



Autistic Adults and other Stakeholders Engage Together

Engagement & Compensation Guide

**Version 2.1
December 2018**

Table of Contents

Authors	3
Contributors	3
Funding	3
Introduction	4
Identity-first versus Person-first Language	4
I. Presumption of Competence	5
II. Compensation of Autistic Adults in Research and Other Settings	6
Considerations for Compensation	7
Guidelines for Monetary Compensation in Research for Specific Roles	7
Principal Investigator (PI)	7
Co-investigators (Co-I).....	8
Key Personnel.....	8
Consultants	8
Guidelines for Compensation of Consultants	9
Non-Monetary Compensation	11
Recognition of Scientific and other Contributions	12
III. Communication Guide	13
Communication Needs of Autistic Adults for Partnering with Researchers	13
Guidelines for Email Communication	13
Guidelines for Telecommunication (e.g. phone, Skype, Zoom)	15
Guidelines for Researchers	15
IV. Measuring Engagement in the Autism Community	16

Authors

Stephen Shore & Teal Benevides (Editors) with authored contributions from Elesia Ashkenazy, Amy Gravino, Becca Lory, Lisa Morgan, Kate Palmer, Jeanette Purkis & Karl Wittig.

Contributors

The Project Team and Community Council of the Autistic Adults and Other Stakeholders Engage Together (AASET) project provided comments and constructive feedback in November 2017 and voted to disseminate for feedback. These individuals contributing and providing input include (in alpha order): May-Lynn Andresen, Elesia Ashkenazy, Daria Blinova, Reid Caplan, Barb Cook, Dena Gassner, Amy Gravino, Anita Lesko, Becca Lory, Jamie Marshall, Lisa Morgan, Lindsey Nebeker, Kate Palmer, Bill Peters, Jeanette Purkis, Brigid Rankowski, Cyndi Taylor, Liane Holliday-Willey, & Karl Wittig.

Funding

This Guide was funded through a Patient-Centered Outcomes Research Institute (PCORI) Eugene Washington PCORI Engagement Award (EAIN# 4208). The views presented in this guide are solely the responsibility of the author(s) and do not necessarily represent the views of the Patient-Centered Outcomes Research Institute (PCORI), its Board of Governors or Methodology Committee.

Introduction

Thank you for your interest in supporting meaningful and inclusive research to advance knowledge and better outcomes for autistic adults. In order for research with adults on the autism spectrum to be meaningful and effective, it is our belief that researchers must include one or more autistic adults in the research process. Inclusion must occur on all future studies. In order for those partnerships to be successful, researchers and autistic adults must discuss and identify shared beliefs, values, and address topics which contribute to respectful dialogue prior to engaging together.

This document represents the work of a project team and community of autistic adults and other stakeholders, who together drafted and contributed to what is believed to represent important topics for meaningful inclusion in the research process. This is a working document, and feedback is always welcome. Please feel free to contribute at: www.autistichealth.org or by contacting the Project Lead: Teal Benevides at tbenevides@augusta.edu.

Identity-first versus Person-first Language

Please note we are using identity-first language in place of person-first language. Many stakeholders who contributed to this document prefer identity-first language that does not separate their experience of autism from who they are. This is an acceptable convention self-advocates use in print descriptions. As with any language, it is important to ask the individuals you are working with whether they prefer to be identified as a ‘person with autism’ or as ‘autistic’. This approach values autonomy and identity, and conveys mutual respect.

I. Presumption of Competence

Authors: Amy Gravino and Kate Palmer

All project team members who engage with the autistic community should presume competence in their work with autistic individuals. Presumption of competence means that individuals are recognized as self-determined, autonomous, and fully capacitated persons who make decisions on behalf of themselves.

Presumption of competence also means that the range of abilities is recognized, and pre-existing beliefs or assumptions about ‘autism’ are suspended to ensure respectful and authentic collaboration and communication occurs with each individual.

It should be assumed that non-speaking individuals understand and can comprehend language (spoken and written), unless evidence suggests the opposite. A person’s right and desire to communicate through augmentative and alternative communication (AAC) methods, including sign, device, or text, should be respected in all research settings.

Respectful engagement occurs when the individual is:

- Not a token—when doing work that matched skill level for something that was a part of their expertise (not underemployment);
- Paid at the skill level they demonstrate;
- Able to give feedback on research activities and when their feedback is given equal weight as other collaborators;
- Provided work and expectations which are the same as others in that research role.

II. Compensation of Autistic Adults in Research and Other Settings

Authors: Becca Lory, Stephen Shore, & Teal Benevides

Rationale: Autistic adults are often called upon to provide input, feedback, ideas and knowledge of lived experiences in research and practice settings. Individuals who are not in traditional faculty or research environments are asked to take part in these activities, frequently in ‘volunteer’ capacities, without the explicit acknowledgement that their input is fundamentally necessary and central to the work being accomplished. Although many research activities are ‘unfunded’, the researchers in these projects still are being paid for their time through their employment contracts. The work of others, however, is not compensated accordingly.

A specific recognition of roles and responsibilities, and the compensation aligned with those roles/responsibilities, allows for open communication between researchers, project members, and community advocates involved distally in research activities. There is a need to recognize the roles, the time spent in those activities, and the possible monetary and non-monetary compensation which could address the imbalance of recognized expertise.

Assumptions & Beliefs:

- All members of a research team, regardless of degree or training, have an invested stake in the outcome of the research.
- Although compensation cannot always be equivalent among members of a research team, nor would this be the expectation in any work environment, the compensation should reflect:
 - the type of role in research (permanent/continuous, such as a Principal Investigator; consultant/temporary such as those contributing to a defined task);
 - the experiences or training (e.g. both formal and informal), with those having greater formal or informal training to support the project activities receiving greater compensation;
 - the needs of the individual, such that those who may be negatively impacted by monetary compensation (e.g. through impact on Social Security Disability, or other support) are reviewed by the research team to determine alternatives in compensation that are ethically similar (e.g. provision of services instead of monetary compensation).
- Mutual respect between the research team and stakeholders is assumed, and commitment to the open communication which underlies that respectful relationship. This is exemplified through communication of the researcher about availability of funds, and the

ability of the invited member to the research project to discuss their needs, training, and role in the context of what is available.

Considerations for Compensation

- Our Project Team and Community Council suggest and recommend that autistic adults be involved in all aspects of study development and design. Depending on the skills of the individual, a variety of roles should be considered. In all roles, however, autistic project team members would like others to know that there may be the need for accommodation for length of time for feedback, amount of structure required for tasks, and the type of communication preferences which are needed to ensure success.
- Members of the project team should recognize that preparation time for an autistic person may be more than someone without autism. This possible need for additional time for preparation for reading, responding, and editing materials should be considered and compensation should not be deducted from people whose processing speeds necessitate more time to finish a project.

Guidelines for Monetary Compensation in Research for Specific Roles

Our Project Team and Community Council, including those with formal training in research, as well as self-advocates, providers, parents, and other stakeholders, developed this document as a fluid and flexible guideline. It should be used to stimulate discussion, rather than set strict limits. Roles, possible responsibilities, and suggested considerations for compensation are outlined below.

Principal Investigator (PI)

The PI is the person who typically writes and submits the project, is responsible for the budget, the writing of roles and identifying necessary project components to meet project outcomes, is responsible for the legal and ethical conduct of research to include all stages of the research process, all the way through dissemination. The responsibilities include: management of all personnel and consultants, responsibility for the submission of deliverables and progress reports on project outcomes, management and oversight of budget, compliance with ethical, institutional, and funder requirements. Depending on the type of involvement and staffing of the project, this role may range from 10-50% effort. Principal investigators time is compensated in line with existing institutional requirements along the salary structure provided upon hiring. Investigators from institutions are compensated through a percentage of time that their efforts on the project require, and the budget takes that percentage from the salary. The PI cannot increase or decrease their salary, as this is an institutionally-set number. The PI can only modify their effort.

- Trade offs: If the PI lowers their effort, management of the project may suffer. Additionally, some funders will not fund projects in which the PI's effort is too low and does not adequately support the project activities.
- Institutions have federally-managed agreements with percentage of projects allocated for fringe benefits. Some funders cap required fringe benefits at 40%, and others allow the institution to negotiate their own rate. The PI has no control over the amount budgeted for fringe, as this is an Institutional requirement.

Co-investigators (Co-I)

Co-Investigators are also responsible for the outcomes of the project, and often were involved in the development of the grant/project. These investigators typically conduct or oversee aspects of the project that their expertise is needed for. Responsibilities include: oversight of specific components of projects, depending on the project deliverables and goals. Depending on the project, the Co-I can have more effort, equivalent effort, or less effort than the PI. Similar to the description above, if the Co-I is located at an academic institution, the effort or percent time on the project to complete activities drives the compensation. The Co-I's existing institutional salary is used to determine the amount budgeted.

Key Personnel

Key personnel on a project are defined by specific roles, which may not require much formal research training, but are essential for success of the project. These responsibilities vary by the role, but can include: recruitment coordinator, data management coordinator, research coordinator. This role is typically paid on a part-time or full-time basis through the institution doing the research. Hourly rates and salaries are typically defined by the institution. For example, the state-managed Augusta University has salary guidelines for administrative roles such as Research Coordinators, with the range of hourly compensation being \$15-\$18/hour. (e.g. https://erecruit.augusta.edu/psp/hrp461/SS/HRSS/c/HRS_HRAM.HRS_CE.GBL)

Consultants

The consultant role is typically used for defined, specific roles with a clear Scope of Work. That Scope of Work identifies the responsibilities of that individual and the timeline in which that individual will complete the work and be paid, as well as the rate of compensation. The Scope of Work becomes a legal document defining the expectations and deliverables for that individual to be paid. Consultants typically have an experience or training background that requires their specific involvement as a consultant. Consultants cannot have conflicting roles with the primary funding institution.

- o There are two ways for Consultants to be paid:
 1. Consultants are paid an hourly wage for a predefined number of hours. The number of hours is typically based on the expectation of how long the task will take. The

consultant is typically obligated to complete the task, regardless if it takes more or less time than is agreed upon.

Example: Consultant to develop a website. The website design and development is expected to take 20 hours. The consultant is paid an hourly rate for those 20 hours. If the consultant takes more than the 20 hours, there is typically no additional budget to pay that consultant, but the consultant has signed a Scope of Work agreeing to complete the work.

2. Consultants are paid a stipend for a predefined task. The task is defined in advance and the payment is made in either one or more lump sums. Typically payment is done for smaller tasks over a shorter time.

Example: Consultant to review an outcome measure and provide feedback for the research team. The consultant is paid \$50 to attend a focus group to review and share feedback about the outcome measure items. The consultant receives a gift card or check at the end of the focus group; no further involvement or responsibilities are needed.

Guidelines for Compensation of Consultants

- Self-advocates and other stakeholders who demonstrate leadership and advocacy skills are valuable members of the research team and should be compensated accordingly.
- Work reflects training and experiences.
- Although grants and project budgets vary, a respectful minimum hourly rate for individuals contributing skilled products or engaged in leadership roles on a study (e.g. leading or running interviews, advising the research team on process or procedures, contributing to the writing or dissemination efforts of grants or publications) is suggested to be \$50/hour. For persons with more or less experience, that hourly rate may be different.
- Compensation for tasks should include both preparation time and task time. For example, if a consultant is asked to run a focus group, the preparation time, to include planning meetings and time for drafting materials, is necessary.
- Occasionally, a task will require the consultant to write up post-task findings, or contribute to follow-up meetings. This time should be considered in the compensation for tasks.

Example of compensation:

Dr. Researcher is conducting a study on mental health outcomes, and would like her autistic partners to read and contribute to the development of a questionnaire to measure anxiety. She anticipates that the development will involve a 2 hour focus group, reviewing the notes and

©Autistic Adults and other Stakeholders Engage Together (AASET), Engagement & Compensation Guide, Edited by Project Leads: S. Shore & T. Benevides, Dec 2018

developed 1-page questionnaire, and a 1-hour follow up meeting. In order to pay her consultants, she should anticipate that the project partners will need: 2 hours for the focus group, 2 hours preparation to review notes and the questionnaire, and 1 hour for the actual follow up meeting, for a total of 5 hours. At a rate of \$50/hour, each consultant will receive \$250 for their participation in this task. Additionally, if extensive travel is required, the travel compensation will be included in the compensation package.

Non-Monetary Compensation

Author: Lisa Morgan

Alternate forms of compensation for members of a research team who would not benefit from monetary compensation are listed below. Gift cards must be useful to the research member being compensated. The gift cards must be redeemable within a reasonable distance from their home and be suitable for the stores, cinemas, restaurants, etc., found nearby. Gift cards are considered compensation and team members who receive these must recognize them as forms of income. Additionally, it should be recognized that not all funders, universities/colleges, or organizations will allow non-monetary compensation. All compensation should be evaluated thoroughly by administrative teams to ensure no conflicts of interest or policies to the contrary are in place for such compensation.

- Gift cards and/or certificates for items and services such as: food, haircut, spa, gas, restaurant, phone card, cinema, etc.
- Recognition where appropriate for the research team member to feel compensated. If the research team member is agreeable, a certificate of participation in the research study can be given as compensation.
- The provision of a professional or personal reference or recommendation related to the quality of the research team member's work product can be a valuable resource when furthering their studies or applying for employment.

Recognition of Scientific and other Contributions

Author: Karl Wittig

Any contributions to research and associated efforts by autistic individuals should always be recognized in an appropriate manner, barring considerations of privacy or confidentiality.

While this is generally required by scientific and research ethics, it is especially significant for autistic contributors, who often have had painful experiences of being marginalized and excluded because of their differences. To them, such recognition represents more than simply another item to include in their resume or curriculum vitae.

The appropriate form of recognition depends upon the nature and extent of the contribution. In the case of a conference presentation, autistic contributors should be named at the end of the presentation (or wherever appropriate) either as an explicit category, or else listed along with others who contributed in the same or comparable capacities.

- In the case of a scientific paper in a research journal or volume (academic or professional), autistic contributors should be acknowledged at the end of the article (or wherever appropriate), along with all other contributors, in whatever manner is most appropriate. If the contribution is of fundamental or otherwise substantial significance, the autistic contributor should be invited to be listed as a co-author.
- In the case of a non-academic (e.g., popular) publication, presentation, or media appearance describing the research in question, significant contributions made by autistics should at the very least be given mention.

In any of these cases, autistic contributors who prefer to maintain anonymity should be given the option of declining public acknowledgement.

The above criteria are for the specific cases mentioned. The same (or at least comparable) considerations should be used in any other cases.

III. Communication Guide

Authors: Elesia Ashkenazy, Stephen Shore, & Teal Benevides

Communication Needs of Autistic Adults for Partnering with Researchers

Autistic adults have different styles of communication. Researchers should understand that an adult with autism who is non-speaking or limited in 'typical' verbal communication does not indicate diminished mental capacity. Often, assistive and alternative communication (AAC) can be used even by speaking individuals, especially in high-stress situations.

Research partnerships should recognize and incorporate the following guidelines into their collaborative activities:

1. There is a saying "less is more." This holds true to the communication needs of those on the autism spectrum. Due to the fact that our mind is bombarded with multiple stimuli simultaneously, excessive wordiness can easily become overwhelming. We function best when communication is presented in short and to the point descriptions.
2. Content is exceptionally well received when presented in numbered or bulleted format with brief sentences. This is true for publications, emails, instructions, and protocols.
3. Requesting and using accommodations for communication by no means indicates diminished or limited mental capacity.
4. Details are important and noticed. For example, when scheduling a meeting, be clear about the date, time, and time zone for clarity.

Guidelines for Email Communication

All email communication should be brief and organized in order for action to occur. When communicating by email with autistic research partners, using an email template to briefly convey the message using the headers below is recommended.

PURPOSE OF EMAIL: [include 1 sentence with the main purpose of the email. If multiple purposes, use numbers or bullets]

DETAILS: [Use bullets to share details or provide necessary information to accomplish the purpose]

ACTION: [Indicate the clear verb requiring an action. If there is no action, and the email was for information only, state it.]

DEADLINE: [Provide a date and time deadline for the action to occur]

OTHER INFORMATION: [If there is any other information that does not fit in a category above, provide it here]

Template developed by © Elesia Ashkenazy, used with permission

Example Email

Purposes of the Email:

- To share results of the Year 1 meeting
- To request feedback on Conference Summary (short, 3 page summary)

Details:

- The Project Team would like feedback on the Year 1 meeting results so that we can provide to the autism community, researchers, organizations, etc.
- We will incorporate feedback from the Community Council prior to sharing with the attendees of the year 1 meeting or posting on Facebook and AASET website.
- Questions include:
 - Are the materials written in a way that is understandable? Clear? Respectful?
 - Is there anything missing that you would want to know?

Actions:

- Read the Conference summary
- Use track changes to share edits or comments on the content of the summary
- Send feedback to sampleperson@emai.com

Deadline: Wednesday October 4, 2017 at 5pm Eastern Time

Guidelines for Telecommunication (e.g. phone, Skype, Zoom)

Some people have preferences for telecommunication. In large groups, it is difficult to meet all communication needs. However, often phone communication can be challenging due to several factors-- the overreliance on auditory attention to accomplish meeting goals, the need for sustained attention to different and unknown speakers (for multi-person calls), and the difficulty with following a conversation if attention is lost for part of the time.

Other alternative forms of communication can be offered, including Zoom(R) or other video conferencing to allow the person to visually see the speaker. Platforms that allow for typing questions or comments, should a person need to communicate via non-spoken language, is important.

Guidelines for Researchers

Due to the possibility of mis-communication between autistic and neuro-typical research team members, it is always important to document decisions, meetings, and requirements of all research team members. Some possible ways to reduce mis-communications include:

- If everyone on the team agrees, use an audio recording device or record Zoom meetings for transparency, and store dated audio files in a shared folder. If any questions arise in the future, resolutions can occur by revisiting the meeting record. *Note: it is illegal in some states to record meetings without the consent of all parties. Therefore, this is something that should be transparently done as a way to ensure trust and commitment to open communication.*
- Document meetings clearly, with bullets and reduced text, to clearly communicate the action or goal for each team member. Provide these within 24 hours of the meeting occurring. Make them publicly available to the team as a matter of record.
- Consider using a cloud-based project management software, in which all team members can visually see the tasks, who is assigned to them, and the timeline.

IV. Measuring Engagement in the Autism Community

Author: Jeanette Purkis

Autistic people engage in research in a number of ways and through many roles. They might be academics, project leaders, consultants, researchers, participants in various research activities (e.g. focus groups, surveys etc.), peer researchers and/or mentors.

Evaluating and measuring levels of engagement is essential to the outcomes of the project. It is critical to gathering the data which informs the research. It is important to evaluate levels of engagement with autistic people who are part of the project team as well as those participating in the research. In general terms, the greater the level of engagement from the autistic community, the greater the quality and depth of the data collected. As such, understanding the factors promoting or limiting autistic engagement and being aware of how to engage autistics is crucial to achieving the outcomes for the project.

While autistic engagement is essential to this project, many autistic people are unwilling to engage in research. This can be due to a number of reasons, including a lack of trust in researchers or the research process, concerns about breaches of privacy and confidentiality, previous poor experiences of participation in research, concerns about tokenism or exploitation and feeling that their contribution will not be useful or used well. Genuine inclusion, having autistic researchers and peer researchers and valuing the views of autistic people and their input at every stage of the project are ways of helping to address this.

Measuring the degree of engagement in research by autistic people is a key way to ensuring that these barriers to participation are being broken down. A high level of engagement from the autistic community is an indication that the research question/s, rationale and methodology are aligned with the needs of the autistic community.

Engagement can be measured in variety of ways. Some qualitative indicators of engagement include:

- Autistic people are willing to participate (e.g. attend workshops, focus groups, seminars etc)
- Autistic people involved in the project as researchers, consultants or project leaders express job satisfaction
- Autistic participants feel they can trust researchers
- Autistic participants express a change in their perception of the value of participating in research
- Research participants would like to be more involved in the research

- The willingness of autistic participants to share information about the project, for example through posting information on the project in social media and discussing it with friends and colleagues.

In quantitative terms, indicators of engagement might include:

- The number of autistic participants in the different elements of the research
- The number of autistic people involved in the project as researchers, consultants or project leaders
- The number of events participated in by each individual
- The number of posts and shares of information about the project on social media
- The number of requests to be more involved in the project / undertake additional activities
- The number of requests for further information on the project
- The number of mentions of the project on autistic-run and more general autism groups online