



**European Chapter of the Extracorporeal Life
Support Organisation
(EuroELSO)**

CHARTER & BY-LAWS

I.



Mission Statement

EuroELSO is an international consortium of health care professionals and scientists practicing in Europe and Israel who are dedicated to the development and evaluation of extracorporeal life support techniques for failing organ systems. These extracorporeal therapies are designed to benefit patients whose needs are not met by conventional supportive therapies.

Guiding Principles

The guiding principles of EuroELSO are:

- **Innovation:** Seeking to identify and promote advances for the application of extracorporeal therapies.
- **Expertise:** Bringing together leaders in the care of critically ill patients for collaboration to advance quality of care through education and publication.
- **Clinical support:** Maintaining a comprehensive registry of data to assist in reducing morbidity and improving survival of patients requiring extracorporeal therapies.
- **Community:** Fostering communication and collaboration among professionals who apply advanced technologies in the treatment of refractory organ failure. EuroELSO supports educational programs for active centres as well as for the broader medical and lay communities.
- **Education:** Sharing expertise and improving standards and knowledge of the provision of extracorporeal life support technologies
- **Research:** To foster research into the development of and clinical roles for extracorporeal life support technologies

Rights and Responsibilities of Euro-ELSO under ELSO Bylaws

EuroELSO is one of the global chapters of ELSO. ELSO authorises the formation of affiliate chapters that represent ELSO centres within a geographical location by majority vote of the ELSO Board of Directors. The chapter has a Chapter Steering Committee with membership limited to active centres in the given geographic location. Active centres are current in annual membership dues and contributing their patient run data to the ELSO Registry, as defined by ELSO's bylaws.

EuroELSO Authority

The EuroELSO Steering Committee may conduct chapter activities, including establishment of a name, charter and bylaws, policy statements, Steering Committee appointments, conferences, and courses, recruiting efforts and grants. The administration and maintenance of ELSO membership, establishment and receipt of dues, and administration and operation of the Registry shall remain the responsibility of the parent ELSO Steering Committee.

EuroELSO shall establish bylaws that are consistent with the goals of the parent organisation and subject to the approval of the parent ELSO Board of Directors.



Activities of EuroELSO

1. Participate in and promote the ELSO Registry using a limited data set to be used for Quality Assurance to improve the delivery of care.
2. Promote use of ELSO Registry data for scholarly studies.
3. Provide for sharing of information on devices and techniques used for organ system support.
4. Provide regional guidelines and education for extracorporeal support devices and techniques and patient management.
5. Provide regional standards for education and endorsement of educational activities.
6. Provide information and communication regarding techniques used for organ system support to active EuroELSO centers, the medical community, professional societies, industry, regulatory and granting agencies, funders and the lay community.
7. Organise an annual conference focused on techniques used for organ system support.
8. Support research into extracorporeal life support technologies and their applications.
9. Submit financial reports on an annual basis to ELSO as part of the owner's annual audit process and to satisfy bylaw requirements that would allow financial assistance from ELSO in times of financial duress.

Corporate structure of EuroELSO

EuroELSO is incorporated with two arms – as a charity and as a trading company. EuroELSO Associates is a registered charity in the UK, company number 08309402. EuroELSO Associates Enterprise is a trading company, company number 09335480. EuroELSO Associates Enterprises is a wholly-owned subsidiary of EuroELSO Associates.

The directors of EuroELSO Associates and of EuroELSO Associates Enterprise are the officers of the EuroELSO steering committee. The officers comprises the current Chair, past Chair, Honorary Treasurer and Honorary Secretary of the steering committee.

The Steering Committee members are the members of EuroELSO Associates, responsible for voting in the Directors and for approving activities of the charity.

The Steering Committee operates as the board of both EuroELSO Associates and EuroELSO Associates Enterprise. The Steering Committee is responsible for making decisions relating to the management and operation of both companies. The executive committee implements the decisions of the Steering Committee subject to their legal duties as directors of companies under UK legislation.



Organisation

EuroELSO will have the following organisation:

1. A **steering committee** which will oversee and agree to all aspects of the work of the society. They will act as members of EuroELSO Associates charity and be responsible for electing the directors, approving the annual accounts and amending its constitution.
2. **Officers** who are the directors of the corporate entities and manage the day-to-day functions of the society, be responsible for signing organisational contracts, provide the financial signatories for the organisation
3. A **scientific committee** primarily responsible advising about the scientific programme of the annual congress and other scientific activities
4. **Working groups** which explore issues of particular interest to the organisation and its membership

Steering Committee Membership

The Steering Committee is comprised of up to 15 voting members including the Chair. The past chair will be an additional voting member of the Steering Committee. There will be one additional (voting) representative from the parent organisation (Current Chair or deputy). Non-voting members will include the ELSO Executive Administrator, two EuroELSO officers (Honorary Secretary and Treasurer) and the Chair of the Scientific Committee.

Of the 15 elected positions on the Steering Committee, they will include the following:

- Two positions shall be held by a Nurse / ECMO-Coordinator
- One position will be for the representative of the European Board of Perfusion
- One additional position shall be held by a Perfusionist
- The other members of the Steering Committee must be physicians from a dues paying member EuroELSO Centre or individual financial members with representation from both paediatric and adult centres.

The term of steering committee membership will be five years, but may be extended in exceptional circumstances by unanimous vote of the Steering Committee. Each year, an election will be held to replace any members leaving the committee. At the discretion of the Steering Committee, a member position may be shared by two persons whose combined voting represents one member. The Steering Committee will undertake a call for applications which will be publicised by contacting member program centre directors and through public notification. Submissions after the closing will not be accepted. The Steering Committee will consider nominations and elect new members by simple majority. The Steering Committee will take into account the applicant's academic, educational and clinical credibility. Consideration must be given to the principles of equality, diversity and inclusiveness, whilst ensuring that the geographical distribution of the Steering Committee reflects that of the membership. The overriding principle is that the elected members must reflect the membership and be able to guide the organisation in fulfilling its aims. Individuals may serve for a maximum of 9 years on the steering and/or scientific committee, including their term as office bearers.



The term of appointment of a newly elected steering committee member commences with the annual congress immediately following his/her election. Steering committee members are required to attend a minimum of 60% of the meetings, of which one must be face-to-face, convened within each 12-month period during the term of their appointment. If a steering committee member is unable to meet this requirement, their appointment as members will automatically cease unless that member can demonstrate, to the satisfaction of the remaining steering committee members (voting unanimously) extenuating circumstances that prevented his/her attendance. Steering committee members may be removed from the Steering Committee for any reason by unanimous vote of the remaining Steering Committee members. Steering committee members may also be removed automatically if they are not permitted to hold office by operation of law. Steering committee members' contributions will be considered by the Chair after 3 years and inactive steering committee members will be removed from the committee.

Steering committee responsibilities

Activities of EuroELSO, both the trading and charitable arms, will be directed by the Steering Committee. The responsibilities of the Steering Committee are:

1. To serve as the committee to define the details and functions of the Organisation.
2. To appoint the officers of EuroELSO
3. To administer finances including dues and grants.
4. To appoint the chair and members of the Working Groups and Scientific Committee, charge each committee, and coordinate committee activities.
5. To determine the priorities of the organisation and implement programs.
6. To communicate the activities of the organisation both inside and outside the group.
7. Act to select new Steering and Scientific Committee members.
8. To act as members of the charity.
9. Steering Committee members should have a presence on the EuroELSO website with photo and brief biography as well as their term of office. Relevant conflicts of interest have to be disclosed.

Steering committee meetings

Steering committee meetings may be virtual or face to face. Meetings are called by the Chair at any time by giving notice by email. There are a minimum of 8 meetings per annum, of which at least two should be face to face. Face to face meetings are held to coincide with the annual scientific congress in the European spring and in the European Autumn. A quorum for a meeting of the Steering Committee is 9 voting members.

Steering committee decision making

All decisions made by the steering committee require a resolution to be passed by way of simple majority, unless otherwise stated in this document. Minutes will be taken and stored by the steering committee secretariat.



Officers

The officers of EuroELSO consists of the present and past chair, the present and past honorary treasurer and the present and past honorary secretary.

The chair of the Steering Committee will be elected every two years by the steering committee from current members of the steering committee. Applications will be received in writing to the Honorary Secretary and current Chair four weeks in advance of the autumn meeting and include a statement of vision for the organisation. The four-year term will be served as chair (2 years) and past chair (2 years). The term as chair and past chair is a voting role. This term is not usually renewable but may be considered in exceptional circumstances by unanimous vote of the Steering Committee.

The Treasurer and Secretary of Euro-ELSO will serve for 5 years with 1 additional year as past Treasurer or Secretary. Their tenure must be confirmed by a vote of the Steering Committee annually. The Treasurer and Secretary will be elected by the Steering Committee from current steering committee members. Applications will be received in writing to the Honorary Secretary and current Chair four weeks in advance of the autumn meeting. The honorary treasurer and secretary roles as well as the past roles are non-voting positions.

Scientific committee

The aim of the Scientific Committee of EuroELSO is to advance the scientific, educational and research goals of the organisation. The scientific committee will undertake organisation of the scientific programme of the annual meeting of EuroELSO overseen by the Steering Committee. The scientific committee will also undertake regular educational webinars of interest to the members of the organisation. Additional scientific committee activity will be defined by the steering committee of EuroELSO to fulfil the organisation's objectives.

The scientific committee will be formed of a maximum of 12 elected members and 3 extraordinary members. One of the members of the steering committee will act as the Congress Chair. Nominations for scientific committee membership must be individual members or from member centres. Scientific committee membership terms will be 4 years, which is non-renewable, but may be considered in exceptional circumstances by unanimous vote of the Steering Committee. Applications will be elected by the steering and scientific committees of EuroELSO jointly. The Steering and Scientific committees will take into account the applicant's academic, educational and clinical credibility. Consideration must be given to the principles of equality, diversity and inclusiveness, whilst ensuring that the geographical distribution of the scientific Committee reflects that of the overall membership.

All votes of the scientific Committee require a simple majority. A quorum on the scientific committee is 7 members.

Membership of the Scientific Committee

1. The Scientific Committee (SciCom) consists of a maximum of 12 elected members. Of those,
 - a. at least 4 members shall be physicians involved in adult care and



- b. at least 2 members shall be physicians involved in pediatric care.
 - c. at least 1 member shall be a nurse
 - d. at least 1 member shall be a perfusionist or an engineer
2. Members of the SciCom should represent different European countries or Israel. In each sub-category (adult/pediatric/nurse/perfusionist), no more than one member per country is suggested.
 3. The regular term of membership is four years. This term is not renewable, but may be considered in exceptional circumstances by unanimous vote of the Steering Committee.
 4. A maximum of 3 positions will be replaced every year to ensure a term length of 4 years and a maximum of 12 elected members
 5. Besides regular elected members, the congress president of the current congress, the following year's congress and the previous EuroELSO congress will be additional extraordinary members of the SciCom.
 6. New members will be elected by anonymous vote by both the members of the SteCom and the SciCom during the autumn meeting. The applicant(s) with the highest count of votes will be elected.
 7. SciCom members should have a presence on the EuroELSO website with photo and brief biography as well as their estimated term of office. Relevant conflicts of interest have to be disclosed.

Role of the Scientific Committee

1. To design the programme of the annual conference in conjunction with the president of the congress. The final programme has to be validated and approved by the Steering Committee.
2. To select abstracts of the annual conference in conjunction with the president of the congress.
3. To select best abstract award winners during the annual conference
4. To design, plan and coordinate webinars for EuroELSO, which are placed on the EuroELSO website later.
5. The chair of the Scientific Committee shall be named as one of the guest-editors of the annual conference journal and plan manuscripts for the special issue

Meeting and reimbursement modalities

1. The SciCom shall meet at least 8 times per year of which two are face to face and held to coincide with the biannual meeting of the Steering Committee. SciCom members are required to attend a minimum of 60% of the meetings, of which one must be face-to-face, convened within each 12-month period during the term of their appointment.



2. The SteCom will inform the SciCom within two months after the last conference, if changes in the programme structure for next year's conference are necessary.
3. A draft of the proposed programme structure for the coming conference shall be distributed to all members of the SteCom four months after the last conference. A more detailed draft including suggested session topics shall be distributed at least two weeks before the autumn meeting.
4. Travel and accommodation costs will be covered according to the pre-specified travel reimbursement rules of EuroELSO.
5. EuroELSO Associates is a charity organisation. All tasks undertaken by elected members are done in an honorary capacity. Therefore, additional reimbursement apart from travel costs and accommodation during meetings is not provided.
6. Members of the SciCom are invited by EuroELSO to the annual conference including participation at the faculty dinner.

Scientific committee chair and deputy chair

The chair and deputy chair of the scientific committee will be elected every two years with the new term commencing immediately after the annual congress. The Scientific Committee will vote on nominations from within the scientific committee and their tenure must be confirmed by a vote of the Steering Committee annually.

Congress Chair

The congress chair will be chosen from the Steering Committee and by the Steering Committee by simple majority vote. The role of the congress chair is to be the Steering Committee representative for the congress organisation and to form a link between the scientific committee and steering committee. The congress chair in collaboration with the steering committee chair, the scientific committee chair, the past congress chair and the future congress chair will set the global themes for the congress and the overall outline of the congress. The congress chair will ensure that feedback from previous congresses is fed back into the congress programme and will implement instructions from the steering committee, including but not limited to issues of equality, diversity and inclusiveness. The congress chair will ensure that the membership of EuroELSO is represented in the academic programme. The congress and scientific committee chairs will provide draft meeting outlines to the steering committee for approval.

Working Groups

EuroELSO will constitute working groups to focus on specific issues at the instruction of the Steering Committee. Themes for the working groups will be selected by the Steering Committee. All working groups will be required to have a minimum of one Steering Committee or Scientific Committee member. Each working group will have a chair nominated from the membership and voted by the Steering Committee. The working group chair will be responsible for:

- Ensuring that the themes raised by the steering committee are explored



- Providing an annual report to the Steering Committee on working group activities
- Contributing to the content of the scientific programme of the Annual EuroELSO Congress in collaboration with the scientific committee chair
- Contributing to the educational programme organised by the scientific committee through the identification of topics for webinars
- Proposals for and preparation of recommendations and position papers
- Proposals for and preparation of member surveys and observational research studies
- Once approved by the steering committee, outputs from the working group will be submitted for review with a view to publication in accordance with the authorship policy of EuroELSO. Consideration should be given to submitting to the official journal of EuroELSO.

Working groups will have unrestricted membership. Working groups will be led by a committee of no more than 10 members including the Chair of the working group. Members of both the working group and the committee will be from member centres or will be individual members of ELSO. Non-ELSO members can be included at the discretion of the chair of the working group. Committee members will be selected by the chair of the working group. The Chairs of the Steering and Scientific will need to approve of all appointments with subsequent ratification by the Steering Committee – approval consists of a simple majority of votes. Elected members will be ratified by vote of the steering committee. Meetings of the working groups will be online with at least one face to face meeting at the annual congress. The frequency will be decided by the chair of the working group but must be at least a minimum of 4 meetings per annum. Members' time will not be reimbursed. Grants are not automatically provided, however working groups can apply for a competitive, peer-reviewed, EuroELSO funded research grant of not more than €10,000 to undertake specific projects.

Membership

Individual or centre ELSO members based in Europe or Israel are considered as members of EuroELSO. Payment of dues and contribution of cases to the ELSO registry defines an active member centre. Individual members and individuals affiliated with active EuroELSO programme centres are eligible to stand for roles in all EuroELSO committees and subcommittees.

Finances

The Honorary Treasurer will supervise the financial operations of EuroELSO and report to the Steering Committee biannually and to the parent organisation annually.

Each year, the Honorary Treasurer of the Steering Committee will submit a budget for the forthcoming year at the time of the annual meeting. This budget will be reviewed and approved by the Steering Committee before the annual meeting. The goal of financial management will be to hold operating expenses, enough to cover one meeting, in reserve and conduct the business of the Organisation to bring the final balance to this amount each year.



EuroELSO Associates is a charitable organisation. The financial operations will be reviewed by the society's accountants. The Treasurer's report will be presented annually. The financial year will run from 1st December to 30th November of the subsequent year. EuroELSO Associates will ensure that appropriate funds are disbursed to support EuroELSO's aims in line with the applicable law and relevant advice from the UK Charities Commissioner.

Centre dues, individual member dues, and corporate member dues will be set annually by the ELSO Steering Committee (parent organisation). EuroELSO shall ensure appropriate means for maintaining and accounting for funds received and distributed. EuroELSO shall be financed through the following:

- Twenty-five percent (25%) of the dues of the chapter's member centres shall be distributed to EuroELSO.
- Proceeds from EuroELSO activities such as educational activities, annual congress and grant awards shall remain with the chapter.
- Additional *ad hoc* allocations from the parent organisation as authorised by the parent Steering Committee.

The Honorary Treasurer will sign all transactions up to a value of €10000. Transactions of €10000 and above require agreement with the Steering Committee Chair and Honorary Secretary with subsequent ratification of the Steering committee.

Official statements and publications of EuroELSO

EuroELSO will contribute to guidelines and policy statements produced by ELSO. Where there are specific regional variations or specific regional guidelines or policy statements which related to EuroELSO members, in agreement with ELSO, EuroELSO will produce guidelines and policy statements. EuroELSO will also provide comment on documents produced by the other global chapters. All internal and external official policy statements require approval by the steering committee.

The sequence for distribution and review of official policy statements is as follows:

- Draft preparation in Standing Committee/working group and approval by majority of the EuroELSO Steering Committee.
- For issues specifically relating to EuroELSO, these documents will be approved by the EuroELSO steering committee, sent to ELSO for approval and then distributed to member centres and consideration will be given to submission for publication in the official journal of EuroELSO.
- For supra-regional documents, EuroELSO will work with ELSO and the global chapters to agree document content. Final approval will be given by the ELSO steering committee.
- A EuroELSO approved policy can be vetoed by the parent organisation by a simple majority vote of the ELSO steering committee. Where this occurs with a regional issue, the EuroELSO chair and ELSO chair will find a mutually agreed solution to the issue of concern.

Relationships with other organisations



The steering committee may enter formal relationships with other scientific organisations operating in Europe or Israel. These relationships will focus on the delivery of education, guidelines and research to deliver the goals of the organisation.

EUROELSO



Appendix 1: Grants

The EuroELSO Grant Programme enables healthcare professionals and scientists to undertake research or develop educational content in line with the objectives of EuroELSO. Specifically, these objectives are to advance and promote the relief of sickness across Europe through:

- the development and evaluation of novel therapies for support of failing organ systems;
- maintaining a registry of such novel therapies;
- using the registry data to support clinical research;
- providing education programmes for medical professionals and lay communities on such novel therapies including organising a scientific symposium each calendar year.

It is anticipated that calls for applications will occur once each year. The maximum value and number of the grants will be decided by the Steering Committee.

Grants can support salary costs, equipment, software, consumables, locally paid taxes and any other items that reasonably support the goals of the Grant. EuroELSO will not accept liability for additional monies that become due that are not outlined in the application.

Applications will be accepted from any healthcare professional (including physicians, nurses, perfusionists, and therapists) or a research scientist. The host institution should be a hospital or university. The host institution should be an active ELSO centre or be affiliated to one.

Applications will be reviewed by members of the Steering and Scientific Committee according to guidelines published to applicants in the call. Successful applicants will have to provide a report to the Steering Committee and will be required to present their results at an annual Scientific Meeting within 2 years of the grant being received.



Appendix 2: Travel Reimbursement

The EuroELSO steering committee has agreed that the following rules are valid for pre-authorized steering committee and working group members travellers who travel on behalf of EuroELSO, authorised in advance by the Chair/Treasurer.

Eligible for reimbursement by EuroELSO are:

- Flight costs (economy class, for exceptions see below)
- Train costs (the cost of a regular economy class ticket)
- Car costs (current official UK rate of the year)
- Taxi service costs exclusively from home-airport-home and from airport-hotel-airport for an acceptable amount. Long drive costs must be part of the travel costs.
- Taxi costs home-airport-home can be replaced by private car parking costs at the airport at reasonable tariffs
- Accommodation at an acceptable, reasonable rate, bed and breakfast only
- Lunches/dinners, only if relating to official EuroELSO business at an acceptable, reasonable rate, bed and breakfast only
- Original receipts should be submitted.

Not eligible for reimbursement by EuroELSO are:

- All other costs including bar, mini-bar, lunches or dinners not related to EuroELSO business.
- EuroELSO will only reimburse direct work-related expenses on trips abroad, other expenses are not eligible.

The Steering Committee members may use business class for long-haul flights (transatlantic flights and those of six or more hours). If steering committee members are travelling on behalf of EuroELSO and in the interest of EuroELSO, they should have the prior approval of the Chair and Treasurer for using business class.

If, because of extenuating circumstances, the present guidelines are not adequate to cover an individual's expenses, they should send a written request to the Treasurer explaining why they should be allowed to travel and the Treasurer will accept or reject the request in consultation with the Chair.

Methods

- Reimbursement will be required by providing receipts, details and bank details to the secretariat

It is strongly advised that all persons travelling on behalf of EuroELSO have adequate personal travel and health insurance cover to cover any unforeseen medical intervention or loss of personal items while abroad. EuroELSO will be held responsible for any travel, health or other expenses whilst travelling. EuroELSO will not fund travel/health insurance.



Appendix 3: Publication policy

EuroELSO Publication Policy and Data Access

This document covers below topics and applies to institutions within Europe or other contributing parties based on specific arrangements:

- A. Access to data collected by EuroELSO for researchers, submitting institutions and other entities
- B. Publication of reports produced by EuroELSO
- C. Publication of data, reports and scientific manuscripts based on EuroELSO data
- D. Authorship

A. Access to data collected by EuroELSO for researchers, submitting institutions and other entities

Data are collected in compliance with the relevant legislation in EU and UK, mainly the WMA DECLARATION OF HELSINKI – ETHICAL PRINCIPLES FOR MEDICAL RESEARCH INVOLVING HUMAN SUBJECTS, <https://paediatric.wma.net/policies-post/wma-declaration-of-helsinki-ethical-principles-for-medical-research-involving-human-subjects/>, Quality assurance framework, version 9 (QAF v9, UK), <https://paediatric.gov.uk/government/publications/quality-assurance-framework-version-nine-qaf-v9> and GDPR, <https://gdpr-info.eu/>.

Anonymised data are provided by the submitting institution, EuroELSO is the custodian of the submitted data. All submitting institutions have unrestricted access to their own data and routine reports generated using this data. Reports are produced by EuroELSO which include standard outcome reports, data analyses as a result of specific requests to EuroELSO and scientific publications using submitted data. EuroELSO supports research using data held in the EuroELSO registries.

Ethics committee approval is required for all intended scientific publications in peer reviewed journals. This should be coordinated by the lead researcher or person in charge of the project from the local institution prior to release of data.

B. Publication of reports produced by EuroELSO

Any abstract, presentation or manuscript resulting from use of data requested from EuroELSO must be presented to the EuroELSO Scientific Committee or its delegate (i.e. the relevant working group) for review before presentation or submission for publication and must comply with the “EuroELSO Publication Policy and Data Access”.

The lead researcher approved by EuroELSO Steering or Scientific Committees is responsible for the security of any data and analyses, and for compliance with the EuroELSO Publication Policy and Data Access. The lead researcher must notify the EuroELSO Scientific Committee or its delegate (i.e. the relevant working group) of any potential risks to individuals, institutions or to EuroELSO that might result from provision of data for research.



Data and reports will be provided through a secure transfer mechanism and will comply with the GDPR EU regulation, <https://eur-lex.europa.eu/legal-content/EN/TXT/?uri=CELEX%3A32016R0679>.

EuroELSO Steering Committee reserves the sole right to control all reports produced by EuroELSO, reports identifying a submitting body will not be provided to any external party.

Ad C. Publication of data, reports and scientific manuscripts based on EuroELSO data

Potential publications produced by researchers or other external bodies must be submitted for review by the EuroELSO Scientific Committee or relevant delegate (working group) and approved by the EuroELSO Steering Committee.

The purpose of the review is to:

- Ensure that the quality and limitations of the data provided have been properly understood and interpreted by the user.
- Provide potential advice on data interpretation and analysis if required.
- Ensure appropriate acknowledgement of EuroELSO.
- Ensure appropriate recognition of individuals, groups or collaborating agencies for the work performed in pursuit of the objectives of EuroELSO.
- Ensure that only institutions who have previously granted permission are identified or identifiable by inference.
- Ensure that a statement about Ethics Committee review has been included.
- Ensure that EuroELSO supports the scientific validity and conclusions.
- Ensure that potential financial conflicts of interest have been disclosed.

Presentation of research findings at public forums such as national and international conferences must be notified in advance to EuroELSO to receive approval. Review of the presentation and support for presentation will be at the discretion of the EuroELSO Scientific Committee or its delegate. Publications must include a statement about requirement for review by a Human Research and Ethics Committee.

Ad D. Authorship

Authorship reflects the International Committee of Medical Journal Editors (ICMJE) guidelines, <http://paediatric.icmje.org/>, and stands for a substantial participation where all of the below conditions are met:

- Conception, design, or data acquisition, analysis or interpretation.
- Drafting the article or revising it critically for important intellectual content.
- Final approval of the version to be published.



- Acquisition of funding, collection of data, or general supervision of a research group, alone, does not justify authorship.
- Authors are required to provide a detailed description of their own contribution, to enable editors to publish such information.
- First or corresponding author (based on all authors' agreement) should be the person who initiated the research activity and therefore holds the intellectual property of the project. The same person is also the lead investigator with the responsibilities of reporting and asking the EuroELSO for an approval as outlined in EuroELSO Publication Policy and Data Access
- Any person who has participated in a substantial way in conceiving, executing or interpreting research (or any part thereof), should be given the opportunity to be included as an author
- The order in which authors are listed should be explained upfront and approved upfront by all authors.
- Where authorship is attributed to a group, e.g. multi-centre projects and trials, all members of the group who are named as authors should meet the criteria for authorship. Where the research is published, including electronically, all co-authors should certify their authorship in writing. Authors of publications should disclose potential conflicts of interest.
- Writing committee and a corresponding author should be named upfront and approved by all members of the working group.
- All others who are not authors but have contributed to the production of the potential publication (e.g. who for example collected data) should be named as collaborators or if not possible acknowledged with a description of their contribution. In accordance with advice from the ICMJE and in collaboration with journal editors, corporate authorship should be used to acknowledge their input. Their affiliation should also be mentioned. Individuals or organisations providing facilities or resources should be acknowledged.

Forms of acknowledgement:

- If appropriate, a working group within the EuroELSO should be acknowledged as well as the writing committee assigned by the EuroELSO Scientific committee to the relevant registry/project.
- Any member of a working group may initiate a substudy or re-analysis of prior data. Substudies must be approved by the leading investigator and the working group, ultimately approved by the EuroELSO Scientific a Steering Committee.
- The following wording should be used to acknowledge EuroELSO contribution to publication: „....the Working Group on XY, on behalf of EuroELSO“



- Institutions which have, through submission to EuroELSO registry, contributed to the dataset used for the publication should be acknowledged and listed as a list of contributors or collaborators. The following wording or similar should be used: “The authors and the EuroELSO Steering and Scientific Committees would like acknowledge and thank clinicians, data collectors and researchers at the following contributing sites.....”.

Expectations:

- Publication of multiple papers based on the same set(s) or subset(s) of data is unacceptable except where there is full and appropriate cross-referencing between papers and EuroELSO approval.
- If data are to be used in a presentation, then EuroELSO should be acknowledged as the provider of the information in the presentation slides.
- Publications should include information on sources of financial support for research.



Appendix 4: EuroELSO Privacy Policy

Our contact details

Name: EuroELSO secretariat

Address:

Phone Number:

E-mail:

The type of personal information we collect

We currently collect and process the following information:

- Personal identifiers, contacts and characteristics (for example, name and contact details, including email address)

How we get the personal information and why we have it

Most of the personal information we process is provided to us directly by you for one of the following reasons:

- You attend one of our annual congresses
- You attend one of our webinars
- You apply for one of our grants
- You apply to be a member of one of our committees or subcommittees

We use the information that you have given us in order to send you information about the event you have enrolled in; advertise future academic meetings; ask you to participate in academic surveys.

We may share this information with our secretariat and professional congress organisers.

Under the UK General Data Protection Regulation (UK GDPR) and the European Union General Data Protection Regulation (EU GDPR), the lawful bases we rely on for processing this information are:

(a) Your consent. You are able to remove your consent at any time. You can do this by contacting [contact details]

How we store your personal information

Your information is securely stored.

We keep [type of personal information] for [time period]. We will then dispose your information by [explain how you will delete their data].



Your data protection rights

Under data protection law, you have rights including:

Your right of access - You have the right to ask us for copies of your personal information.

Your right to rectification - You have the right to ask us to rectify personal information you think is inaccurate. You also have the right to ask us to complete information you think is incomplete.

Your right to erasure - You have the right to ask us to erase your personal information in certain circumstances.

Your right to restriction of processing - You have the right to ask us to restrict the processing of your personal information in certain circumstances.

Your right to object to processing - You have the right to object to the processing of your personal information in certain circumstances.

Your right to data portability - You have the right to ask that we transfer the personal information you gave us to another organisation, or to you, in certain circumstances.

You are not required to pay any charge for exercising your rights. If you make a request, we have one month to respond to you.

Please contact us at [insert email address, phone number and or postal address] if you wish to make a request.

How to complain

If you have any concerns about our use of your personal information, you can make a complaint to us at [Insert your organisation's contact details for data protection queries].

You can also complain to the Information Commissioner's Office (ICO) if you are unhappy with how we have used your data.

The ICO's address:

Information Commissioner's Office

Wycliffe House

Water Lane

Wilmslow

Cheshire

SK9 5AF

Helpline number: 0303 123 1113

ICO website: <https://paediatric.ico.org.uk>