

The Arc of King County

POLICY & PROCEDURE

SUBJECT: Research Studies

POLICY: The Arc of King County's policy regarding research studies is to provide information about studies to individuals and families so they are aware of the possible ways they can participate in research related to Intellectual and Developmental Disabilities, and related subject areas. The Arc will solicit appropriate information from the organization conducting the study to ensure it is operating within our code of ethics, however The Arc does not endorse, nor is it involved with, any of the research study opportunities listed.

For Individuals and Families participating in research studies:

The Arc of King County maintains a list of current research studies pertaining to intellectual and developmental disabilities. When a research team requests we share their study with the community, we include them in the list below. If we do not receive a request, we will not include the research study below. The Arc of King County does not endorse any of the research study listed, nor are we connected with the studies in any way. We merely provide basic information about the study for community access. Each study description includes a contact person to connect with for questions.

For Researchers:

Many universities, research centers, and other organizations ask The Arc of King County to help recruit study participants for various research projects pertaining to developmental disabilities. At this time, The Arc does not partner with research projects, however, with detailed information about the study, we are willing to post information on our website and other communication materials. We do not endorse any research study.

If you would like The Arc to include you research project on our website and in other communications, please submit the following information to

info@arcokingcounty.org:

1. Name of the study

2. Principle Investigator
3. Research institute or organization
4. Basic description of the study
5. Clear description of desired participants (e.g. age, gender, diagnosis, language/cultural group, etc.)
6. Detailed description of participants' commitment, activities, and reimbursement
7. Timeline for study (projected start and end date)
8. Any other relevant information
9. Contact person for this study
10. Website address

CODE OF ETHICS

1. **Honesty.** Strive for honesty in all scientific communications. Honestly report data, results, method and procedures, and publication status. Do not fabricate, falsify, or misrepresent data. Do not deceive colleagues, research sponsors, or the public.
2. **Objectivity.** Strive to avoid bias in experimental design, data analysis, data interpretation, peer review, personnel decisions, grant writing, expert testimony, and other aspects of research where objectivity is expected or required. Avoid or minimize bias or self-deception. Disclose personal or financial interests that may affect research.
3. **Integrity.** Keep your promises and agreements; act with sincerity; strive for consistency of thought and action.
4. **Carefulness.** Avoid careless errors and negligence; carefully and critically examine your own work and the work of your peers. Keep good records of research activities, such as data collection, research design, and correspondence with agencies or journals.
5. **Openness.** Share data, results, ideas, tools, resources. Be open to criticism and new ideas.
6. **Respect for Intellectual Property.** Honor patents, copyrights, and other forms of intellectual property. Do not use unpublished data, methods, or results without permission. Give proper acknowledgement or credit for all contributions to research. Never plagiarize.
7. **Confidentiality.** Protect confidential communications, such as papers or grants submitted for publication, personnel records, trade or military secrets, and patient records.

8. Responsible Publication. Publish in order to advance research and scholarship, not to advance just your own career. Avoid wasteful and duplicative publication.
9. Responsible Mentoring. Help to educate, mentor, and advise students. Promote their welfare and allow them to make their own decisions.
10. Respect for Colleagues. Respect your colleagues and treat them fairly.
11. Social Responsibility. Strive to promote social good and prevent or mitigate social harms through research, public education, and advocacy.
12. Non-Discrimination. Avoid discrimination against colleagues or students on the basis of sex, race, ethnicity, or other factors not related to scientific competence and integrity.
13. Competence. Maintain and improve your own professional competence and expertise through lifelong education and learning; take steps to promote competence in science as a whole.
14. Legality. Know and obey relevant laws and institutional and governmental policies.
15. Human Subjects Protection. When conducting research on human subjects, minimize harms and risks and maximize benefits; respect human dignity, privacy and autonomy; take special precautions with vulnerable populations; and strive to distribute the benefits and burdens of research fairly.