

# International Thymic Malignancy Interest Group Research Proposal

## Policies for studies using ITMIG REGISTRY

The ITMIG Registry is intended to be a resource that will foster advances in thymic diseases and research.

### General Principles

- Any institution or individual contributing data can access their own data at anytime for any purpose, e.g. for research or publication.
- Any organization (e.g. ESTS thymic group, JART etc) can use the registry to house their group's data. This may be accessed and used at any time according to the group's rules.
- Use of the global data for research is encouraged and is the purpose of the registry. This can be conducted by anyone meeting eligibility requirements according to the approved process.
- Any publication or report resulting from the global ITMIG Registry will acknowledge ITMIG, all participating institutions and organizations, and the thymic registry representative at these institutions and organizations
- It is expected that contributors to the registry are willing to allow their data (de-identified and anonymous) to be used for ITMIG approved studies.

### Eligibility to use the ITMIG Registry

- Must be an ITMIG member in good standing
- Must be an active contributor to the registry
- Must not have opted out of allowing their data (de-identified and anonymous) to be used for approved studies
- Project approved by ITMIG Database Committee

### Process to use the ITMIG Registry

- Provide the ITMIG Database Committee via the ON-LINE FORM short outline of the study, the type of data needed, and the intended use (e.g. publication). The Committee assures that all information about the project will be kept confidential. The committee will provide a decision on the project with a 1-month delay.
- Provide permission from their institution (i.e. an IRB waiver) that the study is approved (if applicable)
- The ITMIG Database Committee will provide the data once it has approved the study.
- The researcher may use the obtained data only for the submitted study project and may not share it with other parties without the consent of ITMIG. The project should be completed within 12 months after obtaining the dataset.
- Any publication or report must clearly acknowledge both the ITMIG organization as a source for the data, and list each participating institution as defined above.
- The investigator must provide the Database Committee a copy of any submitted manuscript or report. This will be kept confidential (until available publicly (i.e. in a journal). ITMIG has the right to raise concerns about any unethical use of the data with the investigators or with a journal should such exist. Not providing a copy of a submitted paper or unethical use of the data will potentially forfeit any future proposals for use of the ITMIG Registry.

### Authorship rules

- Authorship will be up to the group carrying out the research study.
- People will not be included as authors if they had no part in a study other than providing data.
- ITMIG and participating centers must be acknowledged as described above.

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**A- Title:**

**B- Investigators:**

Principle Investigator (PI) and Corresponding author:

Co-investigators / Co-authors:

**C- Research question / hypothesis:**

**D- Rationale and Significance:**

**E. Secondary Research Questions:** (List secondary research questions and any exploratory analyses that are planned)

**F- Patient Population:**

**G- Analysis Plan:**

**H- Requested Variables:**

**I- Disclosures:** None

The PI is an active Member of ITMIG in good standing

Yes  No

The PI has been an active contributor to the ITMIG Registry

- Contributor with DTA in place,
- $\geq 20$  patients total with  $\geq 50\%$  completion in the registry
- $\geq 5$  new patients since 2024

Yes  No

All investigators have read and agree with the ITMIG terms of use of the registry.

Yes  No

**Signature:**

**Date of Submission:**

Approved: Yes  No   
Version: 4/172024

Date of decision:

Approved by: