

Central Governance and Operations Handbook for ISSCD Committees

Introduction

The ISSCD recognises and deeply appreciates that committee and regional group members (further referred to collectively as committee members throughout) generously volunteer their time to support the global advancement of celiac disease and share the same mission and commitment to finding solutions and ultimately a cure for celiac disease on a global scale.

To support its members in their roles, this handbook has been created as a practical and comprehensive guide to the governance and day-to-day operations of the ISSCD. As a registered charity, the ISSCD is required to meet relevant government guidelines and regulations, and this handbook helps ensure we do so clearly and consistently.

It should also serve as a guide to provide you with access to standardised tools and templates to simplify implementation, promote best practice, and support compliance.

Committee Structure and Responsibilities

Specialist committees are proposed by current members of the ISSCD and require a sponsor who is a member of the ISSCD Board. ISSCD Board Members may be a sponsor of a maximum of 2 Committees and/or Regional Groups.

Each committee is responsible for guiding research, advancing scientific initiatives and clinical practice, supporting strategic goals, and facilitating collaboration within the ISSCD and amongst external stakeholders within the area of celiac disease and other gluten mediated disorders.

The maximum number of members, including Chairs for each committee is **eight people**. Any additional members will need approval from the ISSCD Board.

If the committee wishes to co-opt working groups to support their work this is the best approach to ensure committees have access to the knowledge they may require for projects.

Committee Mandate - Please refer to your individual Committee Terms of Reference which can be found in the designated Committee SharePoint Folder.

Central Operations Requirements for ISSCD Committees

1. Each Committee Member will receive access via a link to a designated folder on the website to access the Standard Forms and Templates via email. The ISSCD will provide access to the ISSCD SharePoint drive to upload, share and update documentation for each specific Committee and Regional Group.
2. Each Committee is required to submit all financial requirements and funding requests to the ISSCD's Head of Funding and Engagement before any grants or funds are received or requested. This is to ensure a collective approach, where appropriate, can be made across committees and to ensure the ISSCD follows all required financial disclosure and financial management regulations. Especially in the case of a third-party funding donation or sponsorship.
3. Each committee commits to work within the ISSCD branding framework and guidelines by utilising the correct committee logo and following the guidelines for any media including all social media platforms. The central office will be happy to work with you should you be unsure on anything and can be reached on the info@isscd-global.org email.

Governance and Elections

Election Guidelines

Elections occur every two years, following defined nomination and voting procedures. The Chair of a Committee will be appointed by the Board, and the Members of the Committee will be selected by the Chair and the ISSCD Board following a review of expressions of interest. All members and applicants for committees must be registered ISSCD members.

The only positions available within a committee are as follows:

- Chair
- co-Chair
- Committee Member

A member of a patient organisation may be a member of a committee but not serve as the Chair or co-Chair. Industry representatives may be a member of a committee but may not Chair or co-Chair a committee. It is important that the ISSCD remains independent and impartial.

Nomination Process

If committee members would like to nominate future committee members, they should ask the person to apply directly to the email address info@ISSCD-global.org in English. These applications will then be collated by the central office and shared with the Board and Committee Chair(s) for approval.

Candidates must submit the following through to the ISSCD directly to the info@ISSCD-global.org email address:

- Expressions of interest
- Curriculum Vitae
- Declaration of conflicts of interest

All three documents are required for the approval process, which can be expected to take up to 3 weeks from the submission deadline.

Once a committee member is approved, they will need to submit a biography and photograph to the central office on info@isscd-global.org for use on the website and other media.

Applications that are unsuccessful will be responded to by the central office.

Committee Yearly Meeting Commitments

Each committee is required to meet at least once per quarter, and it is the responsibility of the designated committee member to organise these meetings, including the agenda, meeting notes and list of actions, using the templates provided. If you would like someone from the central organisational team to schedule the meeting, please contact the info@isscd-global.org

The Committee agenda and minutes must be uploaded to the relevant committee folder on the central SharePoint and shared with the central office via the info@isscd-global.org email. There is a template available within the Standard Documents and Templates folder on the website. You will receive a link to access this once you join a committee via email.

Each ISSCD committee Chair and co-Chairs are required to meet with the ISSCD Executive Committee a minimum of twice per year. *The central office will co-ordinate the scheduling of these meetings.*

All committee Chairs and co-Chairs are required to meet the ISSCD Board once per year and this should be scheduled to coincide with the timing of the committee's Annual Report, which is a standard requirement and is to be submitted to the central office via the info@isscd-global.org and must be uploaded to the Central SharePoint for the Committee.

The Chair/co-Chairs of the committee are required to attend a scheduled Board meeting for approx. 20 minutes to answer any questions on the Annual Report from the ISSCD Board.

The central office will co-ordinate the scheduling for these meetings.

Quick View Meetings Chart

Committee meetings with Chair/co-Chair(s) and Members	Minimum of 4 per year
Committee Chair / co-Chair meeting with the ISSCD Board Executive	Twice per year
Chair/co-Chair(s) of the Committee Annual Report meeting with the ISSCD Board	Once per year

Annual Report - Each committee is required to submit an annual report as part of their Terms of Reference. The Annual report should also be sent to the central office by email info@ISSCD-global.org to be shared with the Board Executive for review and uploaded on the central committee SharePoint.

Outgoing Committee Members

Outgoing Chairs need to prepare a structured handover document to share knowledge and ensure the committee has the ability to continue moving forward with its projects and objectives. A template for the handover can be accessed within the standard documents and reports folder on the website.

Template Documents to support Committee Members

- Annual Report Template
- Agenda and Minutes Template
- Outgoing Committee Member Handover Document
- Conflict of interests Declaration

Committee Project Management Framework

When considering a new project such as a position paper, survey, webinar events, or workshops, ISSCD committees must complete a project initiation form which can be found on the website, and submit this to the central office for review by the ISSCD Board Executive via the info@ISSCD-global.org email.

There are standard forms and report templates available in the standard documents and templates folder on the website. You will receive the link via email.

1. **Project Initiation Document (PID)** – An overview of the project, its objectives, methodology, desired outcomes and resources and/or funding required and timelines.
2. **Project Progress Report** – Delivers an ongoing update of how projects are progressing.
3. **Final Project Report** - Completed projects require a Final Project Report summarising outcomes, findings, learnings and next steps to support the committee and the ISSCD with future project planning. This is separate from the Committee's Annual Report which is required once per year.
4. **Third party funding Request** – Specific request to access funding from a third party e.g. Corporate, Trust, Foundation.

Governance on ISSCD Acknowledgement and Institutional Affiliation

Transparency of Institutional Involvement

At the initiation of any committee-led project, the Chair or co-Chairs must clearly communicate all institutional affiliations and endorsements, including involvement of the ISSCD to all contributors and collaborators and the central ISSCD office.

This information should be shared **at the start of the project**, prior to substantive contributions and be listed as part of the *Event/symposium creation document*.

This includes:

- Whether the project is formally affiliated with ISSCD
- Whether ISSCD committees, working groups, or leadership are involved
- Whether ISSCD endorsement, branding, or acknowledgment is expected

Use of ISSCD Name and Acknowledgement

The use of the ISSCD name, logo, or implied endorsement in project titles, manuscripts, acknowledgements, or dissemination materials must follow these principles:

- If the ISSCD contributes through committee activity, coordination, or support, this must be **explicitly described** in the acknowledgements section.
- Acknowledgement language should accurately reflect the nature of ISSCD's role and the work of the ISSCD Committee or Regional Group

Example acknowledgement language (**adapt as appropriate**):

“This work was conducted as part of activities supported by the International Society for the Study of Celiac Disease (ISSCD) through its [committee name].”

Responsibility for Compliance

The Chairs and co-Chairs are responsible for:

- Ensuring all contributors are informed of ISSCD's role
- Verifying that ISSCD acknowledgment is accurate and appropriate
- Consulting with ISSCD central office when uncertainty exists

Manuscripts and External Publications

For manuscripts, reports, or other outputs resulting from committee efforts:

- ISSCD acknowledgment requirements must be reviewed **prior to submission**
- Any use of ISSCD affiliation must be agreed upon by the central office and consistent with ISSCD policies
- Contributors must have the opportunity to review and raise concerns about institutional representation before publication

These guidelines are intended to:

- Ensure the ISSCD is recognised for the valuable work its Committees and Regional Groups undertake
- Help to establish the ISSCD as the globally unified voice for celiac disease and gluten mediated disease research.
- Prevent unintended or unclear institutional attribution
- Ensure transparency and trust among collaborators
- Protect both contributors and ISSCD from misrepresentation

Funding and Resource Requests

As a registered charity, the ISSCD operates under strict governing regulations that require its financial practices to be transparent, accountable, and compliant with charitable standards.

The ISSCD also supports its committees by leveraging trusted suppliers that offer competitive pricing, helping prevent unnecessary spending and ensuring financial transparency, accountability and sustainability.

Committees must submit a **Funding and Resource Request Application** for all initiatives requiring financial support such as webinars, workshops, satellite symposia and any external third-party services.

This form also includes the opportunity to request any resources required from the central office such as a Teams channel for communication, marketing, social media, support at an event, applications and grant requests.

The Funding and Resources Request form may be accessed in the standard documents and templates folder on the website.

Events and Conference Activities

Sharing this information ensures that the ISSCD can maximise the impact of its committees' efforts and strengthen its global presence as the unified voice of the celiac disease community.

Committee members planning to attend external events or to host an event should notify the central office via email or complete the Event form which can be found on the central SharePoint. This includes any speaking engagements or events they wish to represent as part of their commitment to the ISSCD work for approval as per the committee terms of reference.

Satellite Symposiums – The ISSCD requires an Event/Symposium creation form for any proposed Satellite Symposium as there will be a new schedule of events managed by the central team which will account for rotation of regions and also support the main ICDS conference which is held every 2 years.

Event/Speaker/Media Requests

Committee members must disclose any speaking engagements, podcast appearance requests or interview requests for transparency and coordination and to maximise the global impact and support from the ISSCD and to ensure the engagement is aligned with the mission and values of the ISSCD.

Once you have submitted a Media Request the Central Office will connect with the host to obtain a full brief and outline the guidelines of participation such as launch dates and scheduling and obtaining editing rights. The central office will also be able to support you as a speaker/guest by providing a basic stats and facts sheet and some guidance on representing the ISSCD.

Event Funding and Reporting

Any funding must also be secured via the central office before any planning or outreach or accepting any offers of funding. This is to ensure full financial transparency under the ISSCD's legal obligations.

1. **Event/Symposium Creation Form** - This form is required for organising conferences, workshops, training sessions, or public events or symposiums that support a committee's activities and strategic goals and ensure central resources are allocated appropriately.
2. **Event Summary Form** – A summary of event outcomes, learnings, and opportunities to support the ISSCD to continue to deliver worldclass congress meetings, symposiums and opportunities to connect professionals from around the world.
3. **Event/Media Request Attendance Form** - Committee members must disclose speaking engagements, podcast appearance requests or Interview requests for transparency and coordination.

Branding Guidelines

There are now official ISSCD logos and branding guidelines for Committees and Regional Groups.

Social Media posts should be actioned by the central ISSCD office through the official ISSCD social media accounts which can then be reshared from professional and personal accounts on platforms such as LinkedIn, Facebook and Instagram, Webinars and YouTube. This helps to establish the ISSCD as the global platform for celiac disease research knowledge sharing and collaboration.

Before promoting any ISSCD committee-initiated event, the central office must be informed and will work with each committee to ensure the appropriate project plan, funding and approval is in place. The central office will then work with the committee to maximise reach, exposure and impact.

ISSCD committee projects that result in publications must always include within the acknowledgments the ISSCD and the specific ISSCD Committee along with any agreed sponsors.

All such publications should be shared with the central office for appropriate marketing and to allow for monitoring impact metrics. It is important for the work of the ISSCD and its committees to be recognised and to ensure any funding is transparent and conforms with regulations.

Social Media Submission Form

Committees who wish to set up an additional Facebook Page, LinkedIn or Instagram page must inform the central office. They will be supplied with the official ISSCD logos for their committee and the brand guidelines.

The central office will support on scheduling and co-ordinating on social media to ensure they link back to the ISSCD website, to allow the ISSCD to monitor the reach, impact and metrics of each committee's outreach.

ISSCD Website

Each Committee is able to submit information about its activities and achievements which they would like shared on the ISSCD website, please share copy and any associated images and/or documents with the central office who will upload the information via the info@ISSCD-global.org.

Summary of standard documentation

The following forms and templates support consistent governance, transparency, and operational compliance across all ISSCD committees. Committees are required to use the appropriate forms/templates as outlined below.

All documents are available within the standard documents and templates folder on the website, which you will receive a link to access to via email.

Standard Reporting Forms

1. Meeting Agenda, Notes and Actions

Required for each committee meeting and is a combined document.

2. Annual Report

Submitted annually as part of the committee's Terms of Reference and the ISSCD's legal obligations.

3. Outgoing Handover Document

Required when a Committee Chair or Committee Member steps down.

4. Third Party Funding Request Form

Required to inform the central office of any funding or resources to be delivered by a third party.

5. Project Initiation Document

Required when starting new projects such as position papers, surveys, webinars, workshops or symposiums.

6. Project Progress Report

Submitted quarterly to report project progress.

7. Final Project Report

Required upon completion of a project.

8. Funding and Resource Request Application

Required for all initiatives needing financial support for webinars, workshops, symposiums and third-party services.

Governance & Committee Membership Forms

Expression of Interest – To be provided by candidate

Required for Committee Membership nominations and applications

Curriculum Vitae (CV) Submission – To be provided by candidate

Required for Committee Membership nominations and applications

9. Declaration of Conflicts of Interest

Required for Committee Membership nominations and applications

Events & Symposium and Conferences Forms

10. Event/Symposium Creation Form

Required to organise conferences, workshops, training sessions, or symposiums.

11. Event Summary Form – Close and Learn

Used to report outcomes and learnings after an event.

Communications & Branding Forms

12. Social Media Submission Form

Used to request approval for social media content.

13. Event/Media Request Form

For speaking engagements, podcasts, interviews or attendance at external events.