# The Role of the Registry Steering Committee

* 1. **Purpose**
* The overall aim of the Registry Steering Committee is to promote the wide use of the data being collected in the registry, through a transparent and simple approach, ensuring the long-term sustainability of the registry. The Registry Steering Committee should ensure the maintenance of the highest levels of custodianship of the data.
* The Registry Steering Committee shall act as the Data Access Committee for the relevant registry.
* Whilst it should have a good knowledge of ethics and data protection, the Registry Steering Committee should not act as another ‘research ethics committee’, which is a responsibility that rests with the data controllers (the Society team).
  1. **Tasks**

The Registry Steering Committee will review all new applications, existing projects, end of project reports and any other outputs.

Specific tasks include:

* Check that the proposed use of registry data complies with the terms and conditions of the ethics approval for the Registry project.
* Look for evidence that the Investigator who is requesting the data is appropriately qualified for use of the data.
* Advise on improving the scientific content and feasibility of the projects and any overlaps with ongoing projects.
* Review all research outputs based upon registry data prior to publication.
* Advise on the dissemination of research outputs and publication plans where appropriate.
* Ensure that the effort of all those involved in the is appropriately acknowledged under the publication plan.
* Provide feedback on their request to each data access requestor.
* Review and advise on registry governance processes in capacity of Data Access Committee.
  1. **Conditions**

All members of the Registry Steering Committee shall:

* Serve a 3-year term, once the project is live, renewable for another 1 yr.
* Communicate with the Project Management Group through the Chair of the Registry Steering Committee.
* Complete, and keep updated, a conflict of interest form relating to the registry.
* Declare any specific conflicts when reviewing an application.
* Treat all data requests confidentially.
* Aim to respond to all data requests promptly.
* Be familiar with the Data Access Policy and ethics approval of the registry project.

**Society for Endocrinology Registry Steering Committee Remit**

Composition Chair: The role of Registry Steering Committee Chair is filled by a current member of the Society who is deemed to be a clinical leader in the topic area. This role will rotate every 3 years but is renewable for a further three at the discretion of the Clinical Committee. The start of the three years is in alignment with the start of the project being open to data entry at sites.

Full Registry Steering Committee Members: At the discretion of the Chair and Project Manager, a diverse group will be selected by invitation and application to form a Registry Steering Committee of 10-15 members who will serve for 3 years. The start of the three years is in alignment with the start of the project. This is renewable for a further year at the discretion of the Chair of the Registry Steering Committee. The group convened to get the project to the official start will be formed of experts needed in the clinical area for items such as protocol writing.

Full members must include but are not limited to, trainee, nurse and patient representation.

Co-opted Registry Steering Committee Members: Added at the discretion of the Registry Steering Committee to provide ad-hoc expertise to the Registry Steering Committee on specific matters. These members will serve for the duration determined by the Chair of the Registry Steering Committee.

**Reporting**

The Registry Steering Committee will report, upon request by the Society Engagement Team, to the Clinical Committee meetings held three times per year. There is also an open reporting line to the Clinical Committee for any advice or expertise sought.

**Remit**

Each Society Registry will be commissioned and approved by the Clinical Committee of SfE for a specified duration in the first instance.

It is intended that the Registry Steering Committee leverages the experiences, expertise, and insight of key individuals at organizations committed to building professionalism in project management. Registry Steering Committee members are not directly responsible for managing project activities, but provide support and guidance for those who do. Thus, individually, Registry Steering Committee members should:

* Understand the strategic implications and outcomes of initiatives being pursued through project outputs;
* Appreciate the significance of the project for some or all major stakeholders and represent their interests;
* Be genuinely interested in the initiative and be an advocate for broad support for the outcomes being pursued in the project;
* Have a broad understanding of project management issues and approach being adopted.

In practice, this means they:

* Develop a protocol, patient information sheet, ethics applications, minimal dataset for the project, identify sites for participation;
* Review the status of the project;
* Ensure the project's outputs meet the requirements of the original proposal;
* Help balance conflicting priorities and resources;
* Provide guidance to the project team and users of the project's outputs;
* Consider ideas and issues raised;
* Check adherence of project activities to standards of best practice both within the organization and in a wider context;
* Foster positive communication outside of the Team regarding the project's progress and outcomes.

**Use of Data**

The Registry Steering Committee will approve data access requests pertinent to the register they govern. Data access requests will come into the Society and be brought to the attention of the Registry Steering Committee. The Registry Steering Committee may approve or not or ask for further information.

The members of the Registry Steering Committee will disclose any conflicts of interest upon joining the Registry Steering Committee and will be asked to keep this information updated with the Society.

The members of the Registry Steering Committee will be able to access the national dataset, having followed the same data access process as an external party, for their tenure of term on the Registry Steering Committee. If no longer a serving member of the Registry Steering Committee, they are subject to the same data cost template as members or researchers.

The members of the Registry Steering Committee are not permitted to access the national data on behalf of a third party at any time.

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**Ethics**

The Registry Steering Committee will write and support the ethics application submission. This includes writing protocols and patient information sheets for the project. They are also responsible for writing any amendments to the project documentation should the need arise.

**Finances**

The Registry Steering Committee will help the Society Engagement Team identify potential third-parties who will provide financing for a specific registry. The Registry Steering Committee will assist with writing the grant application when applicable. The Registry Steering Committee will have oversight of the project funds for the duration of the project and, if appropriate, participate in multiple funding rounds for a particular registry.

**Project Management and Secretariat**

Each project will have a project manager appointed from the Society Engagement Team who will manage the project alongside the Registry Steering Committee.

**Chair of the** Registry Steering Committee

The chairperson of the each registry is approved by the Clinical Committee. The term of office is three years renewable for a further three years. Their role is to:

1. Lead the Registry Steering Committee and motivate local principal investigators. The chairperson will be required to chair two to three steering committee meetings a year and the Annual General Meeting, if undertaken. In addition, regular contact with the project manager is fundamental.
2. Encourage academic exploitation of the register and be responsible for ensuring high standards of research governance are maintained and in particular compliance with ethics regulations.
3. Assist in securing ongoing funding for the project.

**Clinical Committee Remit for Governance of Projects**

The Clinical Committee will review written updates on all projects undertaken by the Society during the three meetings held each year. Updates will include a summary of activity to timelines, funding expenditure, number of data access requests and overall recruitment of patients to the register. If there are any discrepancies or anomalies then the Clinical Committee will write to the Chair of the Registry Steering Committee for clarification. The Clinical Committee will also hold the right to disband a Registry Steering Committee and registry project if there is not sufficient funding or recruitment of patients. There will be an open line of communication for the chair of the Registry Steering Committee into the Clinical Committee for referral of topics that need additional support, for example data access requests where an agreement cannot be made at the Registry Steering Committee.