

## Publications and Presentations Policy

The GALAXY Registry Steering Committee is charged with final review and approval in writing of all manuscripts and abstracts prior to submission and of all oral or written materials prior to presentation. This is a committee consisting of representatives from the clinical centers who are members of the GALAXY Registry, representatives from the Association for X and Y Chromosome Variations (AXYS), and community/patient representatives. The goal of this committee is to ensure submission of high-quality manuscripts, presentations of high-quality content, and appropriate authorship credit.

The purpose of the publication policy is to:

- Encourage the timely preparation of high-quality publications and presentations from investigators.
- Provide appropriate academic recognition to individuals who make significant and substantial contributions to the GALAXY Registry.
- Clearly state expectations for Data Use and Material Transfer Agreements between the University of Colorado as the data management center and other entities

### A. Requests for Data Access from Non-GALAXY Registry Member Investigators/Individuals

See Request for Data Use Policy for more details.

### B. Single Site versus Multi-Site Publications and Presentations

The registry is expected to provide data to produce numerous publications and presentations. It is possible that selected publications or presentations will involve activities specific to a single institution, while others will involve more than one. Any publication or presentation of work that draws data or specimens from the GALAXY Registry will be governed by the rules set forth below. If there are any ambiguous situations, then the issue should be considered by the GALAXY Registry Steering Committee before manuscript or abstract submission and before oral or written presentation.

### C. Presentations

Any abstract, or summary of data for summary of data submitted for poster or oral presentation must be sent to the GALAXY Registry email ([GALAXY@ucdenver.edu](mailto:GALAXY@ucdenver.edu)) no later than 3 weeks before it is due to the conference/presentation offices. (Unusual circumstances requiring shorter time frames will be reviewed on a case-by-case basis.) Members of the GALAXY Registry Steering Committee should submit their comments to the GALAXY Registry Research Microsoft Teams channel within 10 days to return objections. All abstracts and oral presentations must include the “GALAXY Registry” as part of the title of the project. Projects involving summary of data for oral presentation must include acknowledgement of sources of funding if applicable.

### D. Establishing Authorship

The guiding principles of study authorship for GALAXY Registry publications are the same as those recommended by the International Committee of Medical Journal Editors (<http://icmje.org/recommendations/browse/roles-and-responsibilities/defining-the-role-of-authors-and-contributors.html>).

Decisions about who appears as a listed author on a publication can be complex when the work upon which the publication is based ~~has been~~ on the results of collaboration by many individuals. Persons who have taken part in the actual writing of a paper or preparation of a presentation will generally appear as the first authors. Additional authorship is something that

must be worked out by the lead author/investigator responsible for the concept which was the basis for the paper.

The following list is offered as a ~~guideline~~ *guidance*. Any of these items can be modified in consultation with the GALAXY Registry Steering committee in the context of an individual submission:

- To foster collaboration among researchers and motivate all levels of staff involved in the GALAXY Registry, a general governing principle is to recognize as many persons as sensible on a paper or presentation. For the sake of practicality, distinctions must be made between recognition and authorship, particularly when journals limit the number of cited authors.
- Be familiar with the journal being targeted as a publication source so that the policy on authorship is clear from the start and the appropriate number of authors is assigned based on journal limitations.
- If a publication or presentation involves data primarily related to one site, the principal investigator from that site and the lead author (if different) should determine the authors, following journal policy and the plan for developing the manuscript.
- If a publication or presentation makes use of data collected from all or most of the GALAXY Registry sites, at least one person from each site should be named as an author. The lead investigator from each site can choose the specific person to be listed. Depending on the impact of the results presented in such a publication, the primary author may decide to list all GALAXY Registry investigators from all sites. Ideally, this decision should be made in advance of submission of a final paper to the Steering committee. However, during review, the members of the Steering committee may assess the presented information as particularly important and make a recommendation to expand the authorship.
- If a paper is related to an area of investigator expertise, that investigator should assist with manuscript preparation and be included as an author.
- A full list of current consortium members should be included in the Appendix of the submitted paper and is available from the GALAXY Registry by sending an email to [GALAXY@ucdenver.edu](mailto:GALAXY@ucdenver.edu). The list includes names, title and organizational names and ensures that listings are consistently handled across all GALAXY Registry publications.
- To avoid confusion and resulting disputes about authorship in the later stages of preparation, early discussion about authorship is suggested and consultation with the Steering Committee is recommended.

Investigators from all GALAXY Registry participating sites are encouraged to participate in study-related publications.

## **E. Authorship Decisions**

Authorship should be openly discussed, and authors selected as soon as responsibilities are assigned for the preparation of a report or paper. Having agreed on the key objectives, the research collaborators should evaluate the criteria of authorship and make preliminary decisions. These decisions may need to be revised based on actual contributions to the report or paper. In most cases, final authorship should be decided after completion of the first draft.

The primary author should be chosen through negotiations among participants on or before writing the first draft, based on the requirements of primary authorship.

**F. Disputes in Authorship**

The collaborators in a study should first discuss disagreements about authorship. The authors should review the criteria for authorship during such discussions. If disputes still exist, the matter may be taken to the GALAXY Registry Steering Committee. The resolution should be based on the above guidelines and any authorship guidelines that exist for collaborators. Unresolved disputes concerning authorship should be documented by a memo addressed to the GALAXY Registry Publication Committee and submitted to the GALAXY Registry email at [GALAXY@ucdenver.edu](mailto:GALAXY@ucdenver.edu) for distribution to the GALAXY Registry Publication Committee.

**G. Manuscript Title**

The GALAXY Registry must be included in the title of the manuscript, unless precluded by the journal requirements.

**H. Acknowledgements and Credits**

Authors should acknowledge the contributors whose participation is not substantive enough to warrant authorship. A contribution to one of the areas of authorship (for example, advisership, data collection, or review of study) is not sufficient for authorship but should be mentioned in the acknowledgements. The credit(s) should be presented in a format consistent with the requirements of GALAXY Registry Publication Committee and the guidelines established by the journal or publisher.

The GALAXY Registry Steering Committee expects that presentations and publications emerging from the GALAXY Registry will acknowledge the funding sources provided by the Association for X and Y Chromosome Variations (AXYS) and all other sources of funding as appropriate and will acknowledge the source of the data as being from the GALAXY Registry. The following statement should be included in all manuscripts submitted for publication:

“The GALAXY Registry is supported by patient advocacy organizations including AXYS, Living with XXY, and The XXY Project”.

**I. Review Process**

The Steering committee will review draft publications with the following objectives in mind:

- to prepare comments to assist collaborating scientists to publish papers of the highest quality;
- to correct factual and conceptual inaccuracies; and
- to safeguard the rights of volunteer subjects and colleagues.

**J. Papers and pre-prints**

Draft manuscripts should be sent to the GALAXY Registry Research email at [GALAXY@ucdenver.edu](mailto:GALAXY@ucdenver.edu). The paper submitted for final review should be in a final form (title, abstract, tables, references) required by the journal to which it is being submitted. The journal to which the manuscript will be submitted should be indicated. This process should be followed prior to submission to any preprint server as well.

Once received we will make all steering committee members aware of the submission and provide opportunity to participate in critical review. Members of the GALAXY Registry Steering committee should submit their comments to the GALAXY Registry Research Microsoft Teams channel for return to the lead author within 2 to 4 weeks. It is hoped that a consensus will be reached among the reviewers regarding the final text. If there is disagreement among the members of the GALAXY Registry Steering committee, a quorum of 4 reviewers from among Steering committee investigators will verify their availability for

reviewing the document based on their expertise. Each reviewer will be asked to evaluate whether the publication as written will affect the study's progress, its acceptance, or the interpretation of its results. If the reviewers agree that the document is not scientifically rigorous, conflicts with the priorities of the patient community, or other substantial concerns, the manuscript will be returned to the lead author with suggestions for appropriate changes.

#### **K. Public Presentations**

The GALAXY Registry is very interested in having publications and presentations made public as rapidly as possible to have visibility in the international scientific community. Therefore, the Steering Committee should proactively identify the major meetings where it would be appropriate to have a presentation and identify someone who usually attends that meeting to present applicable data.

#### **L. Interviews and Press Releases**

An interview is any discussion with a member of the press, a science writer or radio or television commentator that in turn provides information for public dissemination. Press releases and interviews must acknowledge registry funding sources. In addition, the following specifications should be followed:

If an investigator is solicited for a press release or interview, it may be given without prior review and approval by the GALAXY Registry Steering Committee, provided the substantive content is limited to information available in the final protocol with no added interpretation or inferences. Should a collaborating center be solicited for information other than that detailed above, the center should refer the soliciting party to the GALAXY Registry Steering Committee. The data and interpretation presented should not go beyond what the author discussed in the formal scientific publication. Any required approvals by the authors institution should still be followed.

#### **M. Public dissemination before publication (i.e., social media, websites, etc.)**

The GALAXY consortium supports public dissemination of findings from the registry and supports it being done in an ethical and legal manner. All figures, tables, etc. should accurately reflect the data and conclusions of the research. A reference should be provided to the original publication/abstract when available. Any embargo policies of a conference or journal must be followed. Steps should be taken to ensure appropriate interpretation by non-scientific audiences, especially the patient community.

#### **N. Final documents**

The author is responsible for providing the final submitted/presented abstracts (or posters), published articles, recorded presentations, etc. for us to archive

#### **O. Enforcement**

Should any author or organization not follow the policies outlined above, future access to data from the GALAXY Registry will be revoked.