, information issues, there are all sort s of studies about the connections, so how this affects my family, and any children that I might have.”

Thus, NT participants were open to any self-development that may arise from their participation.

TABLE 59. PERSONAL BENEFITS: LEARNING ABOUT MYSELF
NT participants

STATEMENT	MORE or MUCH MORE	NO DIFFERENCE	LESS or MUCH LESS
It is likely that this research will help you learn more about yourself.	65.3%	31.9%	2.8%

“Knowledge would make me more connected to the bigger picture of life.”

“I'm quite into the psychology behind why we do things and relationships in general, and how my actions might affect dealings with other, or how other people's makeup might be different from mine, and so often when you learn more about yourself it impacts on all those other areas like this.”

“This would be an opportunity, as you're engaging with a process about people. It's a self-growth thing, so if you are self-aware during this process, you will learn new things about yourself, your likes, your dislikes- it's a personal growth thing, part of your personal journey.”

“I am just curious what I might find out about myself.”

“I don't often self-reflect so it’s an opportunity to do this a look deeper, and to learn more in an easy way.”

4.5.3 Convenience – time, place and travel

NT participants commonly indicated that having the choice and flexibility to participate in ways that were convenient and not disruptive to their normal routines was important, if not essential, to ensure their participation in research (Table 60). Similarly, factors that inhibited the convenience of their participation, particularly the time taken to travel to any activities, would deter them from joining or staying in a research study.

TABLE 6.0 CHOICE IN MODE OF PARTICIPATION
NT participants

STATEMENT	MORE or MUCH MORE	NO DIFFERENCE	LESS or MUCH LESS
When we ask you for information for the research, you can choose if you want to do this in person, over the phone, online, or via a questionnaire that we will post to you.	82.2%	16.4%	1.4%

“Different people have different preferences and time constraint so choice is good.”

“It doesn't restrict you've got those options, you're not restricted to "this is the way the research has to be done" because then you'd have to think "can I really commit to this or not", but when there are options, you can do it in your own time and you're more likely to fill something out at night when you have the time rather than taking a call when you are in the middle of something and that becomes annoying.”

“All options have their advantages and benefits. At focus groups it is always fun and interesting to interact with other people and get challenged by their view, and meet new people. But downside is the travelling and fitting it into your schedule.”

As shown in Table 61, NT participants expressed a wide range of preferences for a mode of participating in autism spectrum research so as to suit their individual circumstances.

TABLE 61. HOW DO YOU FEEL ABOUT THIS WAY OF COLLECTING INFORMATION FROM YOU?
NT participants

	WOULD ENJOY	NOT SURE	WOULD NOT ENJOY
Face-to-face interview	68.5%	24.7%	6.8%
Focus group	63.0%	23.3%	13.7%
Online survey	86.1%	8.3%	5.6%
Paper survey	56.2%	21.9%	21.9%
Telephone interview	57.5%	27.4%	15.1%
Telephone survey	50.7%	24.7%	24.7%

Commentary from NT participants indicated that any requirement to travel would be a significant factor in considering how convenient it would be for them to take part in a research study (Table 62). While for most of these participants some reimbursement of travel costs would enable their participation, this was not so for all NT participants.

TABLE 62. TRAVEL
NT participants

STATEMENT	MORE or MUCH MORE	NO DIFFERENCE	LESS or MUCH LESS
As part of your participation in the research, you may be asked to make a round trip of up to 50 km no more than once a year (e.g. to take part in a discussion group).	15.1%	32.9%	52.0%
If you have to travel somewhere as part of your involvement in the research (e.g. to attend a discussion group), we will reimburse your travel costs.	80.8%	15.1%	4.1%

“50 kms seems to be a long way.”

“It’s good to have a venue that is close to a train station.”

“I don't drive, so the distance I would need to travel is an important factor.”

“It would be a big turn off for me. The idea of parking, tolls, being in traffic - I don't like driving at the best of times, and I don't particularly want to sit on the bus and take time that way. I would much rather do it online or where there is the least interaction. I like the idea of getting together every now and then and having a meet and greet with everyone, but the way it as written, it was limited, so if you are doing it all the time it would be a massive turn-off.”

“Reimbursement may make a difference, but it is a mainly the time to travel that is an inhibitor.”

“Time off work, parking in city? I'm a nervous driver so it would have to be local. Covering the cost of petrol would help.”

“Travel would be a big barrier for me, definitely, even if I was reimbursed for travel.”

“I would go only if travel expenses are reimbursed.”

“Distance is what matters, reimbursement will not make any difference.”

“Reimbursement for travel would still not work to motivate me to travel because my family commitments make it difficult for me to travel.”

4.5.4 Extrinsic rewards and acknowledgement

While NT participants indicated that their primary motivation in contributing to autism spectrum research was to help others (Table 63), they were also generally happy to accept extrinsic rewards offered to them (Table 64). Their commentary indicated that this was more so because they appreciated these as acknowledgements of their contribution and as gestures of a personal connection with the project, rather than for any monetary value these rewards may provide to them. Any cash payment was valued as reimbursement to cover the costs of taking part in the research (e.g., transport or babysitting) whereas gifts and gift vouchers were preferred as tokens of appreciation.

TABLE 63. PERSONAL BENEFIT
NT participants

STATEMENT	AGREE	NEITHER	DISAGREE
If I am going to take part in a research project, I want to know that I will personally benefit from the research.	39.7%	8.2%	52.1%

TABLE 64. EXTRINSIC REWARDS AS MOTIVATORS FOR PARTICIPATION
NT participants

STATEMENT	MORE or MUCH MORE	NO DIFFERENCE	LESS or MUCH LESS
You will receive a gift voucher every time you contribute to the research (i.e. once a year).	72.6%	20.5%	6.9%
You will receive a cash payment each time you contribute to the research (i.e. once a year).	69.9%	20.5%	9.6%
If you tell one of your friends about the research project and they then sign up to take part, we will send you a gift voucher as a ‘thank you’.	65.7%	23.3%	11.0%
Three times a year, we will send you a small gift (e.g. a pen, cap or drink bottle) to thank you for participating in our research.	42.5%	42.4%	15.1%
You will receive a card from the research team on your birthday.	31.5%	48.0%	20.5%

“I am doing it for the feel-good factor - that is what I would get out of it, rather than money.”

“Learning in itself so that I can better deal with my son is reward in itself.”

“The outcome is worth much more than the cash payment.”

“We've all got bills to pay, and if it is being offered I think that most people would happily accept the money because we can use it and spend it and it reassures you that my time is well invested. I would put more effort in. You don't want to people to be hurried and rushed. If I as being paid, I would take my time and feel like I am getting paid for it so I should be putting a lot in (to my responses), so rather than doing a one liner I would write a paragraph.”

“I don't like the idea of cash because it's like you are being paid for your time, but are you really doing this to be paid or are you doing this because you want to be part of a research project? So if it's in form of a gift voucher or lunch then it's a form of appreciation, but I would be uncomfortable if I was given cash in the hand. I would take the voucher as a thank-you.”

“The main incentive has to be that you genuinely want to participate. Providing participants with a connection to the study such as via newsletters is a more important way of retaining people in the study. Money is just a gesture of appreciation, it could increase slightly, but you cannot reimburse people completely for their time, so other things are important, you need to connect participants in other ways so that people feel that they are contributing and are part of the research.”

“It is not a key motivator, but it is a nice thank-you gesture.”

“The cash will encourage some people even though their main motivation is to contribute.”

“It really depends on how much time you require, how much time you are asking from the volunteers, and how often.”

“I think I would be more long-term committed to do something if I was getting a push, whether it was money or whatever it was, you could do the first one or two out of the goodness of your heart, but after however long you are going for, you do need a reason to keep participating sometimes.”

“You could offer a gift card with a charity.”

While most NT participants were positive about the concept of being paid or rewarded for inviting a friend to also participate in a research study (see Table 64), comments from some NT participants expressed discomfort with or disapproval of this idea.

“If I was making a conscious decision that I think someone else should contribute to the project, I would be analysing who I thought was best and why and I wouldn't be needing a reward for that, I would be doing it for the reasons of the project and because I believe in the reasons for the project, and that person definitely got something to contribute, and I would just ask them.”

“This makes you feel like a sales person, just doing it to get the gift voucher.”

“If you are getting someone else on board, it doesn't feel like a big effort.”

And while some NT participants valued receiving branded gifts as reminders of their connection with the project, others expressed that they consider such items as junk, clutter and a waste of money, and a different type of gift, such as food consumables, would be better appreciated by them.

“A cup or pen is okay, I would be proud to have something that would remind me of the study, each time you see that you mentally connect with the research and know that something else will be coming up to do.”

”It’s a nice gesture of appreciation.”

“I would rather see the money spent on the research rather than wasted on caps and pens that we all have plenty of anyway.”

“No gift. I hate junk promotional items.”

“This is not necessary, a gift card is enough.”

“A gift that relates to the community that we are helping, such as a ticket to an exhibition, gallery or film about autism, would be more gratifying given the study that we would be participating in, and it could also be a way to involve participants’ partners as they get to take part in the reward.”

NT participants were similarly divided on receiving a birthday card from the research team (see Table 58). Some appreciated t as a nice personal gesture; some considered it to be a waste of the project’s resources, some felt it would be intrusive; others were cynical about this.

“The personal touch is huge, if you're going to be taking time out of your day, you want to be feeling valued so having something like that makes you feel appreciated.”

“It will be opened and thrown in the bin, this is not personal, it would not make any difference.”

“Not very important or meaningful.”

However, NT participants did not consider that all forms of acknowledgement of their participation would be effective in their involvement in a research study. Thus, a considerable proportion of NT participants considered that having a photograph and a brief article about themselves in the project newsletter would discourage them from taking part (Table 65). Only a very small proportion considered that it would make them more likely to participate.

TABLE 65. RECOGNITION
NT participants

STATEMENT	MORE or MUCH MORE	NO DIFFERENCE	LESS or MUCH LESS
You will be given the chance to have your photograph and a brief article about yourself printed in our project newsletter.	9.6%	42.5%	47.9%

4.5.5 Project communication and engagement

NT participants expressed a keen interest in engaging with the research project and being kept up-to-date with information about the project.

TABLE 66. PROJECT COMMUNICATION AND ENGAGEMENT
NT participants

STATEMENT	MORE or MUCH MORE	NO DIFFERENCE	LESS or MUCH LESS
We will send you a copy of the final research report when the project is complete.	86.3%	13.7%	0.0%
You will receive a printed newsletter from the project team twice a year, letting you know how the research is going.	65.8%	31.5%	2.7%
There will be a special website for the research project, where you will be able to ask questions, leave feedback, and engage in online discussions with the research team and other participants.	76.7%	19.2%	4.1%
We will give you the telephone number and email address of one of the researchers. You can contact this researcher at any time if you have a question or comment about the research.	58.9%	37.0%	4.1%
One of the researchers will contact you by phone or email at least once a year, to check we have your correct contact details and tell you what we would like you to do next as part of the research.	54.8%	41.1%	4.1%

In addition to being keen to receive a final report of any research study in which they were a participant (Table 66) so as to know the outcomes and results, NT participants were particularly interested in seeing the outcomes of their own contributions; comparing their responses to those of other participants; and being able to then use the findings of the research study for their own personal purpose, learning or self-improvement.

“*To see other people's responses and how my opinion was the same as or different from other people's opinion.”*

“It would be interesting to see if there are bits that you contributed to, such as the comments, so that you get that connection that way and you have something solid to show for that time and that you took part.”

“When you get the results you also become empowered with that knowledge.”

Some NT participants suggested online or digital versions of communication materials rather than receiving paper. Others specifically expressed a preference for reading in a paper format.

“If get something in hard copy, I am more inclined to read it properly, emails you just put to the side, but you don’t get mail often, so I will open it and might leave it on the bench and maybe later come back to read it.”

“I hate paper, if it is not a bill I assume that it is junk mail and it goes directly to the recycling box next to the letter boxes.”

“I like a choice of online or paper.”

NT participants valued a project website as a central hub for all project information and activities, particularly as it made information and contact accessible on-demand so as to suit their own schedule. NT participants who were parents of autism spectrum children especially valued a project website for the opportunities it provided to network, share information and experiences, and connect to a project community.

“It's one central place to give people access to everything they need over the duration of the study.”

“It would be good to also send everything through this website, via a link, e.g. surveys, newsletters, discussion groups, so that everything is accessible via one central hub.”

“It makes you feel involved.”

“With a website) there's a connectedness, a networking (capacity). Also, people are able to respond to your questions so there's information-sharing. For people with autism in their families, having a child with autism can be very isolating socially, so there's that connectedness that allows you the opportunity for you to learn more, take in more, but also ask advice, share advice in a forum and its will prompt you to come in and stay connected to that over the longer duration of the study.”

“It’s on-demand too so it gives you a sense of control over your participation whereas if all you're doing is getting a yearly newsletter, it's passive participation and it's no control at all.”

Having the contact details of the research team was also seen positively by NT participants, particularly those who were parents of children on the autism spectrum. For some, this was because it provided access to expert information and advice about situations they may face with their autism spectrum children. For others, it was a means of seeking or providing clarification about any questions in the research.

“It would be good to have someone to give you advice about what to do in a situation, accessibility to someone who is an expert would definitely help me, or to discuss a question that you have been pondering for a while.”

“If I am going to the trouble of giving your time to doing something (participating in research), it's good to be able to find out the information you want easily.”

“Just in case I feel like my answers need explaining rather than just being online answers.”

The opportunity to be involved with the project ‘behind the scenes’ (Table 67) appealed to some NT participants and not to others. In their commentary on this topic, many NT participants qualified that their interest and capacity to be involved in this way would depend on the time commitment required, the need for travel and the nature of the activity.

TABLE 67. ADDITIONAL PARTICIPATION
NT participants

STATEMENT	MORE or MUCH MORE	NO DIFFERENCE	LESS or MUCH LESS
You will have the opportunity to be involved with the project ‘behind the scenes’, if you would like: e.g. helping with administrative tasks or the project newsletter.	39.7%	38.4%	21.9%

"I am interested in helping if practicable."

"I like to help where my heart is, but I'm not an envelope licker and I'm not going to travel a long way to do it. I'd want to do something that is useful. I'm already very involved in doing charity work, but if it is something that is going to help my autism spectrum daughter then I would get involved in this way."

"Having the option to be involved is good; might take it up later."

"Depends what the tasks are and if there is a support structure there for participation

"Taking part in the research over an extended period of time is enough for me."

"No time to do the background work."

Participating in the research along with friends or family members was considered as a motivator by some NT participants, but not the majority.

TABLE 68. PARTICIPATION OF FAMILY AND FRIENDS
NT participants

STATEMEN:	AGREE	NEITHER	DISAGREE
I would be more likely to take part in a research project if my friends or family members were also taking part.	34.2%	23.3%	42.5%

Access to either a telephone or to the internet was not identified as a significant barrier to participation for NT participants.

TABLE 69. REGULAR ACCESS TO INTERNET AND TELEPHONE
NT participants

STATEMENT	AGREE	UNSURE	DISAGREE
I have regular access to a telephone (landline or mobile).	97.2%	1.4%	1.4%
I have regular access to the internet.	98.6%	0.0%	1.4%

4.5.6 Social interaction

Most NT participants were either positive or neutral about activities that involved social interaction (Table 70), particularly if these activities required them to travel to attend.

TABLE 70. SOCIAL INTERACTION
NT participants

STATEMENT	MORE or MUCH MORE	NO DIFFERENCE	LESS or MUCH LESS
Once a year, we will invite you to come to a discussion group where you can meet other people who are also taking part in the research.	47.9%	38.4%	13.7%
Once a year, we will invite you to a drinks reception hosted by the research team. We will update you on how the research is going and you can meet other people taking part in the research.	58.9%	31.5%	9.6%

Common points in the commentary of most NT participants about why they would enjoy such activities and events were: the opportunities to engage in and learn from the exchange of ideas and information in face-to-face discussions, to meet others with similar interests, and to meet the research team. This was in addition to the sense of connection with the project and belonging to a community they would feel from such events.

"(In a discussion group) it's a great forum, because there is a lot of human interaction, and everybody's different, and when you are in that sort of forum, you can really see and hear other people's opinions and answers."

"I like discussion groups as I always learn something new."

"A discussion group is more personal than just doing a survey."

"Having a community is always good for people who have similar interest, to come together, so we can help each other out, we might all have a solution for each other, bring in a group creates an entity to work as a team, creates a synergy and support each other, rather than being along and struggling."

"I think that if you didn't meet anybody from the group other than speak to the researcher then there would be an air of suspicion and mystery which is more of a negative connotation, so if you get to meet other people in the group then you feel more real and connected to it, so there is more trust and you are more likely to open yourself up to the researchers."

"Having access to the brains behind the research, it's great, how often do we have access, it's good."

"It makes you feel like you are involved in something bigger than yourself."

Those NT participants who were unable to attend cited family commitments, time and travel as barriers to their participation in such activities.

"I like the idea but it would probably be hard for me to go as I live in a regional area and have two autism spectrum kids."

"I can't get out EVER."

"I could not attend - family commitments, time off work, and travel."

4.5.7 The personal is sensitive

Although most NT participants were positive about the offer to provide a referral to a psychologist if they experienced distress or anxiety as a result of taking part in the research (Table 71), a notable proportion indicated that this offer would discourage them from participating in a research study.

TABLE 71. STRESS AND ANXIETY FROM PARTICIPATION
NT participants

STATEMENT	MORE or MUCH MORE	NO DIFFERENCE	LESS or MUCH LESS
In the unlikely event that you experienced distress or anxiety as a result of taking part in the research, we would refer you to a psychologist for advice and support.	52.1%	31.5%	16.4%

The commentary provided by these NT participants on this topic indicated that great care would need to be taken when communicating any such provision to NT participants, as this offer could be open to misinterpretation by these participants.

"My gosh, I would hope this isn't needed?"

"There should be no need for this. There should be nothing in the research that will cause distress."

"If you told me at the start before I signed up I would start thinking, if I am going to end up with anxiety issues do I really want to part in this, what am I getting myself into, would make me worry, what stress am I going to be put through? "

"Sometimes if you bring up counselling and psychologists, people think - oh, there is nothing wrong with me, so if you're bringing it up really early, I think it could cause a bit of resistance. Although it's good to be clear right from the beginning, but it will definitely make some people worry about why is this required or even a consideration, what's this going to do to me, you need to be careful about it. It depends on how it is expressed; I might misinterpret and over-analyse."

"I don't think that my participation in this is going to make me have anxiety or mental breakdown."

"It gives you sense of trust that the organisation will treat you professionally, shows that you are a valued participant, that your contributions and your health are valued."

"For some people this could be a small security that means it feels good to know this is available; it gives the message 'You will be okay, if for any reason (there is any distress) there is back-up for you'."

Similarly, while most NT participants indicated they were not concerned about the privacy of the personal information they provide when they take part in research (Table 72), most indicated that provision of this information would make them less likely to participate in a research study, even with the assurance that this information would stay confidential and will not be shared.

TABLE 72. CONCERNS ABOUT PRIVACY
NT participants

STATEMENT	AGREE	NEITHER	DISAGREE
I tend to feel concerned about my privacy when taking part in research.	31.5%	16.4%	52.1%
STATEMENT	**MORE or MUCH MORE**	**NO DIFFERENCE**	**LESS or MUCH LESS**
As part of the research, we may ask you for information that is private or sensitive (e.g., about your health or your personal relationships). This information will stay confidential and will not be shared.	15.1%	32.9%	52.0%

"When you have kids with autism your privacy went a long time ago."

"Personally I not really fussed about confidentiality but I know some people are very sensitive about this."

"This is all okay, because the personal, private information won't be identifiable."

"It's a given that if you are doing research, then the information is going to be confidential, and it would be useless information if it wasn't important (private) information."

4.5.8 Physical and mental health

A small proportion of NT participants indicated that their mental health may be a potential barrier to participation (Table 73). None considered that their physical health would inhibit their participation, though some were unsure about this.

TABLE 73. PHYSICAL AND MENTAL HEALTH
NT participants

STATEMENT	AGREE	UNSURE	DISAGREE
My mental health might be a barrier to me taking part in a long-term research project	6.8%	13.7%	79.5%
My physical health might be a barrier to me taking part in a long-term research project.	0.0%	9.6%	90.4%

4.5 RECRUITMENT STRATEGIES

The experience of recruiting participants for this study provided useful insights about the relative effectiveness of different methods of identifying and reaching potential participants for autism spectrum research.

To effectively recruit participants for each of the specific categories required for this study, a ‘broad brush’ method was found to be least effective. Rather, a more effective approach was to tailor the networks, methods, communication channels and messages in order to reach and appeal to each specific category of participants, and indeed to appeal to subgroups of people within the HFA-AS and ASD+ID categories.

4.6.1 Participants with high functioning autism/Asperger’s Syndrome

- Recruitment communications via social media, through the many autism support networks, support groups and service providers was an effective initial step in recruiting HFA/AS participants.
- Enlisting the support and assistance of those individuals in the high functioning autism/Asperger’s community who were active, high profile and well-connected advocates for this community was particularly effective in recruiting HFA/AS participants for both the online survey and particularly the focus groups. As with recruiting Carers via disability service providers, this recruitment via an established person or group within the community provided credentialed and trusted access to the participants.
- Some HFA/AS participants were also recruited through snowballing, by encouraging NT participants who were already recruited to the study to enlist any relatives and friends with autism to also join the study as participants.

4.6.2 Participants with an autism spectrum disorder and an intellectual disability (ASD+ID), and their Carers

The most challenging participants to recruit into the study were those with an autism spectrum disorder and an intellectual disability (ASD+ID).

- Recruiting ASD+ID participants required the longest amount of time and the greatest amount of effort.
- Rather than directly recruiting the ASD+ID participants, the only effective method found in this study was to first recruit their Carers as co-participants. For the ASD+ID participants, their Carers were found to fulfil a role as the ASD+ID participant’s ‘gatekeeper’, and as a general rule the conduit for all communications and consent/assent.
- Carers of ASD+ID participants were most effectively identified and reached through disability networks, rather than through the autism community.
- While a small proportion of Carers and ASD+ID participants were recruited via social media and this was not an invalid recruitment method for these participants, the primary sources of Carers recruited for this study were found through the assistance and co-ordination of disability carer network organisations and disability service providers.
- Identifying and linking in to existing, established disability carer support groups, particularly those organised by or co-ordinated via disability service providers provided credentialed and trusted access to Carers of ASD+ID participants.

4.6.3 NT participants

While the potential pool of neuro-typical participants could be considered to be anyone in the general population who is not on the autism spectrum, the experience of the researchers in this study was that that those neuro-typical participants most likely to be interested in taking part in research about the autism spectrum were those people who had a personal association through family or friends with a person on the autism spectrum.

The two methods found to be effective in recruiting NT participants into this study were:

- Recruitment communication via social media through autism support networks, support groups and service providers
- Snowballing, by encouraging those HFA/AS participants who were already recruited to the study to enlist their neuro-typical relatives and friends to also join the study as participants.

4.6.4 Project co-ordination

With recruitment being implemented through a number of CRC research partners in different locations around Australia, the lead research partner developed a single set of communication materials, with consistent text, content, messages and visuals and thus a clear and distinctive project branding, combined with a co-ordinated approach and schedule to recruitment methods. This ensured a cost-effective use of resources in recruitment and consistent recruitment communications and branding of the study across all locations and partners.

5. Limitations

It is an unavoidable paradox that the scope and applicability of the findings from this study are defined by the relative success of the recruitment approaches employed in this study.

Thus, while every identifiable means (within the time and resource limits of this study) were used to engage as broad a spectrum of participants from each identified category (HFA/AS; ASD+ID, Carers and NT) as possible, the reach of the study is limited by:

- the effectiveness of the recruitment communications, including key messages, visual style and researcher communication style;
- the reach of the recruitment methods used; and
- the relatively restricted time period allocated to recruitment, particularly for the online survey.

The researchers did not gather or evaluate any quantitative data on the effectiveness of the participant recruitment methods used in this study.

The reach of this study is also limited by the limited modes of participation offered to participants.

The literature identifies that surveys, focus groups and interviews can be of limited use and suitability for effective involvement of people on the autism spectrum (Trembath, Germane, Johanson and Dissanayake, 2012), and those with learning, communication and other disabilities in research (e.g., Becker, Roberts, Morrison and Silver, 2004; Butler, Cresswell, Giatros and Teffrey-Wijne, 2012; Fraser and Fraser, 2001; Gates and Waight, 2007; Harrington, Foster, Roger and Ashburner, 2014; Kaehne and O'Connell, 2010; Ninda, 2008; Ottoman and Crosby, 2013; Prior, Walter and Kroll, 2013).

Studies on the use of online communication and social media by adults on the autism spectrum (Burke, Kraut and Williams, 2010; Mazurek, 2013) offer some additional or alternative modes of participation. Examples of such alternatives that allow participants to provide extended responses and engage in open exchange (either participant and researcher only, or researcher and participant group), which could be incorporated into future studies include:

- online asynchronous discussion (Brownlow and O'Dell, 2009)
- video/online conferencing, e.g., via Skype
- discussion or interview via email (Bedford and Standing, 2011).

We did not examine the reasons why non-participants chose not to, or were unable to participate in this study.

In presenting concepts to participants, the study did not differentiate between recruitment and retention. Instead, the overall concept discussed was 'participation' and the individual's likelihood of taking part in research.

The findings of the study are also limited by the extent to which the study fully engaged participants and allowed them to contribute their opinions. This includes:

- the abilities of individual researchers to engage with and draw opinions from participants in focus groups and interviews, and to subsequently interpret those views in the data analysis; and
- the limited involvement of those who participated via the online survey where extended contributions required additional written responses (whereas those who participated in focus groups were stimulated and encouraged to contribute by the process of group discussion).

Based on existing literature, the study method was designed primarily to focus on those options presented to participants. However, the focus group discussions and the free form response facility in the online survey also generated numerous additional suggestions from participants (Appendix 5).

As this study was specifically undertaken to inform future research within the Australian based *Cooperative Research Centre for Living with Autism Spectrum Disorders*, it was conducted with participants who were resident in Australia only. Thus, the findings of this study may be limited in their application in other countries.

Although the researchers sought to gather data from a representative sample of the population based on age and gender, there was no examination of any impact that socio-demographic factors (e.g., age, gender, place of residence, income, employment status, education level, ethnicity) may have on motivators and barriers to participation in longitudinal autism spectrum research. Though focussed on families with children and adolescents, Perez, Ezpeleta and Domenech (2007) found that refusal of participation at the outset of mental health epidemiological (longitudinal) studies was more probable for lower socioeconomic families, minority cultures and those with low school performance. Whether or not this is similarly true for those adults the autism spectrum cannot be determined here.

6. Implications for Future Studies

The aim of this research study was to identify the factors that influence the participation of adults both on and not on the autism spectrum in longitudinal research about the autism spectrum.

The responses gathered from participants in this study indicated there were a small number of similarities, and a larger number of notable differences both between and within the different participant categories with respect to those factors that were likely to influence, either positively or negatively, their participation in research about the autism spectrum.

These similarities and differences both between and within categories of participants are the key determinants of factors that researchers need to consider for inclusion and exclusion from any programs that seek to optimise the recruitment and retention of participants in longitudinal autism spectrum research.

6.1 ONE SIZE DOES NOT FIT ALL IN AUTISM SPECTRUM RESEARCH

As noted earlier in this report, factors that influenced participation in longitudinal autism spectrum research can be categorised as either:

- Motivators - *the reasons why I participate; the outcomes I am seeking through my participation*
- Inhibitors - *factors that discourage or prevent me from taking part*
- Enablers - *factors that make it easier for me to take part.*

In addition, and importantly, some factors that were identified as motivators for certain participants were found to be either inhibitors or enablers for others.

For example:

- For some HFA/AS participants, the opportunity for social interaction with other HFA/AS participants was a key reason or incentive for taking part (a motivator); for other HFA/AS participants, any requirement to interact socially either discouraged or prevented them from taking part.
- For many ASD+ID participants and some NT participants, extrinsic rewards were a motivator for participation. For some HFA/AS participants, such rewards were an inhibitor. For some Carers, NT participants and HFA/AS participants, extrinsic rewards were enablers for their participation.

Thus, to maximise the levels of both comfort and satisfaction for the broadest range of participants while taking part in the study, participation programs need to be carefully designed:

- to be sensitive to the very broad spectrum of all potential participants' differing communication, social and cognitive skills and preferences; lifestyles; and sensory needs; and
- to take into account the incompatibility of the preferences for some participants with those of others.

The particular requirements and preferences identified as being specific to each category who participated in this study are listed in Tables 7, 8, 9.and 10.

6.2 ENSURE RESEARCHER SENSITIVITY TO AND KNOWLEDGE ABOUT THE AUTISM SPECTRUM WORLD

For participants living on the autism spectrum, receiving respect for and understanding of their particular situation and needs was identified as a key enabler for their participation in any research study, and in some cases this was a motivator. Conversely, the absence of such respect and understanding was found to be a key inhibitor of their participation.

Some practical examples of such respect and understanding of the broad spectrum of the lived experience of autism could include:

- Selecting event venues that cater for sensory issues experienced by some autism spectrum people, such as discomfort with excessive noise, light and crowds
- Offering options for data collection that do not require face-to- face communication, social interaction, or travel
- Providing the facility for participants to give additional explanations for any responses to questions and feedback to the research team on research methods
- Eliminating ambiguity and potential for multiple meanings or interpretations in any communication
- Establishing relationships of trust with ASD+ID participants prior to any recruitment or data collection
- Providing the option to come to the home environment of ASD+ID participants to collect data
- Providing in-time reminders and information for any events and activities
- Avoiding any stereotyping of the attributes of people with autism.

Ensuring that all researchers and other staff who are involved in the design and administration of Autism CRC Program 3 studies have appropriate training in and knowledge of the lived experience of people on the autism spectrum is likely to contribute to optimising the recruitment and retention of those participants who are on the autism spectrum in any ongoing research.

6.3 PROVIDE MAXIMUM CHOICE AND FLEXIBILITY

Related to the broad spectrum of participant preferences, a commonality observed across and within all participant categories was the preference for researchers to offer participants a range of choices or options across all aspects of their project involvement, so as to enable participants to engage with the research project in a way that is most convenient for them; most appropriate to their individual lifestyle and their communication, social and cognitive skills and styles; and gives them the greatest level of satisfaction about their participation.

Thus, offering and clearly communicating to participants about the following options can be expected to optimise participant recruitment into the Autism CRC Program 3 research studies:

- How, when and where to participate
- A choice of modes of participation that:
    - provide exposure to social interactions
    - do not require any social interaction
- Opt-in/out to receive communications
- Options for preferred format for communication and materials: e.g. digital/print; telephone/email/ post/face-to-face
- Opt-in/out to receive for rewards and incentives
- Options for different types of rewards and incentives
- A range of options for additional involvement in the research project appropriate for, and sensitive to different participants' interests, capacity and skills.

6.4 TAILOR RECRUITMENT METHODS TO MOST EFFECTIVELY REACH DIFFERENT TYPES OF PARTICIPANTS

The recruitment of different categories of participants into autism spectrum research studies can be optimised by tailoring the choice of community networks, methods, communication channels and messages that are used, so as to most effectively reach and appeal to each specific category of participants.

Participants with high functioning autism/Asperger's Syndrome

- Channel recruitment communications via social media, through the many autism support networks, support groups and service providers as an effective initial step in recruiting.
- Enlist the support and assistance of those individuals in the high functioning autism/Aspergers community who are active, high profile and well-connected advocates for this community, as this provides credentialed and trusted access to the participants.
- The use of snowballing, by encouraging neuro-typical participants already recruited to the study to enlist any relatives and friends with autism to also join the study as participants, can also be effective.

Participants with an autism spectrum disorder and an intellectual disability (ASD+ID), and their Carers

- Allow adequate time in the project schedule for recruiting ASD+ID participants and their Carers.
- It is essential to first recruit and then retain their carers as co-participants.
- Make use of disability networks, as well as the autism community, to reach carers of ASD+ID participants.
- Enlist the assistance and co-ordination of disability carer network organisations and disability service providers, particularly by linking in to existing, established disability carer support groups organised by or co-ordinated via disability service providers to provide credentialed and trusted access to Carers of ASD+ID participants.

Neuro-typical participants

- Potential neuro-typical participants for autism spectrum research can be effectively recruited via social media, including via autism support networks, support groups and service providers.
- Snowballing, by encouraging those HFA/AS participants already recruited to the study to enlist their neuro-typical relatives and friends to also join the study as participants, can also be effective.

6.5 KEY-IN TO PARTICIPANTS' MOTIVATIONS WITH EFFECTIVE RECRUITMENT AND RETENTION COMMUNICATIONS

For those who participated in this study, a key motivation for participation was the desire, and for some, the commitment to advance autism spectrum research that will help to improve the well-being of, opportunities for, and acceptance of people who are living with autism.

Thus, effective recruitment and retention communications that can be expected to assist to optimise participant recruitment into these studies include providing participants with:

- clear communications about the purpose and pragmatic, results-oriented nature of the Living with Autism CRC Program 3 research projects; and
- the option to receive ongoing updates on the progress of the research project and a final report on the study results and outcomes, with a focus on pragmatic programs to assist people with autism that are being or will be developed and implemented as a result of the study findings
- feedback on the impact that their contribution has made and is making to autism spectrum research
- a connection to, and information about, the wider Autism CRC program and community.

In addition, the findings of this study indicate that each category of participants will also be most responsive to recruitment messages that are specific to their key motivations for participating in longitudinal autism spectrum research:

For participants with high functioning autism/Asperger' Syndrome

Any opportunities that the research project would provide for them to:

- have their say, have their voice heard, and be understood for who they were
- be valued for the special talents and perspective that they could bring to autism spectrum research; and
- participate as equal and skilled partners in actively shaping the direction, design and implementation of the research project.

For Carers of ASD+ID participants, who were the gatekeepers, these motivations were:

- The real contribution that their participation would make to the development and implementation of practical programs of support to improve the well-being of and opportunities for their ASD+ID child.
- Any opportunities that the research project will provide for their ASD+ID child to:
    - Learn more about themselves, others and the world around them, particularly in terms of how they as individuals relate to the world and why that is so.
    - Develop skills and experience in, or relevant to, a work environment.
    - Make connections and friendships and, based on their personal interests, share activities and experiences with other similar people living with autism and an intellectual disability.

For neuro-typical participants

Any opportunities that the research project would provide for them to:

- Do something to help others, especially any family members living with autism, in a way that was simple and convenient.
- Learn more about themselves and see how they compare with others.

6.6 ONLY SOME EXTRINSIC REWARDS ARE EFFECTIVE, AND ONLY AS TOKENS OF APPRECIATION

Correspondingly, with the exception of ASD+ID participants, the offer of extrinsic rewards such as gifts, cash and vouchers were not identified as a motivator for participation. However, these rewards were considered to be effective enablers of participation in providing a form of acknowledgement and recognition for the participant's contribution.

To optimise participant recruitment and retention, research studies in the Autism CRC Program 3 could:

- Offer a choice of cash (or pre-paid credit card) or a range of vouchers of no more than a small, token value, such as $30 for a two hour contribution, clearly offered as acknowledgement and appreciation of the participant's contribution.
- Provide the option for participants to donate the value of any reward to either a CRC research project or an autism spectrum-related charity.
- Exclude gifts (especially branded items such as pens, hats and mugs), birthday cards and 'tell-a-friend' rewards from any incentive program, as these types of rewards are likely to generate a negative reaction with many participants with high functioning autism/Asperger's Syndrome, Carers and neuro-typical participants, and may represent a 'waste' of resources.
- The exceptions to this are:
    - if the project is dealing solely with ASD+ID participants, or
    - if the researcher has established a personal one-on-one relationship with the individual participant.

6.7 OFFER REIMBURSEMENT FOR TRAVEL, FOR A FIXED AMOUNT

Where travel will be required by participants to take part in project activities, receiving a reimbursement for all or part of the participant’s travel costs is likely to act as an enabler for participants in all categories.

Future research studies in the Autism CRC Program 3 could optimise participant recruitment and retention by offering participants a standard, flat payment for the travel cost of each round trip they make to participate in a project activity (i.e., an amount that is not inked to the individual distanced travelled or fares/petrol purchased, but is the same value for all participants), paid to participants via either a pre-paid credit card, a generic voucher or direct bank transfer.

6.8 PROVIDE CONNECTION AND A SAFE, CARING COMMUNITY FOR PARTICIPANTS

Across all categories in this study, participants expressed a sense of satisfaction in belonging to a community of like-minded people with similar interests, with whom they could share and exchange information and experiences in a safe, caring and understanding environment.

Thus, initiatives and activities that offer such a facility for project participants can be expected to act as a motivator in the recruitment and retention of participants, such as:

- A secure project website that
  - provides a single, central hub for all project information, communications and activities;
  - engenders a sense of belonging and membership; and
  - provides opportunities for online interaction between participants, and also with the research team.
- Task-oriented forums, discussion groups and social groups, where participants can interact with each other and to meet with and hear from the research team, with a focus around topics related to the autism spectrum or autism spectrum research.
- Invitations to join a group of participants at social events conducted by autism spectrum- related organisations, such as art exhibitions and entertainment/performances. Projects could consider offering participants either free or discounted entry to such events, as part of any reward program for the project.

6.9 APPLY A CO-ORDINATED APPROACH TO PLANNING, RECRUITMENT AND DATA COLLECTION ACROSS ALL RESEARCH PARTNERS IN A PROJECT

The use of a single set of communication materials, with consistent text, content, messages and visuals and thus a clear and distinctive project branding, together with a co-ordinated approach and schedule of recruitment methods developed by and implemented via the lead research partner in each CRC project, will help to optimise recruitment and retention of participants. It will also assist the project to achieve a cost-effective use of resources and compliance with the study’s recruitment and data collection approach across all locations and partners.

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Appendix 1

RECRUITMENT MATERIALS

RECRUITMENT POSTER/FLYER – EXAMPLE

SCREENING QUESTIONNAIRE

APPENDIX 1: RECRUITMENT POSTER/FLYER – EXAMPLE

Why would you volunteer to participate in a research study?

We'd like to invite you to a small focus group discussion in Sydney for 1 - 2 hours in June 2014. **Our aim is to find out what would encourage you to participate in a study about the well-being of people living with ASD and people without ASD.** You will be thanked with a $20 shopping voucher and refreshments will be provided during the session.

Who can participate?

We'd like to hear from you if you are aged 18+ and either:

- you have been diagnosed with ASD or Asperger's Syndrome, or
- you are the parent, sibling or other relative, friend, guardian or carer of an adult diagnosed with ASD, or
- you have not been diagnosed with ASD or Asperger's Syndrome.

Interested?

For more information or to participate, please register via:
autismspectrum.org.au/research or Telephone: 02 8868 8508
or Email: khaas@autismspectrum.org.au

This study is part of the Australian Government Initiative: the Cooperative Research Centre for Living with Autism Spectrum Disorders (Autism CRC) Aspect Ethics Approval No. 1411

autism spectrum
AUSTRALIA

APPENDIX 1: SCREENING QUESTIONNAIRE

Participant screening and recruitment questionnaire
(administered by researcher, by phone)

(administered by researcher, by phone)

Introduction

We are conducting a research study to help plan new research in the future for the Living with Autism CRC program that will last for four years. The information we gather now will help us work out how to go about recruiting people to take part in this study and how we can keep them interested and involved over the whole four years.

In this study now, we are asking participants who are aged 18 years + to come along to one focus group (this is like a discussion group) with a small number of other people like you.
We expect that the focus group will take 1 to 2 hours of your time.

During the focus group session, we will:

- talk to you about why you might like to volunteer to participate in research studies and what things you may not like about participating in a research study
- ask you about the kinds of things that you would like to have as a thank you for taking part in the research and discuss whether these are things that would make you more likely, or less likely, to take part in a long-term research project
- ask you to fill out a short questionnaire asking a few more questions about things that might make it easy or difficult for you to be involved in research.

So we can contact you if we need to, we will ask you for your name and email address and phone number, and we will need to ask you about your age, gender, and any diagnosis for an Autism Spectrum Disorder (ASD) or intellectual disability (ID).

We will not identify you in any report about the study. We will only report by group on the age range of the participants, the number of males and females, the number of people with ASD and the number of people with an intellectual disability who were in the group.

We are interested in talking with adults aged 18+.

The focus group sessions will be:

on [dates]from [time] to [time]
at [venue]

Are you still interested in participating?

☐ YES, happy to participate in focus group-> Go to 2

☐ YES, but not in a focus group--> Go to 1

☐ NO --> *thank caller. Ask caller to pass on information to someone who may be interested in participating, who could call us.*

1 ***For participants who are interested in participating in the study, but not in a focus group, discuss the possibility of an individual session with the participant and the researcher***.

We first need to ask some personal details about you/the person in your care to be able to place participants into the correct focus group.

2 Are you calling

☐ on your own behalf, as an interested participant

☐ as the carer/guardian of an interested participant

3 What is your age/the age of the person in your care at your/their last birthday: _____

4 Gender of participant: ☐ Female ☐ Male

5 Have you/ the person in your care been diagnosed with ASD and/or an intellectual disability?

☐ ASD only	check participants needed for *Category 1: with ASD and no ID*	☐ YES? Go to 7
☐ ASD **AND** ID	check participants needed for *Category 2: with ASD and no ID*	☐ YES? Go to 6
☐ NO ASD & NO ID	check participants needed for *Category 3: with NO ASD & NO ID*	☐ YES? Go to 8

☐ If NO, ask if caller know anyone else who might be able to participate in categories for which you still need participants

6 What is the diagnosed ID?

____

7 a) Year of ASD diagnosis

____

b) Health professional providing ASD diagnosis

____

c) type of ASD diagnosis, if known

____

If caller is unable to confirm an ASD diagnosis, explain to caller that we are seeking to talk with people who have an ASD diagnosis.

8 Contact details

We need to take your contact details so that we can send to you:

- an information sheet about this research study
- an information sheet about the focus group, with details about the place, day and time for your group, and information about how to get there
- a consent form for you to sign.

You will need to bring the Consent form with you when we meet with you.

NOTE: if *in Category 2* ***ASD &ID with Carer***, explain that the participant's legal Guardian will need to:

- sign the Carer Consent Form
- a carer will need to accompany the participant in any meeting.

	Participant	**Carer, for Category 2**
First name		
Family name		
Telephone		
Mobile		
email		
or postal address		

We'll now send to you an information sheet about the research study and a consent form for you to sign. You should receive this in the next 1 to 2 days.

When you receive the information, read through it and if you have any questions about participating in the study, please contact [researcher name].

Our contact details will be on the information sheet we send to you.

If for any reason you change your mind or you cannot come to this focus group, please simply let us know as soon as possible. There is no penalty or consequence for you if you decide you do not want to participate, or you are not able to come.

Thank you ☺ That's all the information that we need - I can now sign you on as a participant.

We look forward to meeting you on [focus group/meeting date, time, place].

Appendix 2

PARTICIPANT CONSENT FORMS

PARTICIPANT INFORMATION STATEMENT

PARTICIPANT CONSENT FORM

PARTICIPANT WITHDRAWAL OF CONSENT FORM

PARENT/GUARDIAN INFORMATION STATEMENT

PARENT/GUARDIAN CONSENT FORM

PARENT/GUARDIAN WITHDRAWAL OF CONSENT FORM

APPENDIX 2: PARTICIPANT INFORMATION STATEMTNT

Participant Information Statement

OPTIMISING RECRUITMENT AND RETENTION FOR LONGITUDINAL RESEARCH
An Australian Government funded Cooperative Research Centres (CRC) Program

Investigators:

- **Dr Debra Costley**: **Autism Spectrum Australia (Aspect) –** ***Lead Researcher,***
  Tel: 02 8868 8502, Email: dcostley@autismspectrum.org.au –
- **Dr Trevor Clark**: Autism Spectrum Australia (Aspect), Tel 02 8868 8511, Email: tclark@autismspectrum.org.au
- **Associate Professor Amanda Richdale**: Olga Tennison Research Centre, La Trobe University, Tel: 03 9479 1742, Email: a.richdale@latrobe.edu.au
- **Associate Professor Kate Sofronoff**: School of Psychology, University of Queensland, Tel: 07 3365 6411, Email: k.sofronoff@psy.uq.edu.au
- **Professor Torbjorn Falkmer**: School of Occupational Therapy and Social Work, Curtin University, Tel: 08 9266 905, Email: t.falkmer@curtin.edu.au

You are invited to participate in a research project being conducted by Autism Spectrum Australia, La Trobe University, The University of Queensland and Curtin University. This project is funded by the *Living with Autism Cooperative Research Centre (CRC)*, under Core Program 3*: Adulthood. Finding a Place in Society* and is led by Dr Debra Costley and Dr Trevor Clark from Aspect. You can find out more about the autism CRC at http://www.autismcrc.com.au/

This information sheet describes the project in straightforward language, or 'plain English'. Please read this sheet carefully and be confident that you understand its contents before deciding whether to participate. If you have any questions about the project, please ask one of the investigators named above.

Is this Study Approved?

This study has been approved by the Aspect Research Approvals Committee on 22 April 2014, reference number 1141.

What is this research about?

The aim of this research is to find out what kinds of things encourage people to take part (and stay involved) in research projects. The areas we are interested in looking at include:

- what would encourage you to be part of the study
- what rewards you would like.

The findings from this research will be used to help plan new research for the Living with Autism CRC program. One of the important CRC studies will last for four years. The information we gather now will help us work out how to go about recruiting people to take part in this study and how we can keep them interested and involved over the whole four years.

You have been invited to take part in this research because you are an adult aged 18 years or older and you fall into one of the following groups:

1. An adult with a diagnosis of ASD or Asperger's syndrome.
2. The parent, guardian, or caregiver of an adult with a diagnosis of ASD, autism or Asperger's syndrome.
3. An adult without ASD.

What am I being asked to do?

We are inviting you to take part in one focus group (discussion group) with a small number of other people like you. We expect this will take 1 to 2 hours of your time. During the focus group we will talk to you about why you might like to volunteer to participate in research studies and what things you may not like about it.

We will ask you about the kinds of things that you would like to have as a thank you for taking part in the research. We will also ask you, along with the other people in the group, to discuss whether these are things that would make you more likely, or less likely, to take part in a long-term research project.

As well, we will ask you to fill out a short questionnaire asking a few more questions about things that might make it easy or difficult for you to be involved in research.

So we can contact you if we need to will ask you for your name and email address or phone number.

So we can correctly research about the views of people with ASD, we will ask you to tell us the date, provider and details of any ASD diagnosis you have received. So in our report we can describe the group of people who took part in the study, we will ask you your age, your gender and if you have an intellectual disability. In our report we will not identify you. We will only use the age range of the group, the number of males and females, the number of people with a diagnosis of ASD, and the number of people with an intellectual disability who were in the group.

What will happen to the information I provide?

One of the researchers will take notes during the focus group, and the group discussion will also be audio-recorded to ensure that we have a record of everything you tell us about participating in research. We will combine our notes and audio recordings from all of the focus groups we run and write a report that summarises the discussions across those groups. The study and report will be completed by the end of 2014.

We will use this information to help us recruit people like you to participate in the Autism CRC adult research projects, especially the 4-year study. Our report may also be used as a basis for journal articles or conference presentations in the future.

If your questionnaire can be identified individually you will have access to it should you request it, in accordance with privacy laws. Any information that you provide can only be disclosed if (1) it is to protect you or others from harm, (2) a court order is produced, or (3) you provide the researchers with written permission.

No individuals will be named in the research report, and the findings will be reported at a group level only (for example: "30 per cent of participants said…").

All paperwork, electronic files and audio recordings relating to this research will be kept in a lockable filing cabinet or on a password-protected computer at the participating institution associated with your focus group. Only the research team will have access to this information. Data will be retained for at least five (5) years following completion of the project or 5-years after the publication of any journal article after which it and will be destroyed (shredded or deleted).

Can I get a copy of the results of the study?

Once the research has been completed, participants can request a written summary report by contacting Dr Debra Costley or Dr Trevor Clark at Aspect.

Early in 2015, you will be able to find a summary of the research on the on Living with Autism CRC (http://www.autismcrc.com.au/) Knowledge Hub. A link to this web page will also be provided via the websites of Autism Spectrum Australia.

What are the benefits of taking part in this research?

There are no direct personal benefits to taking part in this research, although we hope you will find the process interesting and enjoyable. The findings will contribute to the smoother running of future research projects, by providing information on how people can be encouraged to sign up and maintain their involvement as participants in research.

A $20 shopping voucher will be given to each participant as a thank-you. There is only one voucher per family in order to reward the person who the questions are about.

What if I don't want to take part?

Participation in this research is entirely voluntary. There are **no** disadvantages, penalties or adverse consequences for not participating and you do not need to give a reason. You may also withdraw from the focus group at any time while it is in progress. However, due to the 'group discussion' nature of the study data, we regret that it will not be possible to identify and remove your individual data from the focus group notes and audio recordings after the event. You also have the right to have any questions answered by the research team at any time.

What should I do if have a question, complaint or concern?

General questions regarding this project may be directed to the investigator named above at the institution associated with your participation.

If you have any complaints or concerns about your participation in this study that the researchers have not been able to answer to your satisfaction, you may contact

Aspect Research Approvals Committee
Tel 02 8868 8504
Email aspectpractice@autismspectrum.org.au
Please quote the Aspect Research Approval Reference number 1141, 22 April 2014.

APPENDIX 2: PARTICIPANT CONSENT FORMS

Consent Form: Participant

OPTIMISING RECRUITMENT AND RETENTION FOR LONGITUDINAL RESEARCH
An Australian Government funded Cooperative Research Centres (CRC) Program

I (the participant) have read (or, where appropriate, have had read to me) and understood the **Participant Information Statement and Consent Form,** and any questions I have asked have been answered to my satisfaction. I agree to participate in the project, realising that I may withdraw at any time. I agree that research data provided by me or with my permission during the project may be included in a report, presented at conferences and published in journals on the condition that neither my name nor any other identifying information is used.
I understand that this focus group session will be audio-recorded and consent to my audio data being reviewed for the purposes of analysis, subject to the above conditions of confidentiality.

☐ Yes ☐ No

Please note: *You have the right to withdraw from active participation in this project at any time and, further, to request that data arising from your participation are not used in the research project, provided that this right is exercised within four weeks of the completion of your participation in the project. In this case, you are asked to complete the enclosed "Withdrawal of Consent Form" or to notify the researcher by email or telephone that you wish to withdraw your consent for your data to be used in this research project.*

Name of Participant (block letters):___________________________________

Signature: ____________________________ Date _______________________

Name of Carer/Guardian (block letters,) if applicable

APPENDIX 2: PARTICIPANT WITHDRAWAL OF CONSENT FORMS

Withdrawal of Consent for Use of Data Form: Participant

OPTIMISING RECRUITMENT AND RETENTION FOR LONGITUDINAL RESEARCH
An Australian Government funded Cooperative Research Centres (CRC) Program

I, the participant, wish to WITHDRAW my consent to the use of the individual data arising from my participation in this study.

I am aware that due to the group discussion nature of this study, it may not be possible to identify and remove my individual data from the focus group notes and audio recordings after the focus group has finished.

I understand that I can withdraw from the study at any time and that there will be no disadvantage, penalties or adverse consequences for non-participation or withdrawal. From this point on no data about me will be collected or recorded.

Data arising from my participation that can be identified in this research project, as described in the Information and Consent Form, will be removed and not included in the study, and individual questionnaire data from my participation will be destroyed provided this request is received within four weeks of the completion of our participation in this project.

I understand that this notification will be retained together with my consent form as evidence of the withdrawal of my consent to use the data provided by me specifically for this research project.

Participant's name (printed):

…………………………………………………………

Signature:

………………………………………………………… Date: ……………….

APPENDIX 2: PARENT/GUARDIAN INFORMATION STATEMENT

Parent/Guardian Information Statement

OPTIMISING RECRUITMENT AND RETENTION FOR LONGITUDINAL RESEARCH

An Australian Government funded Cooperative Research Centres (CRC) Program

Investigators

Dr Debra Costley, Autism Spectrum Australia (Aspect) – *Lead Researcher*
tel: 02 8868 8502, email: dcostley@autismspectrum.org.au

Dr Trevor Clark, Autism Spectrum Australia (Aspect)
tel 02 8868 8511, email: tclark@autismspectrum.org.au

Associate Professor Amanda Richdale, Olga Tennison Research Centre, La Trobe University
Tel: 03 9479 1742, Email: a.richdale@latrobe.edu.au

Associate Professor Kate Sofronoff: School of Psychology, University of Queensland
tel: 07 3365 6411, email: k.sofronoff@psy.uq.edu.au

Professor Torbjorn Falkmer, School of Occupational Therapy and Social Work, Curtin University
tel: 08 9266 905, email: t.falkmer@curtin.edu.au

The person in your care is invited to participate in a research project being conducted by Autism Spectrum Australia, La Trobe University, The University of Queensland and Curtin University. This project is funded by the Living with Autism Cooperative Research Centre (CRC), under Core Program 3: Adulthood. Finding a Place in Society and is led by Dr Debra Costley and Dr Trevor Clark from Aspect. You can find out more about the Living with Autism CRC at http://www.autismcrc.com.au/

This information sheet describes the project in straightforward language, or 'plain English'. Please read this sheet carefully and be confident that you understand its contents before deciding whether you consent for the person in your care to participate. If you have any questions about the project, please ask one of the investigators named above.

Is this study approved?

This study has been approved by the:

- Aspect Research Approvals Committee [approval date, contact details]
- La Trobe University Human Ethics Committee, [approval number]; contact the Secretary, Human Ethics Committee, Research Services, La Trobe University, Victoria 3086 (Tel: 03 9479 1443, email: humanethics@latrobe.edu.au)
- The University of Queensland Human Ethics Committee [approval number, contact details]
- Curtin University Human Ethics Committee [approval number, contact details]

If you have any complaints or concerns about the participation of the person in your care or yourself in the study that the researcher has not been able to answer to your satisfaction, you may contact
Aspect Research Approvals Committee
Tel 02 8868 8504 Email aspectpractice@autismspectrum.org.au
Please quote the Aspect Research Approval Reference number 114 of 22 April 2014.

What is this research about?

The aim of this research is to find out what kinds of things encourage people to take part (and stay involved) in research projects about living with autism. The areas we are interested in looking at include:

- what would encourage people to be part of a study
- what rewards people would like for taking part in a study.

The findings from this research will be used to help plan new research for the Living with Autism CRC program. One of the important CRC studies will last for four years. The information we gather now will help us work out how to go about recruiting people to take part in this study and how we can keep them interested and involved over the whole four years.

The person in your care has been invited to take part in this research because this person is an adult aged 18 years or older with a diagnosis of ASD or Asperger's syndrome.

What is the person in my care being asked to do?

We are inviting the person in your care, together with either you or another carer for that person, to take part in one meeting of a focus group (discussion group) with a small number of other people like the person in your care. The estimated time for a focus group meeting is one to two hours.

During the focus group we will talk to the person in your care about why they might like to volunteer to participate in research studies and what things they may not like about it. We will ask them about the kinds of things that they would like to receive as a thank you for taking part in the research and along with the other people in the group, discuss whether these are things that would make them more likely, or less likely, to take part in a long-term research project.

As well, we will ask the person in your care to fill out a short questionnaire asking a few more questions about things that might make it easy or difficult for them to be involved in research.

What will happen to the information provided for and by the person in my care?

During the focus group, one of the researchers will take written notes and the group discussion will also be audio-recorded to ensure that we have a record of everything the person in your care tells us about participating in research.

We will combine our notes and audio recordings from all of the focus groups we run and write a report that summarises the discussions across those groups. We will use this information to help us recruit people like the person in your care to participate in the Autism CRC adult research projects, especially the 4-year study.

The study and research report will be completed by 30 September 2014. The report may also be used as a basis for journal articles or conference presentations in the future.

How and when can I access the research findings?

Once the study and research report has been completed by 30 September 2014, a summary of the research findings will be made available to all participants via the Knowledge Hub on the website of the Living with Autism CRC by December 2014, and a link to this web page will also be provided via the website of each research partner organisation (Autism Spectrum Australia, Olga Tennison Research Centre at La Trobe University; Curtin Health Innovation Research Institute; and Minds and Hearts Clinic, Queensland.).

Participants can also request a written summary report by contacting Dr Debra Costley or Dr Trevor Clark at Aspect. If your questionnaire can be identified individually you will have access to it should you request it, in accordance with privacy laws.

What personal information will be collected about participants?

The study will collect the following personal information about each participant:

- Name, email address, age and gender
- If the participant is identified by self or carer as having an intellectual disability
- The date, provider name and details of any ASD diagnosis that the participant has received.

The purpose of collecting these details about each participant is to use in the recruitment of participants, to make sure that each group of participants has approximately the same balance of ages and genders, and in our data analysis, to identify any differences in the viewpoints of people with and without ASD and/or an intellectual disability.

No individuals will be named in the research report, and the findings will be reported at a group level only (for example: *"30 per cent of participants said…"*).

Any information that is provide by or on behalf of the person in your care can only be disclosed if (1) it is to protect the person in your care, you or others from harm, (2) a court order is produced, or (3) researchers have written permission from you or the person in your care to do so.

All paperwork, electronic files and audio recordings relating to this research will be kept in a lockable filing cabinet or on a password-protected computer at the participating institution associated with your focus group. Only the research team will have access to this information. Data will be retained for at least five (5) years following completion of the project or 5-years after the publication of any journal article after which it and will be destroyed (shredded or deleted).

What are the benefits of taking part in this research?

There are no direct personal benefits to taking part in this research, although we hope you and the person in your care will find the process interesting and enjoyable. The findings will contribute to the smoother running of future research projects, by providing information on how people can be encouraged to sign up and maintain their involvement as participants in research.

A $20 shopping voucher will be given to each participant as a thank-you. There is only one voucher per family in order to reward the person who the questions are about.

What if I don't want to take part?

Participation in this research is entirely voluntary. There are **no** disadvantages, penalties or adverse consequences for not participating and you do not need to give a reason. You, together with the person in your care, may also withdraw from the focus group at any time while it is in progress. However, due to the 'group discussion' nature of the study data, we regret that it will not be possible to identify and remove an individual person's data from the focus group notes and audio recordings after the event. You and he person in your care also have the right to have any questions answered by the research team at any time.

What should I do if have a question, complaint or concern?

General questions about this project may be directed to
Dr Debra Costley, Autism Spectrum Australia (Aspect)
Tel 02 8868 8502 Email dcostley@autismspectrum.org.au

If you have any complaints or concerns about your participation in this study that the researchers have not been able to answer to your satisfaction, you may contact
Aspect Research Approvals Committee
Tel 02 8868 8504 Email aspectpractice@autismspectrum.org.au
Please quote the Aspect Research Approval Reference number 114 of 22 April 2014.

APPENDIX 2: PARENT/GUARDIAN CONSENT FORM

Consent Form: Carer/Guardian

OPTIMISING RECRUITMENT AND RETENTION FOR LONGITUDINAL RESEARCH
An Australian Government funded Cooperative Research Centres (CRC) Program

I attest that I am the legal Guardian of the participant listed below and have read and understood the **Participant Information Statement and Consent Form** and the **Parent/Guardian Information Statement and Consent Form,** and any questions I have asked have been answered to my satisfaction. I consent to the participant listed below to take part in the project, realising that the participant may withdraw at any time. I agree that research data provided by me or the participant with my consent during the project may be included in a report, presented at conferences and published in journals on the condition that neither my name, the name of the participant, nor any other identifying information is used.

I understand that this focus group session will be audio-recorded and consent to the audio data of the participation of me and the participant being reviewed for the purposes of analysis, subject to the above conditions of confidentiality.

☐ Yes ☐ No

***Please note: You and the person in your care** have the right to withdraw from active participation in this project at any time and, further, to request that data arising from the participation of you and the participant are not used in the research project, provided that this right is exercised within four weeks of the completion of your participation in the project. In this case, you are asked to complete the enclosed "Withdrawal of Consent Form" or to notify the researcher by email or telephone that you wish to withdraw your consent for the data related to the participant of you and the participant to be used in this research project.*

Name of Participant (block letters):___________________________________

Name of Carer/Guardian (block letters)________________________________

Signature of Carer/Guardian: ____________________________ Date _______________________

Name of Investigator (block letters): _________________________________

Signature of Investigator: ____________________________ Date _______________________

APPENDIX 2: PARENT/GUARDIAN WITHDRAWAL OF CONSENT FORM

Withdrawal of Consent for Use of Data Form: Parent/Guardian

OPTIMISING RECRUITMENT AND RETENTION FOR LONGITUDINAL RESEARCH
An Australian Government funded Cooperative Research Centres (CRC) Program

I, the legal guardian of the participant, wish to WITHDRAW my consent to the use of the individual data arising from the participation of the person in my care and myself in this study.
I am aware that due to the group discussion nature of this study, it may not be possible to identify and remove individual data from the focus group notes and audio recordings after the focus group has finished.
I understand that a participant can withdraw from the study at any time and that there will be no disadvantage, penalties or adverse consequences for non-participation or withdrawal. From this point on no data about me or the person in my care will be collected or recorded.
Data arising from the participation of myself and the person in my care that can be identified in this research project, as described in the Information and Consent Form, will be removed and not included in the study, and individual questionnaire data from the participation of myself and the person in my care will be destroyed provided this request is received within four weeks of the completion of our participation in this project.
I understand that this notification will be retained together with my consent form as evidence of the withdrawal of my consent to use the data provided by me and the person in my care specifically for this research project.

Participant’s name (printed):

…………………………………………………………

Parent/Guardian name (printed):

…………………………………………………………

Signature: …………………………………………… Date: ……………….

Appendix 3

RESEARCH INSTRUMENTS

FOCUS GROUP PROCEDURE

CARDS FOR CARD SORT ACTIVITY

CARD SORT TALLY SHEET AND ADDITIONAL QUESTIONS FOR DISCUSSION

QUESTIONNAIRE

APPENDIX 3: FOCUS GROUP PROCEDURE

Focus group procedure

1

Preparation

Materials – card sets, response boxes, tally sheet questionnaire, procedure
Admin – participant list, PIS and consent forms
Digital recording equipment ready for Discussion

2

Greeting and admin

As participants arrive, collect signed Consent forms.

- For participants in Group 2 accompanied by carers, we must have a signed consent form signed by the legal guardian of the participant.

3

Welcome and housekeeping

- refreshments, toilets

4

Introduction

Our research today is to find out how we can encourage people like you to sign up to take part in a research project that goes over a number of years, and how we can encourage people to stay involved for the whole time of the project.

Why do we want to know this?

This will help us to plan a research project that we will start early next year that will last for four years. The information we gather now will help us work out how to go about recruiting people like you to take part and how we can keep them interested and involved over the four years.

So the purpose of today's focus group is to think about and discuss the things that might motivate you to take part in a research project that went for four years.

We're also interested in the things that might make it difficult for you to commit to this kind of long-term research project or that would discourage you from taking part.

We want it to be very clear that taking part in this focus group today does not commit you in any way to taking part in the four-year project that we've spoken about. Today we're simply interested in hearing your views about what would potentially encourage or discourage you to take part in a long-term project of this kind. However, for those of you who think you would be interested in signing up to the next project, we'll be very happy to give you more information!

APPENDIX 3: FOCUS GROUP PROCEDURE (cont.)

A quick overview of the research project that's coming up.

> *The purpose of the 4 year project will be to find out more about what life is like for adults who have an autism spectrum disorder: for example, how healthy they are, what kind of jobs they do, and how they are involved in the life of their communities. We'll also be asking the same questions about adults who do not have autism, and comparing the two groups to see what the similarities and differences are.*
>
> *Everyone who takes part in the 4 year project will be asked to provide some information about themselves once a year for 4 years. It's not certain at this stage how exactly we'll be collecting this information. We might ask people to take part in an interview, fill in a questionnaire, or come to a discussion group like this one. We'll talk a bit more about these options later on.*

So as we talk today about your thoughts on taking part in a long term research project, those are the things I'd like you to keep in mind. If you took part in this 4 year research, you would be providing some information about yourself once a year for four years.

An overview of what we'll be doing today

Today we three different activities for you to do: the first two you will do as individuals, and then we'll do a group activity together.

In the first activity, we'll give you a set of cards, and we'll ask you to sort them according to what you might like and might not like about taking part in a research project. There's no right or wrong answers – it's about how you feel about the things written on the cards.

The second thing we have to do is a short questionnaire for you each to fill in – it won't take you very long, about 5 to 10 minutes.

We'll then take a short break for about 10 minutes, we'll have something for everyone to eat and drink and you can stretch, your legs or use the bathroom.

in the third and final activity, we'll have a discussion as a group together about some of the things we've asked about on the cards and in the questionnaire, so we can find out and understand what you think in more detail about taking part in a long term research project. We'll give everyone a chance to have a say in this discussion.

By then it should be about X oclock, and we'll all be ready to go home!

5

Card sort activity

Introduce the activity to the participants

1. Give each participant **one set of cards**
- *(for participants with a carer, provide one set only – the carer does not also get a set of cards; the carer's role is to give support to the participant to sort the participant's set of cards.)*
2. Emphasise that some of these scenarios are hypothetical – we don't guarantee these will all be true of the final project.

3. Ask participants to:
    - read each card and decide whether the thing written on it would make them 'more likely' or 'less likely' to take part in a long-term research project, or would make 'no difference'
    - sort their cards into five groups in front of them:
        - VERY MUCH more likely
        - MAYBE more likely
        - No difference
        - MAYBE less likely
        - VERY MUCH less likely
    - Place each group of cards into the **Response box** labelled with the appropriate response
        - VERY MUCH more likely
        - MAYBE more likely
        - No difference
        - MAYBE less likely
        - VERY MUCH less likely

6

Questionnaire

1. When participants have completed the card sort exercise, give out **questionnaire,** ask them to complete it, and hand it back to you.

2. While participants are filling out questionnaire, tally up the responses on the **Tally Sheet**.

3. Wait for all participants to finish the questionnaire and had it back to you.

BREAK

Give participants a short break here for drinks and food, to give you time to quickly tally the results from the questionnaires onto the **Questionnaire Tally sheet**

7

Discussion

1. Digital recording equipment ON! and second person ready to take written notes of the discussion.

2. Introduce this last activity to the group, explaining what it will involve.
    - Emphasise that everyone will have a chance to have their say.
    - Explain that we will be recording this discussion, but all information will remain confidential and the identity of participants and what they say will not be shared outside of the research team.

3. Tell the group which items have a majority vote for 'more likely' and for 'less likely'.

4. For each item on the Tally sheet where there is a majority vote for 'more likely' or 'less likely':
    - If there is a follow up question, prompt a discussion. (Ignore those items for which the majority vote is 'no difference'.)
    - For items with a majority vote for 'more likely' or 'less likely' but with no follow-up questions, prompt a more general discussion, e.g. *"What do you like/dislike about this idea?"*

5. Now do the same with the responses from the questionnaire, based on the totals you've added up on the **Questionnaire Tally sheet.**
    - *In particular, we want to explore people's preferences for particular research methods over others.*

APPENDIX 3: CARDS FOR CARD SORT ACTIVITY

It is likely that this research will help you learn more about yourself.

It is likely that this research will help you learn more about autism spectrum disorders (ASD).

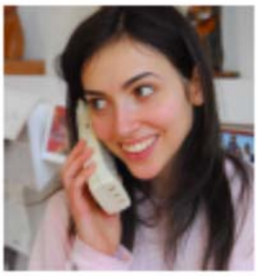
When this research is completed, it is likely to benefit other people, especially those with an autism spectrum disorder (ASD).

Once a year, we will invite you to come to a discussion group where you can meet other people who are also taking part in the research.

When we ask you for information for the research, you can choose if you want to do this in person, over the telephone, online, or via a questionnaire that we will post to you.

One of the researchers will contact you by phone or email at least once a year, to check we have your correct contact details and tell you what we would like you to do next as part of the research.

We will give you the telephone number and email address of one of the researchers. You can contact this researcher at any time if you have a question or comment about the research.



You will receive a card from the research team on your birthday.

We will send you a copy of the final research report when the project is complete.

You will receive a cash payment each time you contribute to the research (i.e. once a year).

APPENDIX 3: CARDS FOR CARD SORT ACTIVITY (cont.)

You will receive a gift voucher every time you contribute to the research (i.e. once a year).

If you tell one of your friends about the research project and they then sign up to take part, we will send you a gift voucher as a 'thank you'.

You will receive a printed newsletter from the project team twice a year, letting you know how the research is going.

You will be given the chance to have your photograph and a brief article about yourself printed in our project newsletter

Once a year, we will invite you to a drinks reception hosted by the research team. We will update you on how the research is going and you can meet other people taking part in the research.

As part of your participation in the research, you may be asked to make a round trip of up to 50km no more than once a year (e.g. to take part in a discussion group).

In the unlikely event that you experienced distress or anxiety as a result of taking part in the research, we would refer you to a psychologist for advice and support.

If we asked you to fill in a questionnaire for the research, we would give you up to one month to complete the questionnaire and send it back to us.

Three times a year, we will send you a small gift (e.g. a pen, cap or drink bottle) to thank you for participating in our research.

If you come to a discussion group as part of the research, we will provide free snacks and drinks.

APPENDIX 3: CARDS FOR CARD SORT ACTIVITY (cont.)

As part of the research, we may ask you for information that is private or sensitive (e.g. about your health or relationships). This will stay confidential and will not be shared.

If you have to travel somewhere as part of your involvement in the research (e.g. to attend a discussion group), we will reimburse your travel costs.

There will be a special website for the research project, where you will be able to ask questions, leave feedback, and engage in online discussions with the research team and other participants.

You will have the opportunity to be involved with the project 'behind the scenes', if you would like: e.g. helping with administrative tasks or the project newsletter.

MUCH more likely

More likely

MUCH less likely

Less likely

No difference for me

APPENDIX 3: CARD SORT TALLY SHEET AND ADDITIONAL QUESTIONS FOR DISCUSSION

	MUCH MORE LIKELY ✓✓	**MORE LIKELY** ✓	**0**	**LESS LIKELY** ✗	**MUCHLESS LIKELY** ✗✗	**Discussion questions**
1. It is likely that this research will help you learn more about yourself						*In what areas would you like to learn more about yourself?*
2. It is likely that this research will help you learn more about autism spectrum disorders (ASD).						*What else would you like to learn about autism spectrum disorders?*
3. When this research is completed, it is likely to benefit other people, especially those with an autism spectrum disorder (ASD).						NIL
4. Once a year, we will invite you to come to a discussion group where you can meet other people who are also taking part in the research.						*If ✓ Why do you like the idea of coming to a discussion group?* *If ✗ Why don't you like the idea of coming to a discussion group?*
5. When we ask you for information for the research, you can choose if you want to do this in person, over the phone, online, or via a questionnaire that we will post to you.						*Which would you prefer?*
6. One of the researchers will contact you by phone or email at least once a year, to check we have your correct contact details and tell you what we would like you to do next as part of the research.						*If ✓ Why do you like the idea of a researcher contacting you directly?* *If ✗* o *Why don't you like the idea of a researcher contacting you directly?* o *Is there another way you would prefer us to stay in touch with you?*
7. We will give you the telephone number and email address of one of the researchers. You can contact this researcher at any time if you have a question or comment about the research.						NIL
8. You will receive a card from the research team on your birthday.						NIL
9. We will send you a copy of the final research report when the project is complete**.**						NIL
10. You will receive a cash payment each time you contribute to the research (i.e. once a year).						*What do you think would be an appropriate sum of money to give people taking part in a research project [in view of the time/effort involved]?* *Do you think we should increase the sum of money we give people each year?* *Would you prefer a cash payment or a voucher (e.g. retail voucher, cinema ticket, phone credit)?*

	MUCH MORE LIKELY ✓✓	MORE LIKELY ✓	0	LESS LIKELY ×	MUCH LESS LIKELY ××	Discussion questions
11. You will receive a gift voucher every time you contribute to the research (i.e. once a year).						*What sort of voucher would you prefer? (e.g. retail voucher, cinema ticket, phone credit)* *What do you think would be an appropriate cash value for the voucher?* *Do you think we should increase the value of the voucher we give people each year?* *Would you prefer a voucher or a cash payment?*
12. If you tell one of your friends about the research project and they then sign up to take part, we will send you a gift voucher as a ‘thank you’.						*What do you think would be an appropriate cash value for the voucher?*
13. You will receive a printed newsletter from the project team twice a year, letting you know how the research is going.						*What would you like to see included in this newsletter?*
14. You will be given the chance to have your photograph and a brief article about yourself printed in our project newsletter.						NIL
15. Once a year, we will invite you to a drinks reception hosted by the research team. We will update you on how the research is going and you can meet other people taking part in the research.						NIL
16. As part of your participation in the research, you may be asked to make a round trip of up to 50km no more than once a year (e.g. to take part in a discussion group).						*If ✓ Would it make a difference if we paid your travel costs?*
17. In the unlikely event that you experienced distress or anxiety as a result of taking part in the research, we would refer you to a psychologist for advice and support.						NIL
18. If we asked you to fill in a questionnaire as part of the research, we would give you up to one month to complete the questionnaire and send it back to us.						NIL
19. Three times a year, we will send you a small gift (e.g. a pen, cap or drink bottle) to thank you for participating in our research.						*What sort of gift would you like to receive?*
20. If you come to a discussion group as part of the research, we will provide free snacks and drinks.						NIL
21. As part of the research, we may ask you for information that is private or sensitive (e.g., about your health or your personal relationships). This information will stay confidential and will not be shared.						*If ✓ Would it make a difference how we collected this information (e.g. would you be happy to write it into a questionnaire but not to discuss it with an interviewer)?*

	MUCH MORE LIKELY ✓✓	MORE LIKELY ✓	0	LESS LIKELY ✗	MUCH LESS LIKELY ✗✗	Discussion questions
22. If you have to travel somewhere as part of your involvement in the research (e.g. to attend a discussion group), we will reimburse your travel costs.						NIL
23. There will be a special website for the research project, where you will be able to ask questions, leave feedback, and engage in online discussions with the research team and other participants.						NIL
24. You will have the opportunity to be involved with the project ‘behind the scenes’, if you would like: e.g. helping with administrative tasks or the project newsletter.						*Are there particular ways in which you would like to be involved?*

Appendix 4

EXTRINSIC REWARDS, INCENTIVES AND PAYMENTS

With the exception of ASD+ID participants, the offer of extrinsic rewards such as gifts, cash and vouchers was not identified as a motivator for participation. However, offering such rewards was considered to be an effective enabler of participation in providing a form of acknowledgement and recognition for the participant's contribution. The following data is for those participants across all categories in the study who responded to specific questions about extrinsic rewards.

DIAGRAM 1. WOULD YOU PREFER A CASH PAYMENT OR A VOUCHER?

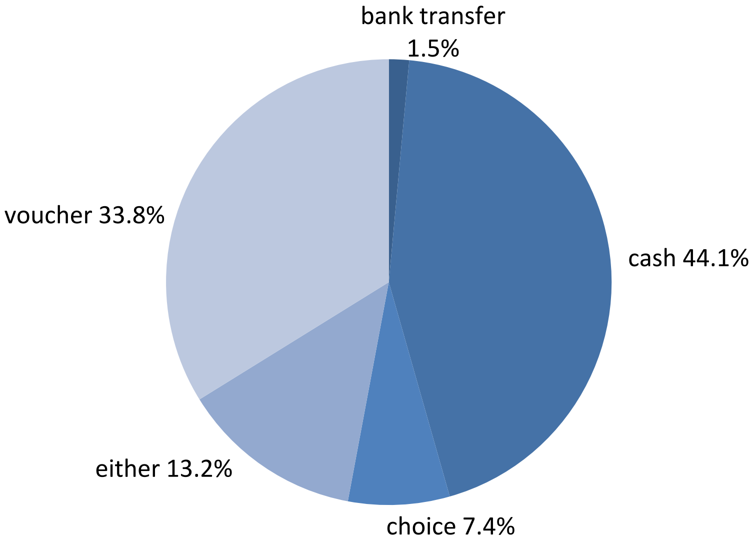


CHART 1. WHAT SORT OF VOUCHER WOULD YOU PREFER?

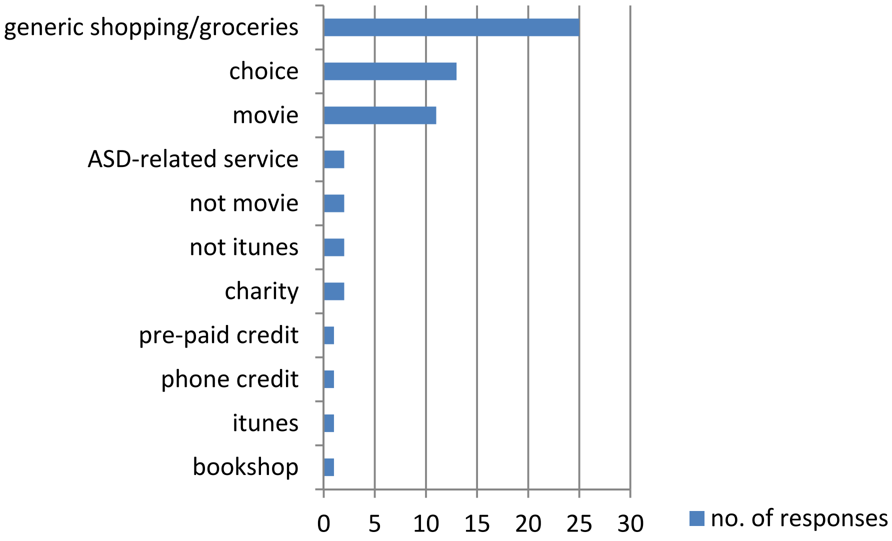


CHART 2A. WHAT DO YOU THINK WOULD BE AN APPROPRIATE AMOUNT TO GIVE TO PEOPLE TAKING PART IN A RESEARCH PROJECT (E.G., PER 2 HOURS)?

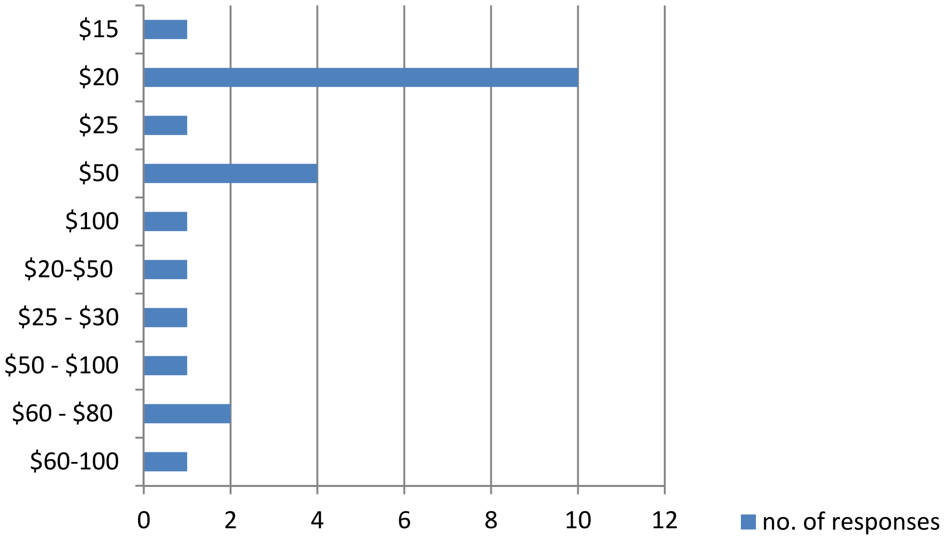


CHART 2B. WHAT DO YOU THINK WOULD BE AN APPROPRIATE (AMOUNT/VALUE) TO GIVE TO PEOPLE TAKING PART IN A RESEARCH PROJECT (E.G., PER 2 HOURS)?

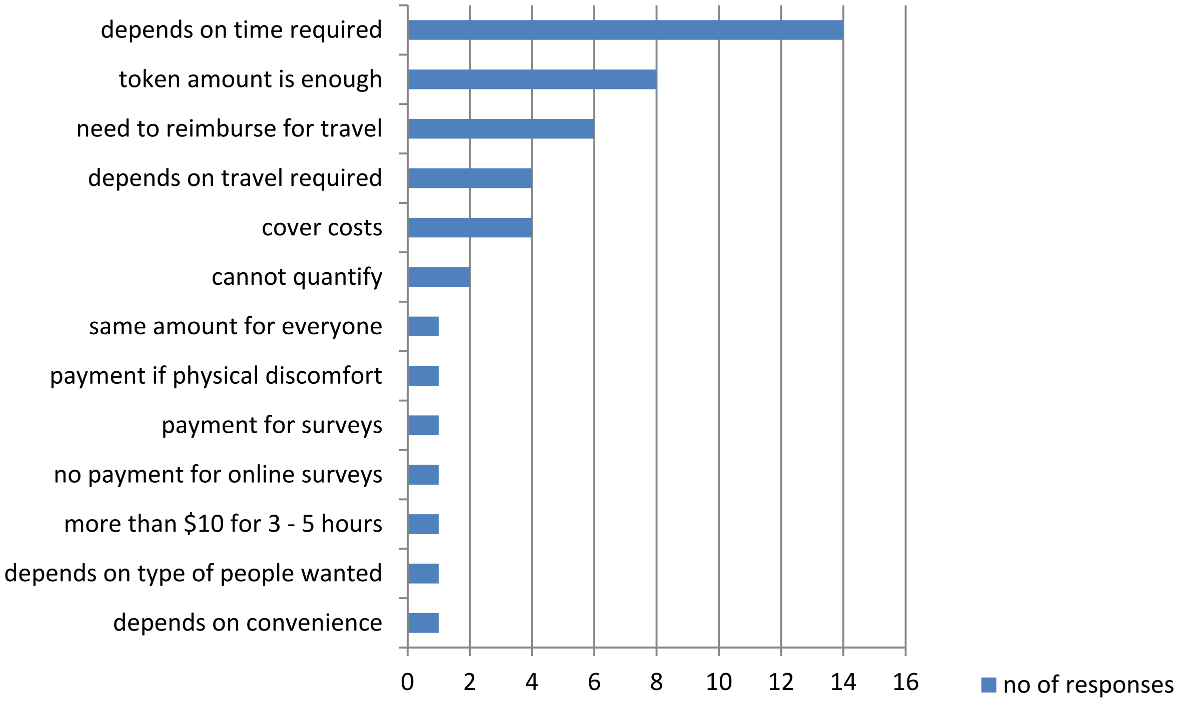
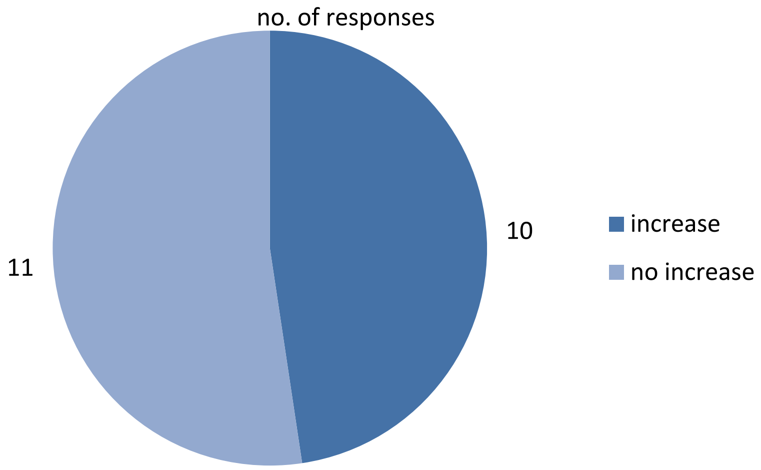


CHART 3. DO YOU THINK WE SHOULD INCREASE THE VALUE OF THE CASH/VOUCHER WE GIVE PEOPLE EACH YEAR?



Appendix 5

SUGGESTIONS FROM PARTICIPANTS

PROCEDURES

provide a facility for participants to advise the study that their contact details have changed

send reminders to participants for tasks and activities

have a feedback facility for participants

COMMUNITY

have 'study buddies' i.e., a friend who is participating with you

use the project to give opportunities for people autism and an intellectual disability to connect with each other through their interests, esp. through social media; this would be more attractive for them and their parents than these participants coming to a discussion group or a drinks event

provide an online forum/discussion board as alternative to discussion groups (for those who are too anxious and scared to meet with new people in a new place).

provide a secret Facebook page for the research study/community - researchers and participants

PARTICIPANT INVOLVEMENT

use a consumer panel/committee of participants to advise on have input to the research project

a certain percentage of researchers and decision-makers in the project should be people on the spectrum

use the methodology of participatory action research

enable participants to be involved in research design, analysis, writing; some participants are already skilled in research

as the consumers of the research, autism spectrum people should be involved in all aspects of the research, similar to consumer participation research

CRC adopt a policy that there will be a certain percentage of autism spectrum people involved in the research and the governance structure

identify specific positions be identified as being available for autism spectrum people, and this should include decision-making positions

share and rotate the roles amongst people living on the autism spectrum

participant could moderate a discussion panel

Newsletters

hand over the newsletter to participants to produce

get participants to write the articles

include an invitation for participants to submit material

include letters to the editor, guest articles by participants

ask participants to review any article about them before it is published

Reports

provide a plain language version/summary of any report

use autism spectrum participant with suitable experience/skills to write a plain language version of academic reports

give participants the opportunity to comment on report and research findings

VENUES AND EVENTS

choose environment carefully – be sensitive to autism spectrum sensory issues

hold events in a quiet place

have events not in a noisy place - only suited to people with superior social skills, and others are left out, intimidated and excluded

not in a public dining place such as café or restaurant - too noisy

use outdoor venue in warmer months - deals with noise and light issues

choose locations that are convenient to public transport

provide some gluten-free food, mixture of savoury and sweet items, drinks with diet options ("sugar-free")

offer a choice of food that does not have a lot of sugar

PROJECT COMMUNICATIONS

provide the option for online or printed

offer an opt-in system to receive newsletters

offer a choice of print or digital format for all communications

the person writing the newsletter article should be aware and sensitive to autism spectrum issues

make sure that digital versions are accessible, esp. for those using assistive technologies - see WC3 guidelines re web accessibility

provide an educational presentation at the beginning of the project where participants learn about autism and meet people living on the autism spectrum and parents of people living on the autism spectrum and to hear their stories

RESEARCH METHODS incl. DATA COLLECTION:

use the methodology of participatory action research

give participants the opportunity to identify one area they wanted to investigate or learn more about (themselves and ASD) and then address that area

consider what responses questions will elicit in participants and if they are likely to elicit anxiety

provide a blog - online

use online forums

if you really want to find out what autism spectrum life is like, you would need to use cameras and microphones etc to observe autism spectrum people in their everyday life

use workshop, seminar, conference type format

ask participants to keep a diary, log, notebook to record notes, observations

if you give me the option to write, I will write up to the word limit. If you do not give a word limit, I will write 20-30 pages. This is why I prefer face-to-face communication format. You need to clearly specify how much you want.

use ways other than verbal communication to gain information and learn about/ get the AD+ID participants to teach us about their experiences and opinions

provide a YouTube channel

provide a psychologist on-site for groups, to be able to help on-site if needed

join a service that gives the study access to a panel of participants who do a range of online surveys and the participants accumulate rewards for completing surveys that are part of this research panel service

REWARDS

send an online birthday card

use pre-paid Visa cards instead of cash

offer a gift card with a charity

option to donate to a charity

option to give your amount to the research project

option to donate your amount to a charity

option for people to either take it or to put it back in to the research project

give the main reward is at the end of the project, with small rewards along the way for each contribution

offer a gift that relates to the community that we are helping, e.g. ticket to an exhibition, gallery or film about autism, would be more gratifying given the study that we would be participating in, could also be a way to involve participants' partner as they get to take part in the reward

encourage and reward participation in the research in ways that are more meaningful for autism spectrum participants other than cash, such as access to services that could help autism spectrum people in their day to day lives - e.g., individual and family counselling, psychologists

offer help to find and coach an employer to see the benefits of an Asperger and help smooth the problems

REIMBURSEMENT

provide the same travel reimbursement for everyone

provide overnight accommodation (for those travelling a long distance)

provide taxi vouchers

Appendix 6

WHAT WOULD YOU LIKE TO LEARN ABOUT ASD?

IMPROVE MY GENERAL KNOWLEDGE AND UNDERSTANDING OF ASD

would be happy to learn more

always something new to learn about ASD, nothing specific at the moment

would be nice to learn more about ASD

would like to learn more

common aspects of ASD

everything

everything there is to know

general knowledge and understanding of ASD, as has not had exposure to people on the spectrum

I don’t know much about autism at all

improve understanding about what life is like for people living on the autism spectrum and for their carers

don’t think it necessarily matters what you are learning, but the fact that you are learning

knowledge would make me more connected to the bigger picture of life

the breadth of the spectrum, and different levels and types of autism, how it is not all the same for everyone on the spectrum

ABOUT ASD

links between autism and foetal alcohol syndrome

relationship between food allergies and ASD, and impact of food allergies on ASD related behaviours

how ASD people react to certain drugs

how ASD affects people, and affects different people in different ways, wrt gender, culture, race, age

how wide is the autism spectrum?

long term impact of ASD

CAUSES OF ASD

why ASD happen

causes of ASD

what are the causes

DIAGNOSIS

the trend I have observed that parents are now being diagnosed (later in their life as adults) following their children being diagnosed

the impact of ASD on childhood family relationships of adults who are now being diagnosed with ASD, family fractures due to lack of understanding and empathy as children where children and/or parents were not diagnosed as having ASD; interesting to look at impact of ASD on the dynamics of those families where the autism spectrum children and/or parents were not diagnosed.

is autism spectrum being over diagnosed and misdiagnosed?

impact of knowing about your ASD vs not knowing about your ASD

GENETICS

genetic differences

genetics of autism

the workings of the ASD brain and genetics of autism

AUTISM SPECTRUM COGNITION

neurological structure and how it influences cognitive profile (both strengths and weaknesses) + possible medical trials to temporarily/permanently alter such traits,

"the way we think"

how do ASD brains work differently from neuro-typical brains

ASD thought processes

coping skills, cognitive functioning

why executive functioning in autism spectrum people is so poor. Why there is such diversity in symptoms of those with autism spectrum diagnosis.

how being ASD impacts people in terms of work performance and study performance, wrt structuring thoughts and ideas, interpreting language and communication

the workings of the ASD brain and genetics of autism

MENTAL HEALTH AND ASD

mental health issues associated with being on the spectrum

the impact of the stress, anxiety and depression that results from feeling of not fitting into neuro-typical structures

FACT AND FICTION ABOUT ASD

the scientific basis of autism What is real and what is just fashion in thinking and research about autism

to sort and know the facts from the fiction about ASD

what is actually true about people with autism

TO RELATE BETTER TO/HELP PEOPLE/FAMILY MEMBER WITH AUTISM

about Asperger's and potential treatments for my son

more effective way to help my son

coping and caring for people living on the autism spectrum

what can be done to help once you know the causes

helping people with autism

ways to help people on the spectrum, conventional and unconventional

managing challenging behaviours - perseverance/OC behaviours

how to interact with people with autism

I have a brother who is on the spectrum: why he acts as he does, how we can communicate better with him, how we can understand each other

This is for me as a carer, there is so much to be learnt general knowledge, has cousin with ASD, to be better informed

I have a cousin who is on the spectrum so anything that I can learn that helps my engagement and interaction with him would be a help, as well as engaging with anyone else about autism and to be able to give people useful information about autism

to help me to be more understanding and tolerant of people who are different

how to treat autism more effectively

ASD AND ME

how ASD manifests in women

effects of ASD on others around us

ASD and social interactions

I was only diagnosed recently, and I'd like to know more about how to read myself and what I am doing, I want to learn more about ASD

starting to realise that everyone is different; would like to understand more about those differences.

ASD IN A NEURO-TYPICAL WORLD

(mis) perceptions about people living on the autism spectrum

acceptance and social attitudes/mores about ASD

what are the positives and the strengths of being ASD

how ASD people form meaningful relationships with non ASD people and what are the benefits of these relationships

how can we react appreciatively to others 1. know our special need, 2.needed to act normal to fit in,3. justify our actions to be accepted to this narrow-minded world

to educate people beyond the stereotypical view of autism, to educate people about all the different levels of autism and many different ways of functioning with autism; to understand how wide the spectrum is

to find a bridge between ASD people and non-ASD people so that we can communicate (with each other)

to find a middle group between ASD people and non-ASD people

the impact of the conceptualisation of ASD as a disability

the breadth of the spectrum, and different levels and types of autism, how it is not all the same for everyone on the spectrum, and how they can participate in the community

where can autism fit into society, how can it be a general part of the wider society, what can we give, it’s a win/win because we are putting ourselves out here and giving and also it would give us meaning in life

BEING AN ADULT ON THE AUTISM SPECTRUM

A lot of the untold story (about autism) is from adults; and that we all have something to give and someone else will have some experience that f don't know about, so it's that potential to exchange. In a lot of ways, adults are the last frontier of autism. There is a lot I don't know, but I don’t know what I don't know, and research is one way of bringing it all together - I'd like to find out what I don't know about autism.

how others are coping

how it impacts on people's lives, people don’t really understand what it is and how it can vary, how this impacts people's ability to get a job

a lot of research needs to go into employment, workplaces and workplace environments, and how to lift the workforce participation rate for people on the spectrum, and everyone is so different, everyone is capable of doing something worthwhile; research into this would help everyone (on the spectrum) from late teens onwards.

AutismCRC

autism spectrum AUSTRALIA

Curtin University

LA TROBE UNIVERSITY

THE UNIVERSITY OF QUEENSLAND AUSTRALIA

Autism CRC Ltd *Cooperative Research Centre for Living with Autism Spectrum Disorders*
Level 3, Forestry Building, Long Pocket Campus, The University of Queensland, Q4072
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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