

Publications and Presentations Policy

The Publications Committee is charged with final review and approval 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 member of the InsignTS Registry and of representatives from the Turner Syndrome Global Alliance (TSGA). 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 participants who make significant and substantial contributions to the InsignTS Registry.

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

Requests for InsignTS Registry data access from non-member investigators and/or individuals must be accompanied by written verification of sponsorship by an investigator who is a member of the InsignTS Registry. It is expected that the sponsor will work closely with the investigators and/or individuals for use of data to produce abstracts, manuscripts and/or presentations of high-quality content. See Request for Data Use Policy for more details.

B. Single Site versus Multi-Site Publications and Presentations

The registry is expected to produce numerous publications and presentations. It is possible that selected publications or presentations will involve activities specific to a single participating site, while others will involve more than one site. Any publication or presentation of work that utilizes InsignTS Registry data or specimens will be governed by the rules set forth below. If there are any ambiguous situations, then the issue should be considered by the InsignTS Registry Publications 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 oral presentation must be sent to the InsignTS Registry email (Insights@ucdenver.edu) no later than 3 weeks before it is due to the conference/presentation offices. (Unusual circumstance requiring shorter time frames will be reviewed on a case-by-case basis.) Members of the InsignTS Registry Publications Committee should submit their comments to the InsignTS Registry Research Microsoft Teams channel within 10 days to return objections. All abstracts and oral presentations must include the “InsignTS 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 InsignTS 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 the result of collaboration by a large

number of 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. Any of these items can be modified in consultation with the InsignTS Registry Publications Committee in the context of an individual submission:

- To foster collaboration between researchers and motivate all levels of staff involved in the InsignTS 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 InsignTS 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 InsignTS Registry investigators from all sites. Ideally, this decision should be made in advance of submission of a final paper to the Publications Committee. However, during review, the members of the Publications 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 particular 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 InsignTS Registry by sending an email to Insights@ucdenver.edu. The list includes names, title and organizational names and ensures that listings are consistently handled across all InsignTS 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 Publications Committee is recommended.

Investigators from all InsignTS 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 InsignTS Registry Publications 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 InsignTS Registry Publication Committee and submitted to the InsignTS Registry email at Insights@ucdenver.edu for distribution to the InsignTS Registry Publication Committee.

G. Manuscript Title

The InsignTS Registry must be included in the title of the manuscript.

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 InsignTS Registry Publication Committee and the guidelines established by the journal or publisher.

The InsignTS Registry Publishing Committee expects that presentations and publications emerging from the InsignTS Registry will acknowledge the funding sources provided by the Turner Syndrome Global Alliance (TSGA) and all other sources of funding as appropriate, and, will acknowledge the source of the data as being from the InsignTS Registry. The following statement should be included in all manuscripts submitted for publication:

The InsignTS Registry is supported by the Turner Syndrome Global Alliance (Overland Park, KS).

I. Review Process

The Publications 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.

J. Papers

Draft manuscripts should be sent to the InsignTS Registry Research email at Insights@ucdenver.edu. The paper submitted for final review should be in a final form (title, abstract, tables, references) required by the journal to which they are being submitted. The journal to which the manuscript will be submitted should be indicated.

Members of the InsignTS Registry Publications Committee should submit their comments to the InsignTS Registry Research Microsoft Teams channel for return to the lead author within 4 to 6 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 InsignTS Registry Publications Committee, a quorum of reviewers from among Publications Committee investigators will verify their availability for reviewing the document based on their expertise in the subject matter of the particular document and for their understanding of the study as a whole. Each reviewer will be asked to judge whether or not the publication as written will affect

the study's process, its acceptance, or the interpretation of its results. If the reviewers agree that the document is not scientifically rigorous, the manuscript will be returned to the lead author with suggestions for appropriate changes.

K. Public Presentations

The InsignTS Registry is very interested in having publications and presentations made by members of the Steering Committee as rapidly as possible in order 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 make a presentation.

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 that the registry is funded by the TSGA. 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 InsignTS 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 InsignTS Registry Publication Committee.