



ISOQOL

INTERNATIONAL SOCIETY FOR QUALITY OF LIFE RESEARCH

POLICY MANUAL

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Ancillary Events at ISOQOL Activities

The International Society for Quality of Life Research (ISOQOL) leadership requires ALL organizations (commercial and non-profit) that wish to hold functions of any size or nature at the ISOQOL meeting venue during an ISOQOL meeting, educational event or ISOQOL sponsored activity to submit an Ancillary Event Request Form.

Applicable Dates - The policy shall be in effect for the day prior to the start of the first educational event through the last ISOQOL programmed activity.

Black Out Times - Designated ISOQOL Leadership Activities, Conference/Scientific Program, ISOQOL Membership Business Meeting, Awards Ceremony, Receptions and other times as needed for the business of the Society.

Available Meeting Times - Scheduled breaks (including breakfast, lunch and longer session breaks of 30 minutes or more), after the conclusion of the last educational session of the day (some restrictions apply), or two or more days prior to the start of the first educational session.

FREQUENTLY ASKED QUESTIONS

What is an Ancillary Event?

An ancillary event is any function held adjunct to an ISOQOL meeting by another society or party other than ISOQOL. All ancillary events must receive ISOQOL authorization. Ancillary events may include:

- Advisory Board Meeting – A small gathering of corporate board members, which may also include some related experts in the field of discussion
- Educational Event – A meeting that includes educational content. The meeting can, but does not have to, include the option for participants to earn CME credit for attending that may be initiated by the host of the ancillary event.
- Focus Group – A small meeting designed to evaluate services or test new ideas
- Hospitality Suite (in a meeting room) – A room/lounge for attendees to come and go as desired. Planned meetings in hospitality suites that include meeting attendees are prohibited during the blackout times
- Investigator Meeting – A closed (invitation only) meeting of participating and potentially participating investigators concerning clinical trials, either in progress or proposed
- Investor Meeting – A small gathering for corporate investors
- Press Event – press briefings, news conferences, press receptions, satellite media tours, etc.
- Social Event – A networking function that is non-educational in nature

How do I submit an Ancillary Event Request?

Please contact the ISOQOL office for an event request form (info@isoqol.org).

Do I have to complete an Ancillary Event Request if I am not using ISOQOL function space?

Yes, ISOQOL leadership requests that ALL organizations (commercial and non-profit) that wish to hold functions of any size or nature at the Headquarters Hotel/meeting venue during an ISOQOL meeting to complete an Ancillary Event Request form.

What are the deadlines for submitting an Ancillary Event Request?

Applications are accepted at any time. However, function space will be allocated on a first come, first served basis.

What are the guidelines for Ancillary activities held during an ISOQOL meeting or symposium?

Ancillary activities, including media events, should not conflict with the agenda or events of the ISOQOL meeting or symposium. The nature of activity should be in keeping with the educational focus of an ISOQOL meeting or symposium. Venues, agendas, and media coverage for ancillary activities should be conducive to scientific interchange; even for social functions, promotion should emphasize scientific themes, not entertainment activities. Promotional activities should be tasteful, appropriate, and professional in nature.

What are the procedures for activities and events held at the ISOQOL meeting venue?

An Ancillary Event Request must be submitted by contacting the office for the appropriate form. ISOQOL will determine whether the proposed activity meets ISOQOL standards and requirements, and will make every effort to notify the applicant via e-mail within seven business days if the event has been authorized. Upon authorization,

ISOQOL will release and assign hotel space for the requested event. From this point forward the requesting organization will work directly with the assigned hotel to plan the event.

What are the guidelines for use of the ISOQOL name and other trademarks?

All names, marks, brands, logos, designs, trade dress, slogans, and other designations of ISOQOL are the sole and exclusive property of ISOQOL. Use of any ISOQOL branding without ISOQOL's prior written permission is strictly prohibited, except for use of ISOQOL's name as required in the disclaimer for signage and in other materials associated with ancillary events. The rules, requirements and process for requesting use of the ISOQOL Brand is outlined in the Communications Standards policy.

Can I market products and services at an ISOQOL meeting or symposium?

Commercial firms and other organizations may not engage in marketing activities through, for example, the use of hotel television channels, individual company distribution of marketing materials in hotels (e.g., giveaways, flyers or door drops), or the branding of beverage napkins, hotel keys, etc. At the meeting venue, marketing materials may not be offered, distributed, or displayed anywhere other than the Exhibits unless a specific prior exception has been granted by ISOQOL.

What is the process for sending a pre-meeting mailing to registered attendees?

ISOQOL allows exhibitors and other organizations the opportunity to purchase membership and attendee mailing lists for pre and post marketing for each meeting. Only mailing information will be provided; phone and fax numbers and e-mail addresses are not available for purchase. The lists are sold for a one-time use only. Samples of the mailing (including invitations to ancillary events) must be submitted and approved by ISOQOL prior to an organization receiving the list. ISOQOL strongly encourages organizations to submit their samples early to allow for adequate production and mail time. For more information on membership and attendee mailing lists and/or to purchase a mailing list, please contact the ISOQOL office or e-mail info@isoqol.org.

What are ISOQOL's policies for holding press events?

Organizations planning media events during any ISOQOL meeting are required to coordinate with ISOQOL's Meeting Manager. With the exception of events sponsored by ISOQOL, press events such as media briefings, news conferences, press receptions, etc. are not permitted onsite at ISOQOL meetings. Organizations may submit requests for hotel space to hold press events on meeting days; however, events must not conflict with the ISOQOL meeting, specified blackout times, or ISOQOL policies, including ISOQOL's Media Interactions policy.

What are the guidelines for signage and other written descriptions of ancillary events?

Signage for ancillary events is not permitted at the meeting venue or in public space except for immediately outside of the designated room that the event is to occur. Meeting signage may NOT include the ISOQOL name, logo, or name of ISOQOL meeting. In addition, no marketing pieces, invitations, communications of any kind, advertising, or other written or spoken descriptions of the event may use the ISOQOL name or logo, or otherwise suggest or imply that ISOQOL has endorsed or sponsored the event.

- The name of the ISOQOL meeting or symposia may be mentioned one time in each communication for identification purposes, in a reasonably-sized, neutral font
- ISOQOL or the name of the ISOQOL meeting may not be part of a title or heading of the ancillary event, be prominently featured, or listed first in print materials
- ISOQOL slide templates, color schemes, logos, meeting graphics or other means of confusing the event with an ISOQOL-sponsored event may not be used
- The following statement must be included on all advertisements, marketing pieces, invitations, meeting materials, etc. for the event: *"For the convenience of our members, ISOQOL has enabled this event to be held in proximity to our annual conference. This is not an official event of the International Society for Quality of Life Research (ISOQOL), nor endorsed by ISOQOL."*

Who do I contact with questions about Ancillary Events and the release of ISOQOL function space?

Please contact ISOQOL office by telephone at 414-918-9797 or e-mail info@isoqol.org.

Anti-Trust

The International Society for Quality of Life Research (ISOQOL) is a not-for-profit organization, recognized by section 501 (c) (3) of the Internal Revenue Code. ISOQOL is not organized to and may not play any role in the competitive decisions of its members or their employees, nor in any way restrict competition among members or potential members. Rather it serves as a Society for a free and open discussion of diverse opinions without in any way attempting to encourage or sanction any particular business practice.

ISOQOL provides a Society for exchange of ideas in a variety of settings including its annual meeting, educational programs and committee meetings. The Board of Directors recognizes the possibility that ISOQOL and its activities could be viewed by some as an opportunity for anti-competitive conduct. Therefore, this policy statement clearly and unequivocally supports the policy of competition served by the antitrust laws and communicates ISOQOL's uncompromising policy to comply strictly in all respects with those laws.

While recognizing the importance of the principle of competition served by the antitrust laws, ISOQOL also recognizes the severity of the potential penalties that might be imposed on not only ISOQOL but its members as well in the event that certain conduct is found to violate the antitrust laws. Should ISOQOL or its members be involved in any violation of federal or state antitrust laws, such violation can involve both civil and criminal penalties that may include imprisonment for up to 3 years as well as fines up to \$350,000 for individuals and up to \$10,000,000 for ISOQOL, plus attorney fees. In addition, damage claims awarded to private parties in a civil suit are tripled for antitrust violations. Given the severity of such penalties, the Board of Directors intends to take all necessary and proper measures to ensure that violations of the antitrust laws do not occur.

Policy

In order to ensure that ISOQOL and its members comply with antitrust laws, the following principles will be observed:

- ISOQOL or any committee, task force, or activity of ISOQOL shall not be used for the purpose of bringing about or attempting to bring about any understanding or agreement, written or oral, formal or informal, expressed or implied, among two or more members or other competitors with regard to prices or terms and conditions of contracts for services or products. Therefore, discussions and exchanges of information about such topics will not be permitted at ISOQOL meetings or other activities.
- There will be no discussions discouraging or withholding patronage or services from, or encouraging exclusive dealing with any supplier or purchaser or group of suppliers or purchasers of products or services, any actual or potential competitor or group of actual potential competitors, or any private or governmental entity.
- There will be no discussions about allocating or dividing geographic or service markets or customers.
- There will be no discussions about restricting, limiting, prohibiting, or sanctioning advertising or solicitation that is not false, misleading, deceptive, or directly competitive with ISOQOL products or services.
- There will be no discussions about discouraging entry into or competition in any segment of the marketplace.
- There will be no discussions about whether the practices of any member, actual or potential competitor, or other person are unethical or anti-competitive, unless the discussions or complaints follow the prescribed due process provisions of the ISOQOL bylaws.
- Certain activities of ISOQOL and its members are deemed protected from antitrust laws under the First Amendment right to petition government. The antitrust exemption for these activities, referred to as the Noerr-Pennington Doctrine, protects ethical and proper actions or discussions by members designed to influence: 1) legislation at the national, state, or local level; 2) regulatory or policy-making activities (as opposed to commercial activities) of a governmental body; or 3) decisions of judicial bodies. However, the exemption does not protect actions constituting a "sham" to cover anticompetitive conduct.
- Speakers at committee meetings, educational programs, or other business meetings of ISOQOL shall be informed that they must comply with ISOQOL's antitrust policy in the preparation and the presentation of their remarks.
- Meetings will follow a written agenda. Minutes will be prepared after the meeting to provide a concise summary of important matters discussed and actions taken or conclusions reached.

At informal discussions at the site of any ISOQOL meeting, all participants are expected to observe the same standards of personal conduct as are required of ISOQOL in its compliance.

Apparent Authority

It shall be the ISOQOL policy that any communication on behalf of the society shall be official, at the direction of the President, Board of Directors or Executive Director. No statements shall be made, either verbal or written that conflict with the position or policy of ISOQOL. Leadership and staff should understand that by virtue of their position, that statements may be perceived by the public as official and on behalf of ISOQOL. To control official communications, stationary and business cards shall be for use of the elected president and staff only.

Members of the board, committees or ad hoc task forces may not use society letterhead. Staff will prepare letters sent on behalf of the organization with a copy remaining in the office. Exceptions may be made to the policy so long as the purpose of the communication is made known and approved by the President and/or the Executive Director in advance; if the exception is approved, a copy of the communication shall be provided to staff within 24 hours of dissemination for permanent file retention.

Awards

President's Award

The President's Award is awarded to an individual who has advanced HRQL research and has made outstanding contributions to the Society in one or more of the following areas: education of professionals, patients or lay individuals about HRQL's value; promotion or execution of HRQL or other scholarly activities; and facilitating or furthering policy initiatives that have an impact on HRQL. The awardee is selected by the Executive Committee and endorsed by the Board of Directors. The recipient of the award receives a plaque, a \$1000 honorarium, and partial reimbursement of travel expenses up to \$1000 to attend the ISOQOL Annual Conference.

Nominations

Nominations for the President's Award are due in May each year. Successful nomination packets will include a letter from the nominator specifying the nominee's contributions, the curriculum vitae of the nominee, and an external support letter.

Emerging Leader Award

The Emerging Leader Award was established in 2011 to honor and commemorate past-President Donna Lamping's contribution to the leadership of the Society. It will be awarded to an ISOQOL member who has shown exceptional leadership skills and potential. The award nominee must be a current member of ISOQOL and have been active on an ISOQOL committee, SIG or working group for at least 2 years, having shown exceptional leadership skills and potential. Individuals must be within 10 years of completing a PhD (or equivalent), MD, or Master's Degree. Current and past ISOQOL board members are ineligible.

Nominations

Nominations for the Emerging Leader award are due in May each year. Nominees may self-nominate or accept nomination by a sponsor. Successful nomination packets will include a nominations letter and two-page curriculum vitae.

Outstanding Article of the Year Award

The Outstanding Article of the Year Award recognizes the single best article dedicated to HRQL research published in *Quality of Life Research* during the previous calendar year. This award recognizes the author(s) for significant intellectual contributions that promise to advance the state of the art in HRQL research methods or theory.

Nominations

All articles published in *Quality of Life Research* are considered for this award.

Student/New Investigator Awards

Each year, ISOQOL recognizes the best overall oral and poster presentations at the Annual Conference made by full time students and investigators in the early stages of their career in HRQL research. Before the conference, finalists are chosen based on review scores in four categories: student oral presentation, student poster, new investigator oral presentation, and new investigator poster. Each of the finalists is judged during the conference and one winner is selected for each category. Each winner receives a cash prize.

Nominations

At the time of submission, authors will have the opportunity to select if they qualify for either of these awards. Student applicants must be enrolled in a full-time program when applying for the award, and new investigator applicants must be within 5 years of the end of their position as full time student or postdoctoral fellow.

Outstanding Poster Awards

The Outstanding Poster Awards are given to those Poster submissions for the Annual Conference that received the highest evaluations during the review process. All submitted posters are automatically considered for this award, but there will be an option to "opt-out" of consideration during abstract submission.

The top 6 poster contestants, **based on cut-off of abstract scores**, will be invited to present at the conference and be reviewed by a panel of judges. The panel will score the posters using a score sheet provided by the ISOQOL office.

Acknowledgement and Award

The Final Program will indicate the top 15-25 poster contestants, **based on cut-off of abstract scores**, with a special symbol/box. An award ribbon is added to the poster board to each of the six (6) finalist and the posters will be prominently displayed throughout the conference. Finalists will be acknowledged on a PowerPoint slide at the Awards Presentation during the ISOQOL Members Business Meeting. At this time, the winner will be announced and presented with a framed certificate. No monetary award is provided.

Note: Applicants are not eligible to receive both the Poster Award and the Student/New Investigator Award. Applicants will designate interest in the award on the abstract submission form.

Board Member Orientation

It shall be the policy of ISOQOL to conduct yearly board orientation. The orientation shall take place at the Annual Conference or shortly thereafter. Current and new board members will be present. This structure will allow for a shared experience between new and current board members, as well as serve as a refresher for current board members.

Check Signing

Individuals who will have the authority to approve payment of expenditures include the Executive Director, Treasurer, and President. The Executive Director approves and/or signs all checks \$5,000.00 and under. Checks in the amount of \$5,000.01 and over require the Executive Director and Treasurer's approval and/or signatures [or if Treasurer is unavailable President]. Payments over the amount of \$20,000, which have not been previously approved in the budget, will require approval from the Executive Director, Treasurer, and President. Signature cards will be reviewed and updated every year by the Executive Director upon election of a new President or Treasurer.

Code of Ethics

Members of the Board of Directors, Executive Committee and Committee Chairs, Task Force and Advisory members are committed to observing and promoting the highest standards of ethical conduct in the performance of their responsibilities to ISOQOL. Members of the Board of Directors, Executive Committee, and Committee Chairs pledge to accept this code as a minimum guideline for ethical conduct and shall:

Accountability

- Faithfully abide by the Articles of Incorporation, Bylaws and policies of the organization.
- Exercise reasonable care, good faith and due diligence in governing and managing affairs.
- Fully disclose, at the earliest opportunity, information that may result in a perceived or actual conflict of interest.
- Fully disclose, at the earliest opportunity, information of fact that would have significance in Board of Directors, Executive Committee, and Chairs/Members decision-making.
- Remain accountable for prudent fiscal management to ISOQOL members, the nonprofit sector, and where applicable, to government and funding bodies.

Professional Excellence - Integrity

- Maintain a professional level of courtesy, respect, and objectivity in all matters and activities.
- Strive to uphold those practices and assist other members of the Board of Directors, Executive Committee, and Committee Chairs in upholding the highest standards of conduct.

Personal Gain - Self-Dealing

- Exercise the powers invested for the good of all members of the organization and Quality of Life community rather than for personal benefit.

Equal Opportunity - Diversity - Inclusivity

- Ensure the right of all members to access benefits and services without discrimination on the basis of culture, geography, political, religious, or socio-economic aspects.
- Ensure the right of all members to access benefits and services without discrimination on the basis of the organization's volunteer or staff make-up in respect to gender, sexual orientation, national origin, race, religion, age, political affiliation or disability, in accordance with all applicable legal and regulatory requirements.

Confidential Information

- Respect the confidentiality of sensitive information known to Board and committee service and used for the purposes of governance and management. Understand and support the concept that what is learned or heard as a representative of ISOQOL will remain the intellectual property of ISOQOL.

Collaboration and Cooperation

- Respect the diversity of opinions as expressed or acted upon by the committees and membership, and formally register dissent as appropriate.

Violations

- Violations of the Code of Conduct may result in disciplinary action in accordance with the governing documents. Discipline may include removal of a Board of Director Member, Executive Committee Member, or Committee Chair from position.

Collaboration

Directive

The Board of Directors or Executive Committee may from time to time enter into a collaborative agreement with other societies or organizations for the purpose of advancing the scientific study of health-related quality of life (HRQL) and other patient-centered outcomes to identify effective interventions, enhance the quality of health care and promote the health of populations. With each collaborative effort, the Executive Committee will review the purpose and goals of the agreement and develop the ISOQOL directive for the project. This directive will be forwarded in writing to the ISOQOL representative working within the collaborative project.

Election of ISOQOL Representative

In the event that the Collaborative Agreement includes volunteer representation to the board or committee, the Executive Committee will review candidates and invite ISOQOL volunteers to represent ISOQOL as the delegate or seat on the board/committee.

The ISOQOL representative must be:

- An ISOQOL member in good standing
- Have a working knowledge of ISOQOL, its mission and initiatives
- Have the ability and capacity to participate in various conference calls and meetings of the collaborative partner
- Adhere to the ISOQOL Code of Ethics and Policies

The ISOQOL representative will be forwarded the ISOQOL Directive from the Executive Committee and asked to represent ISOQOL and their directive within the Collaborative project. Each member can be granted appointment to no more than two concurrent delegate or seat positions.

Collaborative Communication

As substantive issues and events affecting ISOQOL and its mission are presented to the ISOQOL Representative, this communication will be forwarded to the Executive Director for review by the President and/or Executive Committee. The President and/or Executive Committee will develop the ISOQOL directive/response to each issue or event. The directive will be forwarded to the ISOQOL representative for presentation to the collaborative partner.

All formal communication or correspondence with intersociety or collaborative partners must obtain prior approval from the Communication Committee/President and/or Executive Committee.

Reporting

In order to keep the ISOQOL leadership informed as to the process of working with our collaborative partners, ISOQOL representatives would update the ISOQOL office by:

1. Each ISOQOL representative(s) holding a seat on a board of another society/collaboration would forward a copy of the meeting minutes when possible to the ISOQOL office. The ISOQOL office will forward the information to the Secretary and Board of Directors of ISOQOL.
2. On a quarterly basis, the Secretary and Executive Director would receive a Summary Report from the ISOQOL representative(s). The Summary Reports are forwarded to the Executive Committee for review and the Secretary will report at the next meeting.
3. The ISOQOL representative will be kept informed by the Secretary and Executive Director of any direct communication from ISOQOL to their respective collaborative partners.

Communication Standards

In an effort to standardize the presentation of The International Society for Quality of Life Research (ISOQOL) documentation, correspondence and marketing communications should follow the guidelines below in all ISOQOL communications:

1. Written Communication

First Reference of ISOQOL: The International Society for Quality of Life Research (ISOQOL). Thereafter, abbreviate as ISOQOL.

Logos, Typography and Typesetting: All written documents displaying the ISOQOL name or logo should adhere to ISOQOL's Brand Standards (outlined in a separate document).

When considering placement of the ISOQOL logo or when appropriate, the ISOQOL Annual Conference logo on collateral, ISOQOL alignment with, or perceived endorsement of, companies and products should be evaluated. It is the responsibility of ISOQOL staff to carefully choose how the logo is used on internally generated collateral, as well as the conditions under which outside entities are allowed to use the ISOQOL logo on or in any and all media, print, or electronic pieces. Use of the ISOQOL logo must conform to the ISOQOL Brand Standards to ensure the image/brand identity of ISOQOL is maintained, protected and reinforced.

2. General Logo Use

The ISOQOL Logo should:

- Have consistent appearance, as it is critical to the ISOQOL identity. Acceptable layouts are outlined in the official ISOQOL Brand Standards documents.
- Be clearly prominent on all documents and promotional materials

3. External Use of the ISOQOL Brand

External entities who request use of the ISOQOL logo must complete the "External Logo Usage Request Form". These requests will be reviewed by ISOQOL staff. Many requests from external organizations may be related to the Annual Conference. For example, an entity may request to place the ISOQOL logo (or meeting logo) on a city guide, piece of hotel-dropped collateral or even dinner napkins.

In general, use of the logo by an outside entity may not be used in any manner that, at the sole discretion of ISOQOL:

- Discredit or tarnish the reputation and good will of ISOQOL
- Imply endorsement or alignment with a product/company
- Is false or misleading
- Violate any law or regulation

It will be important to carefully review any piece of collateral prior to providing consent for use of the ISOQOL logo. The content and quality of the piece should impact the decision to grant limited logo usage. It will be important to understand distribution and usage plans. ISOQOL Communications Committee may need to be brought in as reviewers if scientific or clinical information is referenced.

The logo will be made available in camera-ready and electronic form to eligible parties following review of the formal request. Use of the logo is only granted for the specific project time requested with a maximum duration of 1 year. If at any time ISOQOL feels that the ISOQOL logo is being used improperly or tarnishing the image of ISOQOL, it will demand that usage be stopped immediately. The logo always remains the exclusive property of ISOQOL.

Conflict of Interest and Confidentiality

Purpose

The purpose of this conflict of interest form is to protect the interests of the International Society for Quality of Life Research (ISOQOL) when entering into a transaction or arrangement that might benefit a Board member, Committee member or one or more of its key employees/consultants.

This policy, part of the overall ethics construct of the society, has the following goals:

- To identify conflicts between personal interests and the interests of the membership;
- To ensure that persons in leadership positions act in the best interest of the membership when engaged in activities related to their position with ISOQOL;
- To ensure full disclosure of any potential conflicts of interest; and,
- To establish guidance for appropriate handling of conflicts of interest.

Principle

The affairs and decisions of ISOQOL shall be conducted and made in a fair and impartial manner, without influence from Board members and key employees whose interests conflict with those of ISOQOL.

Definition

A conflict of interest arises when a Board member or key employee who is required to exercise judgment and make decisions on behalf of ISOQOL also has financial, professional, personal, or reciprocal relationships that are likely to or directly compromise his/her ability to make an impartial judgment for ISOQOL.

An apparent conflict of interest is present if there is a potential for the financial, professional, personal, or reciprocal relationships of a person to be at odds with the person's obligation to ISOQOL and the circumstances are such that a reasonable person with knowledge of the relevant facts would question the person's ability to act in ISOQOL's best interests.

Conflicts that may need to be disclosed

Financial, Professional, Personal, and Reciprocal Relationships - In determining whether you have a conflict to disclose, consider: 1) the definitions and examples below and; 2) whether the interest or relationship in question has the potential to affect decisions made on behalf of ISOQOL.

• **Financial**

Financial interests are defined as direct financial holdings, (exclusive of mutual funds) valued at \$10,000 or greater in any company with which ISOQOL could conceivably transact or is transacting business including, but not limited to: consulting firms; companies that sponsor, have sponsored, or could be invited to sponsor ISOQOL's annual conference or other events; and publishing firms. Disclosure is required if you, your spouse, partner, minor children or someone with whom you directly share income has financial holdings.

Other Possible Financial Conflicts

- Paid consultancy or expert testimony within the past two years
- Research funding (identify subject matter and funding organization, if permissible)
- Honoraria, stipends, or gifts exceeding \$100 in value per engagement directly received from an entity
- Royalties

• **Professional**

- Membership on another entity's board of directors or its advisory committees (whether for profit or not-for-profit).
- Employment with an entity with which ISOQOL could conceivably transact or is transacting business.

• **Personal**

Close personal relationships that are likely to interfere or appear to interfere with judgment used when decisions are made on behalf of ISOQOL.

• **Reciprocal and Business Relationships**

- Family Relationships
The USA Internal Revenue Services (IRS) requires an annual disclosure on the IRS 990 Tax Form if any of the organization's officers, directors, trustees, or key employees, had a family relationship with

another of the organization's officers, directors, trustees, or key employees, at any time during the organization's tax year.

o **Business Relationships**

The IRS also requires an annual disclosure on the IRS 990 Tax Form of any business relationships between two persons which include any of the following:

1. One person is employed by the other in a sole proprietorship or by an organization with which the other is associated as a trustee, director, officer, key employee, or greater-than-35% owner.
2. One person is transacting business with the other (other than in the ordinary course of either party's business on the same terms as are generally offered to the public), directly or indirectly, in one or more contracts of sale, lease, license, loan, performance of services, or other transaction involving transfers of cash or property valued in excess of \$10,000 in the aggregate during the organization's tax year. Indirect transactions are transactions with an organization with which the one person is associated as a trustee, director, officer, key employee, or greater-than-35% owner. Such transactions do not include charitable contributions to tax-exempt organizations.
3. The two persons are each a director, trustee, officer, or greater than 10% owner in the same business or investment conducts investment entity (but not in the same tax-exempt organization).

Ownership is measured by stock ownership (either voting power or value) of a corporation, profits or capital interest in a partnership or limited liability company, membership interest in a nonprofit organization, or beneficial interest in a trust. Ownership includes indirect ownership (for example, ownership in an entity that has ownership in the entity in question); there may be ownership through multiple tiers of entities.

Privileged relationship exception: A "business relationship" does not include a relationship between an attorney and client, a medical professional (including psychologist) and patient, or a priest/clergy and penitent/communicant.

Practices

Before ISOQOL members run for office or accept Board appointments they shall be made aware that all winning candidates and appointees must divulge financial, professional or personal relationships that could give rise to conflicts of interest as defined below.

- Annually, each Board member and key employee shall be asked to review the conflict of interest policy and acknowledge, in writing, that s/he has done so.
- Annually, each Board member and key employee shall complete a disclosure form identifying any relationships, positions or circumstances that could give rise to a conflict of interest.
- At the outset of every Board meeting, the Board president or presiding officer shall request that any Board member or key employee with a conflict of interest related to an agenda item make it known. Such disclosure shall be noted in the minutes.
- If or when a Board member holds a financial, professional, or personal relationship that represents an actual or apparent conflict of interest, the Executive Director or any Board member is entitled to request that such Board member recuse him- or herself from decision-making deliberations that could be affected by such relationship.
- Members who have a conflict of interest on a matter that comes to a vote shall abstain from voting; such abstention shall be noted in the minutes.

ISOQOL's President shall make the final determination of situations representing actual conflicts of interest.

Officials with conflicts of interest will recuse themselves from the following activities:

- Discussing or voting on issues related to the conflicts of interest;
- Participation on committees, subcommittees, or task forces charged with addressing issues involved in the conflicts of interest.

ISOQOL officials shall not offer, solicit, or accept gifts (including money, benefits, loans, or other payments) from any entity with which ISOQOL does or seeks to do business, or from any entity seeking to do business with ISOQOL. However, the following gifts are acceptable:

- Nominal gifts, social amenities, and entertainment which are given in normal business practice and which would not create the appearance of undue influence;
- Gifts for a non-business reason, which are motivated by a family relationship or personal friendship;
- Books, journals, media, software, and other informational material provided to assist the officials in performing their duties for ISOQOL.

Disclosure of Confidential or Proprietary Information

When in the course of performing services to ISOQOL officials have access to information that is confidential or proprietary to ISOQOL, officials shall

- Maintain the confidentiality of such information;
- Use their best efforts to prevent unauthorized disclosure of confidential or proprietary information.

Consent Agendas

It shall be the policy of ISOQOL to utilize a consent agenda at all Board of Directors' meetings. The consent agendas will be used when there are a number of non-controversial business items on which the Board of Directors needs to vote. Complete information will be provided in advance of the meeting to all Board of Directors, so that each knows what is being proposed and has the opportunity to consider whether the item truly is non-controversial. Consent agenda items may include matters that a bylaw or some other rule or regulation requires to be formally approved by the board, yet there is no value added by engaging the Board of Directors in discussion about the item. The consent agenda will not be used to hide actions that will be controversial.

Items will stay on the consent agenda only if all Board of Directors agree; if even one member considers a specific item to need discussion, it will be removed and placed on the regular agenda for the board meeting.

Copyrighted Materials Usage

(Use of Copyrighted Materials by Speakers in Materials Developed for ISOQOL Educational Activities)

ISOQOL's copyright policy is provided to each speaker and panel member of an ISOQOL-sponsored educational activity for information, review and compliance. Compliance with this policy is a condition of speakers and panel member participation in an ISOQOL-sponsored activity.

Visual presentations and handouts are essential components to quality continuing education. It is not uncommon for speakers and panel members preparing such presentations and materials for a presentation sponsored by an educational organization such as ISOQOL to include materials copyrighted by another party.

Although use of limited portions of copyrighted materials of others may be permissible under applicable copyright law, it is the policy of ISOQOL to exercise utmost effort to respect the proprietary rights of authors and other creators of medical education works in ISOQOL-sponsored activities.

ISOQOL requires that speakers and panel members preparing visual presentations, handouts and other materials for use in connection with live activities sponsored by the ISOQOL be aware of the following policies:

1. Speakers and panel members of ISOQOL-sponsored events must refrain from incorporating materials copyrighted by others whenever possible unless: (a) the speaker or panel member is satisfied that the amount of such copyrighted work and the nature of its use is permissible as a "fair use" under copyright law; or (b) the written permission of the author or other copyright holder is obtained for the use of such materials.
2. When copyrighted material of others are used as described in Item 1 above, the speaker or panel member must cite the source of the copyrighted material, which must include a valid copyright notice (i.e., "Copyright © 2003. John Doe, MD") as well as the phrase, "Reprinted with permission of the copyright owner."

Crisis Response

A crisis is an event that creates victims and/or explosive visibility. For our purposes, a crisis is any incident that has the ability to severely impact the health or financial well-being of meeting attendees and/or negatively impact the long-term reputation, service or assets of the ISOQOL, its credibility, or the trust of its members or the public.

1. Crisis Management Team Members and Responsibilities

Leadership Team The Crisis Management Leadership Team will convene to guide the ISOQOL's actions during a crisis. The team members include:

- ISOQOL President
- ISOQOL President Elect
- ISOQOL Past President
- ISOQOL Consulting Partner
- Executive Director
- Legal Counsel (*if necessary*)

Information Officers Several ISOQOL staff members would take on roles specific to the dissemination of information to key audiences during a crisis. They are:

- Crisis Response Team Leader:
(Leads efforts of Information Officers. Also serves as a liaison between the Hotel and the Crisis Management Leadership Team if necessary to facilitate safety measures)
- Staff & Situation Officer:
(Monitors the situation and keeps staff and the Leadership Team informed of any developments. Also coordinates staff duties pertaining to the crisis.)
- Media Officer:
(Monitors incoming inquiries and facilitates outgoing statements by the Society)
- Delegate Officer:
(Distributes information to delegates, monitors incoming information and answers questions as appropriate)

Executive Office Staff The Executive Office may be the first contact for members of the media, and family members of delegates. Reception and/or the "at home point person" (TBD) is responsible for:

- Fielding calls that come in to the office directly seeking information
- Distributing calls/messages to appropriate Information Officers (see list above).
- Keeping Executive Director apprised of any new information received about the situation or that may impact the situation.
- Receiving general media statements from the Media Officer and coordinate dissemination to requesting parties, including families, affiliated organizations, etc.

2. Crisis Actions and Duties

IF YOU WITNESS AN INCIDENT OR ONE IS REPORTED TO YOU:

A staff member who observes or is informed of an incident he or she thinks may be a crisis should immediately contact Executive Director or Situation Officer before reporting to the scene for on-site evaluation. If you witness or happen upon an incident, contact Executive Director immediately and then fill out as many details as you can on the incident report form.

THEFT OR THREAT OF BODILY HARM:

If you witness or have an incident reported to you that requires outside assistance from hotel security, police, fire department, etc. such as theft or threat of bodily harm, please be sure to keep yourself safe first. Immediately report to Executive Director or Situation Officer as many details as you can of the incident at hand and the urgency of the matter. They will then get the appropriate parties involved. If there is imminent danger of bodily harm, immediately contact the hotel security (extension at hotel TBD) or dial emergency (911) or local emergency number. Write down the details as soon as possible on the incident report form in case further investigation is required.

MULTIPLE INJURIES:

If an event occurs that includes multiple injuries, establishing that staff is safe is a priority. Once you are informed of such an event, please let your on-site leader know of your whereabouts. If you do not have a cell phone or radio contact information for your on-site leader, leave a voice mail for them on EDI voice mail.

DOCUMENTATION:

Staff is asked to write down everything they observe on an Incident Report Form (or whatever is available) including: comments from delegates, the media, or others about the incident and how the staff member handled the unexpected situations that arose. These observations will be invaluable for evaluating the impact of the crisis.

STAFF INFORMATION CENTER:

The ISOQOL staff office will be the staff information center. If that office is unavailable due to the event, the Hotel's Registration Desk will serve as the staff information center. If both sites are affected, the Crisis Management Leadership Team will meet in the hotel's Main Lobby or at a place designated by the Crisis Management Team Leader depending on the situation.

SHARING OF INFORMATION:

All staff members representing ISOQOL at the Annual Conference and in the Executive Office share responsibility for transmitting only the factual information about the incident provided in correspondence developed by the Executive Director. Information updates, based on approved statements and agreed upon information to be released, will be provided by the Executive Director. Staff should limit their responses to crisis inquiries to the information provided in these updates. This includes, but is not limited to, inquiries from ISOQOL members, meeting delegates, members of the media, general inquiries from hotel or emergency personnel and questions from staff members' family and friends. Further inquiries should be directed to the appropriate staff information officer for the request. In particular, all media inquiries should be directed to the Media Officer.

DELEGATE INQUIRIES:

At the meeting, delegates seeking information about the crisis or conditions of injured delegates should be directed to the Registration Desk (unless another area has been indicated) where the Delegate Officer or a designee, will provide appropriate contact information.

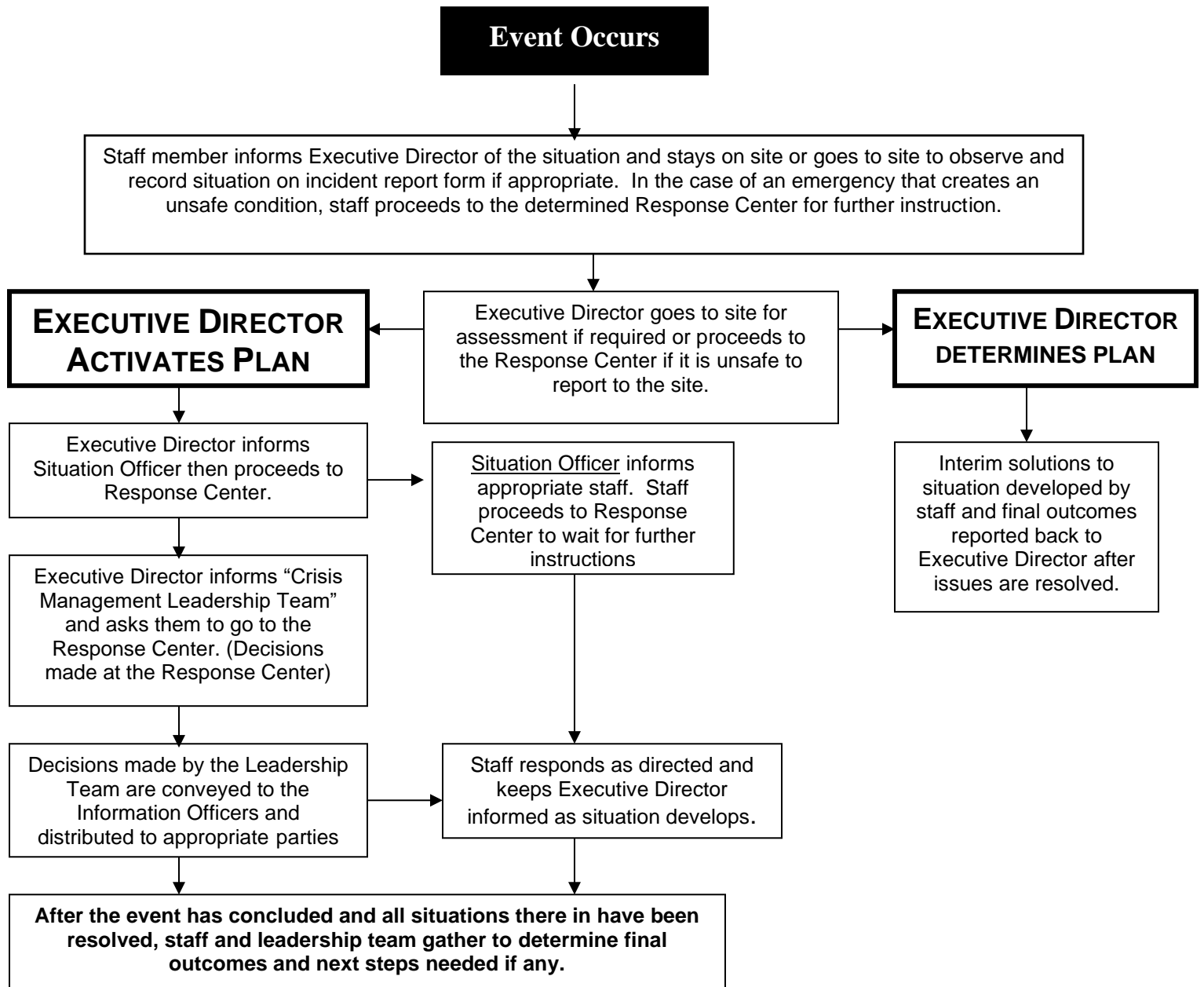
SEPERATION FROM TEAM MEMBERS:

If you are unable to find your on-site team leader, contact the EDI office at (888) 807-8017 or (414) 276-6445 during the day. If it is after business hours, leave a voice mail message at EDI office with the COO (ext. 3031). Also leave a voice mail for your on-site team leader. A listing of important contacts and numbers including local emergency contact information will be included in this ISOQOL Operations Manual.

3. Media Involvement

It is essential that the ISOQOL respond to media inquiries in a way that is clear, concise, accurate and timely to help ensure the media reports accurate information and offers an accurate view of the incident. In the event a member of ISOQOL is approached to comment on a crisis, they should adhere to ISOQOL's Media Interactions policy.

4. Crisis Response Chain



If the CRISIS RESPONSE PLAN is implemented, keep the following in mind:

- **RESPONSE CENTER:** The Staff Office serves as the central meeting place unless otherwise noted or unsafe.
- **DELEGATE COMMUNICATIONS:** The Registration Area serves as the base for the Delegate Officer and delegate communication unless a different site is designated or it is unsafe to do so.
- **MEDIA COMMUNICATIONS:** All media inquiries/responses will be overseen by the Media Officer and Crisis Response Team Leader. Official statements can only come from the ISOQOL President, Executive Director or other official designee.
- **HOTEL SECURITY:** There is hotel security on duty at all times if extra assistance is needed. Dial (# TBD) from a house phone to be directly connected.

Document Destruction **(Policy for Document and Records Maintained by EDI)**

After One Year

Routine correspondence of unimportant nature with members, customers or vendors

After Three Years

Expired insurance policies
General correspondence
Internal audit reports and working papers
Internal reports
Membership applications

After Seven Years

Bank statements
Cancelled stock and bond certificates and expired options
Cash books
Commission records
Contracts and leases (expired)
Inventory records (products, materials, supplies)
Invoices to customers and from vendors
Sales records
Stock and bond certificates (cancelled)

Permanent Records

Articles of Incorporation
Audit reports of CPAs
Capital stock, bond records: ledger, transfer registers, stubs showing issues, record of interest coupons, options, etc.
Cash books
Chart of accounts
Copyrights
Correspondence (legal and important matters only)
Deeds, mortgages, and bills of sales, as well as contracts and leases still in effect
Depreciation schedules
Financial statements – end of year (other months optional)
General and private ledgers
Insurance records, claims policies
Licenses and permits
Minute books of directors and stockholders, including by-laws and charter
Property records – including costs, depreciation reserves, and end-of-year trial balances, depreciation schedules, blueprints and plans
Tax returns and worksheets, Documents relating to determination of income tax liability
Trademark registrations

Educational Activities Disclosure

ISOQOL has implemented a process for presenters to disclose all relevant financial relationships with any commercial interest, and will personally attest that these relevant relationships will not inappropriately affect their presentation. A Presenter Disclosure Form will be completed by all presenters. Refusal to disclose relevant financial relationships or agree to the expectations outlined on the disclosure form may disqualify individuals from presenting. In addition to completing the Presenter Disclosure Form, presenters should include the relevant information in a Disclosure slide (for oral presentations) or on their poster.

Ethics Review

The Executive Committee will oversee compliance with the Policy Manual, Code of Ethics and all Conflict of Interest Disclosure (COI) forms for the Board of Directors, Executive Director, ISOQOL Staff/Consultants, Committee Chair/Members, Faculty/Speakers and any other volunteers in positions subject to society influence. The committee identify COIs, review appeals and serve as the final arbitrator for any unresolved conflicts of interest.

From time to time, the committee shall review the Conflict of Interest procedures and make recommendations to the ISOQOL Board of Directors.

Executive Session

If the need for an executive session (closed-door without staff) arises the following steps will be taken to ensure that the session is conducted appropriately.

1. Prior to calling an executive session a motion must be passed by the Board of Directors and/or Executive Committee to identify the specific topics to be addressed.
2. The discussion shall be limited to those topics.
3. Upon conclusion, actions of the executive session shall be reported to the Board of Directors for inclusion in the official minutes of the current minutes or the next leadership meeting, summarizing what was discussed and any decisions made in the executive session.

External Events/Projects Endorsement

The mission of the International Society for Quality of Life Research (ISOQOL) is to advance the science of quality of life and related patient-centered outcomes in health research, care and policy. Therefore ISOQOL is willing to endorse different courses/conferences and research projects/programs which will strengthen this objective.

LETTER OF SUPPORT

At our discretion, ISOQOL may issue a **Letter of Support** to members' research projects/programs which will strengthen the ISOQOL mission.

Application Process

Researchers must submit a Letter of Support application form and the corresponding documents to the ISOQOL executive office. Applications must provide the credentials of the organizers, scientific merit, independent review process, and financial disclosure and conflict of interest disclosure. The applicant(s) will receive ISOQOL's response within 30 days from the date when the application is received at ISOQOL office.

Liability

The International Society for Quality of Life Research will have no fiscal or legal responsibility for the project/program. Excess revenue or expenses are the sole responsibility of the independent researcher(s). Any research involving human subjects, as defined by the World Medical Association Declaration of Helsinki (<http://www.wma.net/en/30publications/10policies/b3/>), requires compliance with the Declaration. The projects must be reviewed and approved by an appropriate independent ethics committee (e.g., a university, hospital or private institutional review board) or exempted as appropriate. If available, the letter of approval from the ethics committee must accompany the application to the ISOQOL Executive office, and ISOQOL reserves the right to request the research program application, protocol, or additional information.

Qualifications

ISOQOL will use the following guidelines that pertain to research when considering a Letter of Support. Please contact ISOQOL office with any questions.

1. ISOQOL will only issue a Letter of Support for programs that are in keeping with ISOQOL's mission and principles. ISOQOL leadership will evaluate the relevance of the matter to the ISOQOL mission, and may seek input from the Board or other ISOQOL members with relevant expertise. The ISOQOL leadership will vote on the application and determine ISOQOL's respond.
2. ISOQOL will not endorse programs that are for-profit entities.
3. Applicants must be active ISOQOL members to apply for a Letter of Support.

Agreement

The applicants agree to:

1. Acknowledge the International Society for Quality of Life Research for its support of the project/program.
2. If relevant (for projects of longer duration) provide the ISOQOL Executive Director with a summary report on an annual basis.
3. Submit a final brief summary report stating the key conclusions of the project/program and include any publications or other forms of dissemination resulting from it. ISOQOL reserves the right to request additional documentation.

MEETINGS/EVENTS

Program

ISOQOL is willing to endorse different conferences/courses/meetings, etc. (events), around the world, which will strengthen its mission. At our discretion, ISOQOL may endorse non-ISOQOL events in fields related to the scientific

study of health-related quality of life and other patient-centered outcomes that do not coincide or deter from ISOQOL events.

Application Process

Event organizers must submit a proposed program, including topics and faculty for the event along with the Endorsed Events application form to the ISOQOL executive office. Applications for Endorsed Events must provide the credentials of the organizers, scientific and educational merit, independent review process, and financial disclosure and conflict of interest disclosure. The applicant will receive ISOQOL's response within sixty (60) days from the date when the application is received at ISOQOL office.

Liability

The International Society for Quality of Life Research will have no fiscal responsibility for the event if debt is incurred and no liability for any event. Excess revenue or expenses are the sole responsibility of the event organizer(s) unless specifically stated in a formal agreement between the ISOQOL and the event organizer(s).

Qualifications

ISOQOL will use the following guidelines when considering endorsement of events that pertain to health-related quality of life research. Please contact ISOQOL office with any questions.

1. ISOQOL will only endorse and support events that are in keeping with the mission and principles of ISOQOL. Any profits from endorsed events should be used for activities or programs that are in line with the mission and principles of the ISOQOL (such as funding other educational activities or research). ISOQOL will not endorse events that are for-profit entities.
2. ISOQOL will not endorse or support a program that competes with its own existing or planned events in terms of content, time, or location.
3. The Chair and/or a fair representation of the event's faculty should be ISOQOL members.
4. If the event is Industry supported, participation should not be exclusionary or limited to a single company.
5. ISOQOL will not incur any financial liability for the endorsed event.
6. ISOQOL will not be responsible for any expenses for the faculty members (ISOQOL members or otherwise).

Agreement

The event organizers agree to:

1. Credit the International Society for Quality of Life Research for its endorsement of the event in all-event's publications and announcements.
2. Provide ISOQOL with copies of all event literature including program, abstracts, proceedings and promotional material.
3. Provide ISOQOL with complimentary booth space at the event if applicable.
4. Provide ISOQOL with a two time usage attendee list upon request.
5. Submit a final summary report including attendance, key outcomes and if appropriate participants' feedback within 60 days of the end of the event.
6. ISOQOL Endorsed Event may use the ISOQOL stamp in promotional materials for the event. The ISOQOL stamp consists of the ISOQOL logo with the following statement: "Endorsed by the International Society for Quality of Life Research". The ISOQOL logo and name may not be used for any other purpose unless approved by the ISOQOL Executive Committee.
7. ISOQOL will promote the Endorsed Event on the ISOQOL Website.

Faculty, Leadership and Staff Disclosure for ISOQOL Educational Activities

ISOQOL has implemented a process where everyone who is in position to control the content of an ISOQOL sponsored educational activity has disclosed all relevant financial relationships with any commercial interest, and has personally attested that these relationships will not inappropriately affect their role in the activity. Refusal to disclose relevant financial relationships or agree to the expectations below may disqualify you from being a part of the planning and implementation of the activity. Disclosures will be made available to attendees in the on-site meeting materials.

FACULTY EXPECTATIONS

- I will disclose to ISOQOL all relevant financial relationships, and hereby allow ISOQOL to disclose this information to learners in print.
- The content and/or presentation of the information with which I am involved, including any presentation of therapeutic options, will be well-balanced, evidence-based and unbiased. It will promote quality or improvements in healthcare and will not promote a specific proprietary business interest of a commercial interest.
- I have not and will not accept any additional honoraria, payments or reimbursements beyond that which has been agreed upon directly with ISOQOL for the educational activity.
- I understand that ISOQOL may need to review presentations and/or content prior to the activity, and I will provide educational content and resources in advance as requested.
- I understand that a monitor will be attending the event to ensure that all presentations are educational in nature.
- If I provide recommendations involving clinical medicine, they will be based on evidence that is accepted within the medical profession as adequate justification for their indications and contraindications in the care of patients. All scientific research relating to this activity in support of a patient care recommendation will conform to the generally accepted standards of experimental design, data collection, and analysis.
- If I discuss specific health care products or services, I will use generic names to the extent possible. If necessary, I will use trade names from several different companies when available.
- If I discuss any product use that is off label, I will disclose that the use or indication in question is not currently approved by the EMA or FDA.
- If I have been trained or utilized by a commercial entity or its agent as a speaker (e.g., speaker's bureau) for any commercial interest, the promotional aspects of that presentation will not be included in any way with this ISOQOL sponsored activity.
- If I am presenting research funded by a commercial company, the information presented will be based on generally accepted scientific principles and methods, and will not promote the commercial interest of the funders.

Faculty Release Request **(For Online Hosting of Presentation Slides and Webinars)**

This Policy is delivered to each faculty member delivering an oral presentation at an ISOQOL-sponsored educational activity.

Due to overwhelming requests from meeting attendees and members, ISOQOL would like to host presentations from its live events online at www.isoqol.org. ISOQOL therefore requests permission to post speaker presentation slides and/or webinars of audio-visual (AV) recordings of their oral presentation.

Slides

ISOQOL requests all speakers to indicate their permission to allow the Society to post their presentation slides to the Society website. Speakers are informed of the following security measures and rights to intellectual property:

- *The information you provide will have security measures put in place to protect your data, including the conversion of your presentation to a PDF format before posting. If certain data needs further protection, there is also the opportunity to eliminate specific slides from your presentation before they are posted online.*
- *Allowing ISOQOL to utilize your presentation for this purpose does not require you to give up any rights to the data or information you have provided. You retain all rights and privileges to the intellectual property therein.*
- *If your presentation is pending publication in a scientific journal, please confirm with the publisher if you are able to release this information to post on the ISOQOL website. By granting permission below, you confirm that you have acquired permission from co-contributors or co-authors to post the slides on the ISOQOL website.*

If there is a specific situation that prohibits the speaker from release of the presentation, a request detailing the circumstances to forgo the requirement can be made to the ISOQOL office.

Audio-Visual Recording and Webinars

For many ISOQOL-sponsored programs, ISOQOL desires to make an AV recording for potential use in development of webinars, podcasts and/or other electronic media. For such programs, ISOQOL requests speakers' permission to allow the Society to record their presentation and use the recording in the production and online hosting of their presentations in these formats. Specifically, ISOQOL requests the speaker to grant ISOQOL and/or its authorized provider the following:

- *The royalty-free right to reproduce for web casting and/or CD-ROM/DVD as deemed appropriate for educational purposes by ISOQOL the audiovisual recording of my presentation at the ISOQOL-sponsored live event {Program Title} taking place in {Location}, on {Program Date}, including all materials prepared or provided by me (collectively, the Program).*
- *The right to use my name, voice, photograph, likeness, and biographical information in connection with the exercise of the rights granted above.*
- *The right to engage ISOQOL's authorized provider/agent for purposes of producing the web cast and distributing the same under the direction and guidance of ISOQOL.*

I hereby release and discharge to ISOQOL, its authorized provider and its officers, employees, and agents from any and all claims, demands, and causes of action that I may have against it by reason of its exercise of its rights hereunder including, without limitation, any claims based on the right of privacy, the right of publicity, copyright, libel, or slander related to the materials prepared by me that are unaltered, unedited, and maintained in their original form, format, and content. Further, I warrant that, to the best of my knowledge, the Program does not contain any defamatory material or any factual inaccuracies, given the status of the scientific basis of the materials at the time they were produced. Opinions expressed in the Program represent my own personal opinions, not necessarily those of ISOQOL or its officers, employees, and agents.

The grant contained herein does not limit the right of the Speaker to make any other use of his or her intellectual property in any other way.

Financial Audit Requirement

Financial Audit Process

Annually, the Board of Directors will contract with a Certified Public Accounting firm to conduct an independent audit in accordance with Generally Accepted Auditing Standards. The audit firm will be selected by the management company and every attempt will be made to rotate lead auditors or audit companies every three to five years. A copy of the audit shall be provided to the office file, Treasurer and each Executive Committee member.

Fiscal Year

The fiscal year is January 1 through December 31.

Notice of Funding Information

On occasion ISOQOL receives requests from various groups requesting research grant information be distributed to the membership. This information is announcing funding opportunities that may be of benefit to our members.

ISOQOL has established the following policy and guidelines for distribution of external research grant funding communication to our membership:

- (1) The organization's request must support the mission and values of ISOQOL.
- (2) The request may be from a nonprofit or for-profit organization.
- (3) The research grant funding opportunity must be perceived as of benefit to our members.
- (4) To ensure brevity, the information should be no longer than a one page document and must be presented in an unbiased manner.
- (5) The research grant funding opportunity will not be endorsed by ISOQOL nor should the distribution of the request give the perception of bearing ISOQOL endorsement. It is suggested that the request begin with "ISOQOL has been made aware of..."
- (6) To ensure timeliness, these External Funding Opportunity requests will be distributed as a Weekly Update and/or within the Newsletter or other similar acceptable means approved by ISOQOL.

Insurance

It shall be the policy of ISOQOL to on a yearly basis maintain General Liability and Directors and Officers (Society Professionals) insurance coverage. When appropriate, ISOQOL will also secure additional liability insurance such as earthquake, liquor or terrorism insurance. Current insurance information listed below:

Description: **Commercial General Liability Coverage and Umbrella Policies**

Agency: Affinity Insurance Agency
1120 20th St. NW Ste. 600
Washington, DC 20036-3406
Agent:

Great American Insurance
Administrative Offices
301 E 4th Street
Cincinnati OH 45202-4201

1,000,000	Each Occurrence Limit
100,000	Damage to Premises Rented to You Limit
5,000	Medical Expenses Limit (Any One Person)
1,000,000	Personal and Aggregate Limit
2,000,000	General Aggregate Limit
2,000,000	Products/Completed Operations Aggregate Limit

Description: **Non-Profit Organization Directors and Officers Liability Policy**

Marsh U.S. Consumer
A service of Seabury & Smith, Inc.
540 W. Madison Street
Chicago, IL 60661

1,000,000	Non-Profit D&O liability
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Description: **Convention Cancellation Insurance**

Arthur J. Gallagher
One Church Street #400
Rockville, MA 20850

719,209	Cancellation
150,000	Physical Loss to Personal Property
125,000	Door Registration Receipts

Investments

The ISOQOL Board of Directors acknowledges the need to maintain sufficient liquid assets to cover the Society's anticipated operating budget each fiscal year. In addition, the strategic objective of diversifying its revenue streams is important, given the potential for uncertainty in the economy.

The Executive Committee is charged with review and oversight of the investment portfolio and quarterly review of the ISOQOL finances to determine the necessary operating budget. ISOQOL has an investment portfolio with Schwab One Account #3741-6670.

This statement of investment policy reflects the investment policy, objectives, and constraints of the ISOQOL Board of Directors (Board).

Purpose of the Investment Policy Statement

This statement of investment policy is set forth by the ISOQOL Board in order to:

1. Define and assign the responsibilities of all involved parties.
2. Establish a clear understanding for all involved parties of the investment goals and objectives for assets.
3. Offer guidance and limitations to all investment managers regarding the investment of Society assets.
4. Establish a basis for evaluating investment results.
5. Manage assets according to prudent standards as established in common trust law.
6. Establish the relevant investment horizon for which the assets will be managed.

In general, the purpose of this statement is to outline a philosophy and attitude which will guide the investment management of the assets toward the desired results. It is intended to be sufficiently specific to be meaningful, yet flexible enough to be practical.

Delegation of Authority

The Board is the governing body of ISOQOL. The Treasurer as advised by the Executive Committee is authorized to delegate certain responsibilities to professional experts in various fields. These include, but are not limited to:

Custodian(s). The custodian(s) will (or through agreement with a sub-custodian) maintain possession of securities owned by ISOQOL, collect dividend and interest payments, redeem maturing securities, and effect receipt and delivery following purchases and sales. The custodian may also perform regular accounting of all assets owned, purchased, or sold, as well as movement of assets into and out of the Fund accounts.

Investment Manager(s). The investment manager has discretion to purchase, sell, or hold the specific securities that will be used to meet the Society's investment objectives.

Additional specialists such as attorneys, auditors, and others may be employed to assist in meeting its responsibilities and obligations to administer the assets as directed by the Board.

Definitions

1. "The Fund" shall mean the ISOQOL investment accounts.
2. "The Board" shall refer to the ISOQOL Board of Directors overseeing the investment accounts.
3. "Securities" shall refer to the marketable investment securities which are defined as acceptable in this statement.
4. "Investment Horizon" shall be the time period over which the investment objectives, as set forth in this statement, are expected to be met. The investment horizon is five to seven years.
5. "Investment Manager" shall mean any individual or group of individuals, employed to manage the investments of all or part of the Fund assets.

General Investment Principles

1. The assets shall be invested with the care, skill, prudence, and diligence under the circumstances then prevailing that a prudent man or woman acting in like capacity and familiar with such matters would use in the investment of a fund of like character and with like aims.
2. Investments shall be so diversified as to minimize the risk of large losses, unless under the circumstances it is clearly prudent not to do so.

3. The Fund may employ one or more investment managers/funds of varying styles and philosophies to attain the Fund's objectives.
4. Cash is to be employed productively at all times, by investment in short term cash equivalents to provide safety, liquidity, and return.

Investment Objectives

In order to meet its needs, the investment strategy of the Fund is to emphasize total return; that is, the aggregated return from capital appreciation and dividend and interest income.

The Fund seeks a combination of long-term growth of principal and current income while avoiding excessive risk. Short-term volatility will be tolerated in as much as it is consistent with the volatility of a comparable market index.

Over the investment horizon established in this statement, it is the goal to meet or exceed:

The return of 90% of the S&P 500 index and 10% Barclays's Gov't Credit Index

The investment goals above are the objectives of the aggregate Fund, and are not meant to be imposed on each investment account. The goal of each investment manager, or the investment horizon, shall be to:

1. Meet or exceed the market index, or blended market index that most closely corresponds to the style of investment management.
2. Display an overall level of risk in the portfolio which is consistent with the risk associated with the benchmark specified above. Risk will be measured by the standard deviation of quarterly returns and by beta.

Goals of the Investment Accounts

The overriding objective of the Funds is long term growth of capital. That is, the objective is to grow the aggregate portfolio value at least at the rate of inflation over the Fund's investment horizon.

Liquidity

The Board recognizes its responsibility to help minimize any potential loss occasioned by the sale of securities needed to meet a liquidity need. Therefore, the Treasurer will periodically provide investment consultant with an estimate of expected net cash flow to allow sufficient time to build up necessary liquid reserves.

Marketability of Assets

The Board requires that all of Fund assets be invested in liquid securities, defined as securities that can be transacted quickly and efficiently for the Fund, with minimal impact on market price.

Investment Guidelines - Allowable Assets

1. Cash Equivalents
 - Treasury Bills
 - Money Market Funds
 - STIF Funds
 - Commercial Paper
 - Banker's Acceptances
 - Repurchase Agreements
 - Certificates of Deposit
2. Fixed Income Securities
 - U.S. Government and Agency Securities
 - Corporate Notes and Bonds
 - Mortgage Backed Bonds
 - Preferred Stock
3. Equity Securities
 - Common Stocks
 - Convertible Notes and Bonds
 - Convertible Preferred Stocks
 - American Depository Receipts (ADRs) of Non-U.S. Companies and non US Companies
4. Mutual Funds and Pooled Accounts

Selection of Fund Managers

The selection of investment funds/manager(s) is to be based on the recommendations of the Treasurer and approved by the Executive Committee. A qualifying investment manager must be a registered investment advisor under the Investment Advisors Act of 1940, or a bank or insurance company.

Performance Review Evaluation

Performance reports generated by the Investment Manager shall be compiled at least quarterly and communicated to the Treasurer for review. The investment performance of total portfolios, as well as asset class components, will

be measured against commonly accepted performance benchmarks. Consideration shall be given to the extent to which the investment results are consistent with the investment objectives, goals, and guidelines as set forth in this statement. The Treasurer and Executive Committee intends to evaluate the portfolio(s) over at least a five year period, but reserves the right to terminate a fund/manager for any reason including the following:

1. Investment performance which is significantly less than anticipated given the discipline employed and the risk parameters established, or unacceptable justification of poor results.
2. Failure to adhere to any aspect of this statement of investment policy, including communication and reporting requirements.
3. Significant qualitative changes to the investment management organization.

Leadership Duties and Responsibilities **(For Board of Directors and Committee Members)**

General Committee Members

- Determine and understand the organization's mission and purposes
- Support the president, Board of Directors and Executive Committee
- Support the management staff
- Assist in completing the objectives of their Committee by accepting and collaborating on specific tasks
- Work to meet established deadlines in order to advance their Committee's objectives efficiently
- Determine, monitor and strengthen programs and services for members
- Promote the organization's image
- Ensure legal and ethical integrity in the organization
- Attend all assigned committee meetings
- Prepare for meetings by reviewing the agenda and supporting documents
- Treat all information learned or shared at meetings as ISOQOL intellectual property and confidential, including conversations and discussions
- Start and end meetings on time
- Study and understand the mission and bylaws, policies and goals
- Promote the organization to others
- Recruit members and future leaders to help govern the organization
- Stay current on issues and trends impacting the organization and membership
- Readily communicate with the office for needed information and assistance

At Large Board of Directors Member

- Determine and understand the organization's mission and purposes
- Support the president and Board of Directors
- Support the management staff
- Ensure organizational planning
- Allocate resources for programs and services
- Determine, monitor and strengthen programs and services for members
- Promote the organizations image
- Ensure legal and ethical integrity in the organization
- Help recruit new leaders
- Assess and measure organizational performance
- Serve as board liaison to a committee, task force or program
- Attend all board meetings
- Prepare for meetings by reviewing the agenda and supporting documents
- Treat all information learned or shared at meetings as ISOQOL intellectual property and confidential, including conversations and discussions
- Start and end meetings on time
- Study and understand the mission and bylaws, policies and goals
- Promote the organization to others
- Recruit members and future leaders to help govern the organization
- Stay current on issues and trends impacting the organization and membership
- Assist with fund raising
- Refrain from working around the President and making special requests of the staff
- Readily communicate with the office for needed information and assistance

President

- Serve as the chief elected officer over the organization
- Preside over all meetings or identify a designee
- Interface with the executive director, board of directors, executive committee, and committees
- Appoint committee chairs
- Appoint ad hoc committees or task forces
- Co-sign checks over \$20,000, which have not been previously approved in the budget

President-elect

- Serve in the absence of the president
- Perform such duties as identified in the bylaws or as assigned by the president

Secretary

- Oversee the custody of all organization records
- Monitor the accuracy and timely distribution of meeting minutes
- Serve as liaison to review bylaws
- Perform such duties as identified in the bylaws or as assigned by the president

Treasurer

- Oversee the custody of all organization funds
- Work with staff to create an annual budget for board approval
- Co-sign checks over \$5,000
- Perform such duties as identified in the bylaws or as assigned by the president

Required Meetings

January	Board of Directors' Teleconference Call
April	Spring Board of Directors' Meeting (in person)
October:	Fall Board of Directors' Meeting (in person)
November:	Board of Directors' Teleconference Call
As needed:	Strategic planning, crisis response, others as needed.

Board and Executive Committee Voting

Official Board/Executive Committee votes can take place electronically or during a board meeting. During a Board Meeting, any items not on the agenda or items that arise on the floor cannot be voted on during the same board meeting to allow adequate research and discussion to take place. These items can later be voted on electronically or during another board meeting.

List Rental

1. Member Mailing List Request Policy *(for vendors, sponsors, industry and related organizations)*

To request mailing lists of ISOQOL members, interested persons must first fill out the Mailing List request form, found on the ISOQOL G-drive. The request form shall include:

- General Contact Information
- Sample of the piece to be distributed to ISOQOL delegates
- Payment information (check, Visa, MC, AMEX)
- Signed confidentiality clause
- Sort type (alpha, zip code, international, etc.)

The Confidentiality Clause shall state:

- The mailing list is the intellectual property of ISOQOL and that it may only be used for the purpose of mailing the approved piece to ISOQOL members. The list will be distributed in label format for one-time use only. Should any labels not be used, the recipient of the list agrees to destroy any unused labels.

Upon satisfactory completion of the specified materials and receipt of payment, the mailing list will be sent to the requestor, within a reasonable time period.

ISOQOL reserves the right to deny request for any reason.

It is ISOQOL policy that email addresses of delegates are never sold or distributed

2. Delegate List Request Policy

To request a list of registered delegates for the ISOQOL Annual Conference, interested persons must first fill out a list request form, found on the ISOQOL G-drive. The request form shall include:

- o General Contact Information
- o Sample of the piece to be distributed to ISOQOL delegates
- o Payment information (check, Visa, MC, AMEX)
- o Signed confidentiality clause
- o Sort type (alpha, zip code, international, etc.)

The Confidentiality Clause shall state:

- o The list is the intellectual property of ISOQOL and that it may only be used for the purpose of distributing the approved piece to ISOQOL delegates. The list will be distributed in hard copy or electronic PDF format.

Upon satisfactory completion of the specified materials and receipt of payment, the delegates list will be sent to the requestor, within a reasonable time period.

ISOQOL reserves the right to deny any request for any reason.

A maximum of two lists will be rented per requestor, one pre-meeting registration list and one post meeting delegate registration list.

The delegate information provided will only include full name, designation, institution, city, state or country.

It is ISOQOL policy that email addresses of delegates are never sold or distributed.

Listserv and Bulletin Boards

The following are the rules and conditions of participation in the International Society for Quality of Life Research listserv. By subscribing to and participating in this listserv, users hereby agree to be bound by and warrant their full compliance with the following terms of participation:

This listserv, including project management software, is a service provided by the International Society for Quality of Life Research ("ISOQOL") in furtherance of its nonprofit and tax-exempt purposes. This listserv may be used only by ISOQOL members and only for the purpose of discussing matters related to or arising out of the profession of health-related quality of life research.

ISOQOL accepts no responsibility for the opinions and information posted on this listserv by others. ISOQOL disclaims all warranties with regard to information posted on this listserv, whether posted by ISOQOL or others; this disclaimer includes all implied warranties of merchantability and fitness. In no event shall ISOQOL be liable for any special, indirect or consequential damages, or damages of any kind whatsoever, resulting from loss of use, data or profits, arising out of or in connection with the use or performance of any information posted on this listserv.

Do not post any defamatory, abusive, profane, threatening, offensive, or illegal information or material, and do not utilize the listserv in any illegal manner. Do not post any information or other material protected by copyright without the permission of the copyright owner. Do not use any words, logos or other marks that would infringe upon the trademark, service mark, certification mark, or other intellectual property rights of the owners of such marks without the permission of such owners. Do not post any confidential information or any information that would infringe upon the proprietary, privacy or personal rights of others. Do not post any information or other material that constitutes or could reasonably be construed as constituting advertising, marketing, solicitation of business, vending, attempting to sell or promote products or services, or otherwise engaging in or attempting to consummate commercial or professional transactions.

By posting material, the posting party warrants and represents that it owns the copyright with respect to such material, has received permission from the copyright owner, and/or that the material is in the public domain. The posting party further warrants and represents that it otherwise has the full and unencumbered right to post such material and that such posting will not infringe any rights or interests of others. In addition, the posting party grants ISOQOL and users of this listserv a non-exclusive, perpetual, irrevocable license to display, copy, publish, distribute, transmit, print, and use such information or material in any manner, without payment to the posting party.

This listserv shall not be utilized in any manner that violates federal or state antitrust laws or other laws prohibiting anticompetitive practices. The antitrust laws generally prohibit any agreement or understanding inconsistent with the right and obligation of competitors to exercise independent business judgment in pricing their products or services, dealing with their customers and suppliers, and selecting the markets in which to compete, among other business practices. No express agreement or understanding is required; one can be inferred from statements or conduct. Do not post any information regarding specific prices or fees charged or paid, and do not post any information concerning prices, pricing practices, discounts, or other terms or conditions of sale either obtained by or offered to another entity. Do not post any information concerning market shares, salaries, costs, sales territories, profit margins, or encouraging the selection or rejection of customers or suppliers.

All postings shall be of an informational nature and for informational purposes only. Commercial use or any other unauthorized use of this listserv is prohibited. Do not use the listserv to solicit or conduct business, including the direct or indirect marketing of users' products or services, in any manner. The listserv may not be used to provide information, materials, products, or services in exchange for compensation of any kind.

ISOQOL does not generally monitor this listserv for inappropriate postings, and does not on its own undertake editorial control of postings. However, in the event that any inappropriate posting or unauthorized use of the listserv is brought to ISOQOL's attention, including but not limited to prohibited posting and usage as outlined herein, ISOQOL will take all appropriate action, in its sole discretion. ISOQOL reserves the right to terminate, without prior notice, the listserv access of any user who does not abide by these guidelines, and/or to take other disciplinary action against violators.

Media Interactions

It is essential that the ISOQOL respond to media inquiries in a way that is clear, concise, accurate and timely to help ensure the media reports accurate information while respecting and protecting the privacy and personal information of ISOQOL associates. Interactions with external media outlets on behalf of ISOQOL are overseen and coordinated by the ISOQOL office. ISOQOL is committed to the principles of free speech, and nothing in this Policy is intended to restrict the freedom of ISOQOL members or staff to engage in their scholarly activities or their personal involvement in community activities, express personal opinions on University or non-University actions and policies, or otherwise engage in free expression.

Spokespersons

Only ISOQOL President or a designated spokesperson may make statements on behalf of ISOQOL. No ISOQOL representative may make official or “off the record” statements on behalf of ISOQOL without consultation with, and express authorization from the ISOQOL Executive Committee or Board.

Any inquiries from media representatives received by ISOQOL members requesting information or comment from them as to ISOQOL’s statement or position regarding a matter must be directed to the ISOQOL office, who will, depending on the circumstance:

- Follow up with the reporter to determine topic(s) being covered and information being sought
- Advise spokespersons about the matter prior to coordinating a response
- Coordinate and provide a response on behalf of the ISOQOL

News/Press Releases

All press releases to promote the ISOQOL mission and initiatives to media outlets should be written by the ISOQOL staff in consultation with ISOQOL leadership as appropriate.

Partnership News Releases that Mention ISOQOL

In the case where ISOQOL is working in partnership with an external entity on an event, program or initiative for which the other entity is issuing a press release, the ISOQOL office must be informed with seven business days’ notice prior to its intended issuance date to provide an opportunity for leadership and/or ISOQOL staff to review a draft of the release and related plan for distribution.

Public Records and Open Meetings

Nothing in this policy is meant to restrict in any way ISOQOL’s timely compliance with laws regarding access to public records or open meetings.

Subject Matter Expertise and Personal Expression

ISOQOL staff and members may choose to speak with representatives of the media to express their personal position or opinion, but they do not have to do so. If they do so, they must clarify and distinguish that it is a personal opinion when doing so and not offer it by virtue of their position at ISOQOL.

As a courtesy, members and staff are strongly encouraged to inform the ISOQOL office when they have been contacted by or spoken with a media representative, but are not under any obligation to do so. ISOQOL facilitates accurate, ethical and timely news coverage of significant programs and the achievements of its members and can help prepare members for an interview.

When members are contacted for their scholarly or professional expertise, they should make it clear to media representatives that they are not speaking on behalf of ISOQOL. Discussion of articles and plain English summaries

published in one of ISOQOL's official journals falls under this section of subject matter expertise and personal expression unless otherwise directed by the ISOQOL Executive Committee or Board of Directors.

If asked to represent ISOQOL by a media representative, members should follow the procedure outlined in the next section of this policy.

Declining Media Interactions

In instances where you are asked to speak to media on behalf of ISOQOL when you are not designated to do so, regarding confidential material, or when you are otherwise uncomfortable speaking to the media, use the following guidelines:

- a. Decline requests for an interview or a statement. Do not, under any circumstance, say "no comment."
An acceptable response is:

"I'm sorry, I cannot speak with you at this time, but if you let me know what information you are looking for, I will have the appropriate person respond to you."
- b. Ask the media or other inquiring individuals the following questions:
 - *Can I get your name and the organization you are with?*
 - *What information are you seeking?*
 - *What is your e-mail address and telephone number where you can be reached?*
 - *What is your deadline for receiving this information?*
- c. End the conversation by saying "I will pass your message along to the appropriate people and someone will get back to you. Thank you."
- d. Report the inquiry to ISOQOL Staff or the Executive Director. Provide the topic, who contacted you, and the outcome of the inquiry so that it can be recorded in ISOQOL's Media Inquiry Log.

Meeting Minute Distribution

Accurate minutes will be kept for all official meetings. Minutes will include place, date, time and participants at the meeting. Minutes will also include a record of what was considered and accomplished at the meetings.

Staff will distribute to presiding volunteer for approval prior to distribution to the full body of participants.

Minutes will be distributed within a four week period for approval and review of the full body of participants. Distribution may be electronic according to the governing documents or at the next meeting of the committee if within six weeks of the event. A "file" copy will be housed at the headquarters office and an electronic file will be kept on the ISOQOL G-drive housed at the headquarters office.

Membership

Membership in ISOQOL is open to all those throughout the world who subscribe to the purposes of the Society and who have an active interest in research, education, and the application and use of quality of life measures. Individuals who make application for membership and pay the annual dues may be designated members in good standing and shall be entitled to all privileges of membership and may vote, serve on committees, and hold office.

Membership Categories

Honorary Members: The Board may offer Honorary Membership status with all the privileges afforded that status to a member who has made an extraordinary contribution to the field of Quality of Life research.

Regular Members: Regular members are professionals, patient partners and individuals in the field of health-related quality of life and patient-centered outcomes interested in supporting the purposes of the Society. Members in good standing shall be entitled to all privileges of membership and may vote, serve on committees, and hold office.

Patient Research Partners: Patient Research Partners (PRP) are persons who self-identify as a patient, subscribe to the purposes of the Society, have an active interest in research, education, and/or the application and use of quality of life measures and support the patient voice in quality of life and patient-reported outcomes research. PRPs bring forward their experiential knowledge to ensure that the patient's voice is heard. There are two member types available to the PRP.

1. **Regular Patient Research Partners (RPRP):** Regular Patient Research Partner members are professionals, patient partners and individuals in the field of health-related quality of life and patient-centered outcomes interested in supporting the purposes of the Society. Members in good standing shall be entitled to all privileges of membership and may vote, serve on committees, and hold office.
2. **Affiliate Patient Research Partners (APRP):** Affiliate Patient Research Partners (APRPs) are entitled to limited membership benefits including membership to Committees, Task Forces and Special Interest Groups but would not have the privilege of voting, elected leadership positions or holding a board seat. APRPs can purchase a subscription to ISOQOL's Quality of Life Research (QLR) Journal. APRP may be eligible for lower dues.

Retired Members: Retired membership is reserved for a professional or member that has retired and is no longer practicing in the field of health-related quality of life and other patient-centered outcomes. This member type retains all benefits and is eligible for lower dues.

Special Members: Special membership is available to individuals eligible for regular membership who reside in a developing nation or have an annual income less than \$15,000. This member type retains all benefits and is eligible for lower dues.

Student Members: Student/Trainee membership is reserved for those who are enrolled in a full-time, accredited training program in a relevant field or in a pre/post-doc, resident or fellowship program. This member type retains all benefits and is eligible for lower dues.

- Student/Trainee members must provide education information and dates on their new member applications or renewing member forms
- Student/Trainee members must submit proof of status

The Board of Directors may establish such other membership categories as it deems appropriate, shall establish the benefits of membership and dues for each category, and may grant waivers for admission to membership categories as well as waivers for dues payments as it deems necessary.

Membership Dues

1. The Board of Directors may impose dues on membership in any class of membership to the extent consistent with their Bylaws in such amounts as shall be determined by the Board of Directors from time to time. The payment of dues as a condition of any class of membership may be waived or postponed at the discretion of the Board of Directors.

Resignations, Termination and Discipline:

1. Unless excused by the Executive Committee in writing for just cause, members of any class required to pay membership dues may be terminated for failure to make payment of dues in accordance with such procedures as the Board of Directors may establish from time to time.
2. Charges of unprofessional or unethical conduct may be brought against any member of the Society by written complaint signed by a member of the Society and delivered to the Secretary. The Executive Committee will investigate said complaints and decide on the necessary actions. The rules governing disciplinary proceedings based upon such charges shall be as established from time to time by the Executive Committee.
3. Resignations are at will.

Press Attendance at ISOQOL Educational Programs

To gain access to ISOQOL educational programs open to the public, journalists and medical/science writers must register and provide the information below, as well as abide by the policies of ISOQOL as noted below. The registration fee for working press representatives is waived.

ISOQOL Policies:

Media Registration/Press Pass

Members of the press representing print, broadcast, internet media, and medical or healthcare publications are invited to attend the ISOQOL events.

To register as a member of the press, journalists must provide media identification (press card), a business card, or a letter of assignment. The business card must be issued by their news organization clearly show media affiliation and position. A letter on official letterhead from an editor of a recognized publication or a producer of a broadcast program certifying that the individual is covering the conference for the respective organization.

Freelance writers must provide a letter of assignment on a news organization letterhead or bylined articles from a recognized news organization. Press passes will only be issued to journalists representing the editorial staff of print, broadcast or internet media.

ISOQOL does not issue press passes to exhibitors and representatives of industry, marketing, advertising or public relations firms and sales representatives.

Due to space limitations, ISOQOL reserves the right to restrict the number of press badges issued to a single news organization.

All members of the press must register in advance either through the ISOQOL website or by contacting the ISOQOL Office at info@isoqol.org.

Press passes allow journalists access to the ISOQOL events including oral and poster sessions, plenary sessions, and symposium sessions. Journalists may not attend ticketed events without purchasing tickets. Journalists may attend ticketed sessions as space is available. Tickets can be purchased onsite at the conference.

Members of the press are responsible for providing their own meals and accommodations throughout the ISOQOL events. The press pass does not include conference meals.

Journalists must display their press passes at all times while attending the conference.

Any press pass holder who sells or markets a company or organization to a meeting registrant will have their ISOQOL Annual Conference access revoked.

Embargoes

All materials are embargoed according to the following:

- All releases issued by ISOQOL ahead of the ISOQOL event are embargoed until the date stated in the release.
- Abstracts accepted for presentation are published within a supplement to ISOQOL's journal, *Quality of Life Research Journal (QLR)* or *Journal of Patient-Reported Outcomes (JPRO)*. As a general rule, coverage of a conference abstract or poster is strictly prohibited until the researcher's presentation.

Audio Recording, Video Recording and Photography

Video, audio recording, and photography are not allowed in educational sessions. However, press is permitted to use handheld audio recording devices for note taking purposes only. Members of the press who wish to film, record or photograph at the conference must receive advance permission from ISOQOL staff.

Exhibitors/Public Relations Professionals

Exhibitors and individuals representing academic institutions, industry, advertising, marketing or public relations firms:

- Press releases and media alerts must be reviewed and approved in advance by ISOQOL staff. Drafts should be emailed to the ISOQOL Office at info@isoqol.org. Press releases and media alerts must be embargoed for release until the time of presentation at the conference.
- Press releases, media alerts and related materials may not indicate ISOQOL endorsement or use the ISOQOL logo.
- Non-ISOQOL news briefings or other media events are prohibited in meeting areas during the ISOQOL Annual Conference.
- Under no conditions will lists of past or current registered press be made available.

Individuals, companies, organizations or institutions found in violation of these policies will have their ISOQOL conference access revoked. Additional sanctions may apply.

Privacy Statement for Members Records

Membership records shall be retained by the Society. These records are confidential files and will not be open to the public unless permission is granted by the member. The records will be kept in file cabinets in the ISOQOL designated office space in the headquarters office and/or kept electronically in the membership database, iMIS.

Public Records Request

If anyone requests a copy of the organization's Form 990 Federal Information Return, the President and Treasurer shall be notified. All such requests should be in writing and accompanied by a \$20 reproduction and handling charge. The IRS requires that the last three years of federal tax returns, the IRS letter of determination, and the IRS application for tax exempt status be made available to any person making the request. Members of the Board of Directors receiving an inquiry must advise staff of the request on the same day the inquiry is received.

Publication Authorship & Endorsement

The International Society for Quality of Life Research (ISOQOL) relies upon its diverse, well-networked and engaged membership to build and sustain its reputation as a leader in integrating health-related quality of life into research, care and policy. This document is intended to provide guidance regarding ISOQOL's policy on the publication of papers arising through the activities of and on behalf of an ISOQOL working group, task force, committee, or special interest group (SIG). In these circumstances, it is appropriate to acknowledge ISOQOL's role in the process of creating a publication, and to seek ISOQOL's endorsement for a publication.

This policy extends to, but is not limited to, papers that may serve as a review of the literature, best practices, or state-of-the-science, a strategic plan for future research in health-related quality of life (HRQL), ISOQOL's response to a specific health policy or practice, or serve as official policy of ISOQOL as it relates to defining, measuring, or applying HRQL in research and practice.

Several principles should underlie these publications:

1. The content is relevant and consistent with ISOQOL's mission.
2. The authorship process has been inclusive at both the planning, writing and review stages to incorporate the perspectives and experiences of ISOQOL members.
3. Any conflict of interest in the content or the authorship is fully disclosed.

ISOQOL encourages its members to collaborate on publications, and to submit their publications to the official journals of the Society. It does not require that all authors be members of ISOQOL or restrict where such papers can be published. The policy also includes papers produced in response to scientific and lay publications, reports, media releases, guidance statements, and other materials that relate to the broad field of quality of life research where such a response *is not* deemed 'urgent' by the Executive Committee of ISOQOL. For example, a media release may require an 'urgent' response but an article may not. When such a response is deemed 'urgent', the procedure for publication should follow ISOQOL's Rapid Response policy.

Recommended Steps:

1. **Concept Proposal and Review:** Prior to beginning a paper on behalf of ISOQOL (SIG, Committee, Working Group, or Task Force), an abstract/concept should be submitted to the ISOQOL Executive Committee (EC) via the Executive Director. The proposal should include the target journal with alternatives; proposed procedures for inclusiveness or explanation why not appropriate; and proposed authorship. The EC at this point may decide, depending on the type of publication, level of ISOQOL involvement and desired authorship, to review and approve the concept proposal or to forward the proposal to the full Board for review and approval. Note that if the need for a response is deemed urgent, the process will proceed under ISOQOL's Rapid Response policy. Receiving approval for the concept of the paper avoids overlap and increases the likelihood of approval of the final paper. The ISOQOL EC or Board will have 3 weeks¹ to return an approval. Approval by at least 51% of the EC or Board is required.
2. **Writing the paper:** For papers initiated by ISOQOL SIGs and committees, all members of the group should be given an opportunity to participate in the writing process. For a paper initiated by a working group or task force, this might include an open invitation to the entire ISOQOL membership or a relevant SIG to be involved in the writing process. Members should be given two weeks to indicate an interest in participation. It is acceptable to limit the number of individuals in a writing group for pragmatic reasons, but deliberate and intentional actions should be taken to form a diverse writing group that includes at least one or more new investigators and global perspectives.
3. **Publication Review:** After the manuscript has been approved by the writing committee and sponsoring group (e.g. SIG or committee), the corresponding author should submit the final draft manuscript ready to be submitted for publication to the Executive Committee via the Executive Director indicating whether they are seeking review/approval from the Board of Directors (part a below) or the entire membership (part b below).

¹ This allows approximately 1 week for the EC, 10 days for the board and 4 days for administrative flow.

- a. Approval by Board of Directors (Disclaimer that the paper does not reflect the views of the entire ISOQOL membership): For all papers published on behalf of ISOQOL, the full Board of Directors will have an opportunity to review the paper and have editorial authority over the paper. The Board will respond to the first author on the paper within 3 weeks of submission to the Board.² Approval by at least 2/3 of the Board is required. If the Board of Directors does not approve the paper, the author(s) may revise the paper accordingly, or withdraw ISOQOL's association with the paper prior to publication. If ISOQOL resources have been utilized to develop the paper (financial or staff), the paper must be revised to meet the Board of Directors' approval.
 - b. Review by full ISOQOL Membership: For papers requiring review by the entire membership, the manuscript will be posted on the ISOQOL website and the full membership will be invited to comment on the paper. Members will be given a month to post comments. The comments from ISOQOL members and the response by the writing committee will be reviewed by three members of the ISOQOL Board of Directors (or a designated editor from QOLR or JPRO if that is the target journal) to confirm that appropriate suggestions have been incorporated or dissenting opinions are acknowledged. The Board will make final approval of the manuscript per section 3a above.
4. Conflict of Interest by reviewers: Board members involved as authors on the paper must recuse themselves from commenting or voting on the matter. If this reduces that voting group (e.g. EC or entire board) to less than a quorum, the voting body will be supplemented from the Council of Past Presidents.

Authorship:

Alternate forms of authorship might be considered. The preferred format, especially for policy statements and reports from large committees, would first list the named ISOQOL working group, committee or SIG followed by members of the writing committee, as in: "ISOQOL Translation Special Interest Group, John Doe (chair), Jane Aardvark, ...". In the alternative format, the authors of the writing group are followed by the named ISOQOL working group, committee or SIG, for example, "Jane Doe and Richard Roe on behalf of the ISOQOL Psychometrics Special Interest Group." The alternative format should include justification of why the preferred format is infeasible (e.g. journal policy) or why the alternative is more appropriate. Included in the considerations of the two alternatives should be issues of conflict of interest, specifically recognizing that authorship is a benefit. Authorship plans should be documented in advance using the usual standards that recognize the level of involvement. An appendix may list all group members.

Acknowledgement/Disclaimer:

Any paper written on "behalf of ISOQOL" needs to be reviewed and approved by the ISOQOL Board of Directors. If the ISOQOL membership has been given an opportunity to review and comment on the manuscript, after ISOQOL Board approval, the authors should acknowledge, "This paper was reviewed by membership of the International Society for Quality of Life Research (ISOQOL) and is endorsed by the ISOQOL Board of Directors.

If the ISOQOL membership does not review and comment on the manuscript, then after ISOQOL Board approval, please acknowledge, "This paper was reviewed and endorsed by the International Society for Quality of Life Research (ISOQOL) Board of Directors as an ISOQOL publication. It does not reflect an endorsement of the ISOQOL membership.

Note: additional disclaimer language can be added to the endorsement statement by the Executive Committee or Board at their discretion.

² Authors should plan on 3 weeks for the initial review and additional time to respond to any critique.

Type of Publication	Required Actions	Optional Actions
Paper attributed to the whole society ('on behalf of ISOQOL')	<ul style="list-style-type: none"> - Plan for inclusiveness - Proposal review and approval by the Board. - Manuscript review and comments by Membership - Manuscript review and approval by Board 	
Paper representing work of SIG, working group or task force.(i.e., on behalf of that group/committee)	<ul style="list-style-type: none"> - Plan for inclusiveness - Proposal review and approval by the Board. - Manuscript review and approval by board 	- Manuscript review and comments by membership
Paper representing personal observations on ISOQOL activity (e.g. meeting summary by chairs)	- Paper review and approval by EC	<ul style="list-style-type: none"> - Paper review and approval by board - Paper review and comments by membership
Publications not involving any organized ISOQOL group (e.g. SIGs, working groups, task forces) nor representing ISOQOL in authorship or endorsement.	- None	

Rapid Response

Rapid Response

There is a need for an ISOQOL policy and concomitant procedures for responding in a timely manner to scientific and lay publications, reports, media releases, guidance statements, and other materials that relate to the broad field of quality of life research. This could be in the form of a statement published on our website, a media release, an editorial in our journal, a position paper, a support letter, and/or an interview that reflects the ISOQOL position on the topic or topics of interest.

Given the diversity of perspectives and opinions within the ISOQOL membership, it would be difficult, if not impossible, to generate a statement or to take a position that would receive support from the full membership. Nevertheless, it is important that ISOQOL have a voice in public debate and dialogue about issues related to its mission to advance the science of health-related quality of life (HRQL) research. The challenge of coming up with such a response that enjoys legitimacy (i.e., explicit or implicit endorsement of the membership) is difficult enough, but is even more challenging when there is a need for a rapid response.

In principle, as elected bodies, the ISOQOL Executive Committee and Board (should) have the ability to express ISOQOL's position on any given issue. At the same time, the larger membership should have the opportunity, whenever possible, to provide feedback and help to shape any scientific or policy position.

1. Any matters identified by the Executive Committee, the Board, Advisory Council of Past Presidents, Committees, SIGs, or by members of the Society at-large as possibly requiring a formal ISOQOL response should be brought to the attention of the Executive Committee in writing.
2. The Executive Committee makes an initial evaluation of the relevance of the matter to the ISOQOL mission, the necessity/desirability for a formal ISOQOL response, and the urgency involved. The EC may seek input from the Board, Advisory Council of Past Presidents, Quality of Life Research journal editors, or individual ISOQOL members in regard to these issues and who (individual or group) may be in best position to provide the ISOQOL response. The EC will then vote (majority rule*) if ISOQOL should respond and in what manner given the urgency of the response.
3. Following a positive vote, the ISOQOL EC will then write to the nominated individual(s) to request they prepare a "response" (e.g., media release, written commentary, scientific paper, interview, support letter, etc.) on behalf of ISOQOL.
4. When the ISOQOL "response" is prepared to the satisfaction of the assigned individual(s), the "response" will need to be reviewed by at least one of the following ISOQOL representative bodies:
 - a. the ISOQOL EC;
 - b. the ISOQOL Board;
 - c. the ISOQOL membership-at-large

In the ideal setting with enough time, all 3 bodies will have an opportunity to respond with comments and to review revised "responses". However, the urgency of the request may require one or more review bodies to be skipped. At the minimum, the ISOQOL EC must review the response. It is the discretion of the ISOQOL EC which bodies are included in the formal review process with the understanding it is desirable to have the larger bodies involved whenever possible.

5. When the ISOQOL "response" has been reviewed, the "response" will need to be approved (majority vote) by either the ISOQOL EC or the ISOQOL Board. It is expected that the ISOQOL Board should vote on the "response", but the urgency of the request may allow only an ISOQOL EC vote*. It is the discretion of the ISOQOL EC which bodies are included in the approval process.
6. Once approved at the ISOQOL EC level, the "response" will be considered as representing the ISOQOL position on the topic or topics of interest.

Note: *When an ISOQOL EC member is in conflict, a representative from the ISOQOL Advisory Council of Past Presidents will be asked to vote in place of the EC member in conflict. Again, it is not feasible to generate/publish an ISOQOL statement/position that reflects the perspective of the entire membership. There will always be dissenting opinions. Nevertheless, the Executive Committee and the Board have the responsibility of representing the Society in public forums, and to do so in a way that does justice to the diversity of views and opinions within its membership. At the same time, too many caveats can seriously weaken the impact of any statement made or position taken. This will require good judgment on the part of the Executive Committee, and should be the subject of periodic review.

<p style="text-align: center;">Record Retention (Policy for Document and Records Maintained by EDI)</p>

After One Year

Personnel employment applications (in EDI HR Department)
Routine correspondence of unimportant nature with members, customers or vendors

After Three Years

Employee personnel records after termination (exceptions: pension, retirement plan – in EDI HR Dept.)

After Seven Years

Accident reports and claims (settled cases, in EDI HR Department)
Accounts payable and receivable ledgers (in EDI Accounting Department)
Bank Reconciliations (in EDI Accounting Department)
Employee personnel records after termination (in EDI HR Department)
Employment tax reports (in EDI Accounting Department)
Expense reports (in EDI Accounting Department)
General journals (in EDI Accounting Department)
Inventory records (products, materials, supplies)
Payroll records and summaries, including payment to pensioners (in EDI HR Department)
Retirement Plan accounting records (to correspond with returns and reports – in EDI HR Dept.)
Subsidiary ledgers to the general ledger and trial balances (in EDI Accounting Department)

Permanent Records

Correspondence (legal and important matters only)

Confidential Documents

All confidential and sensitive documents will be shredded before discarding.

Registration Fee Refund

ISOQOL reserves the right to cancel any event due to lack of enrollment or other factors. In the event of a cancellation, registered participants will be notified by e-mail and will have the option to exchange their ticket for an available alternative, or to receive a complete refund.

All refund requests must be submitted in writing to the ISOQOL office for review. Each event will publish their refund policy in the materials and on the website. All refunds will be paid after the conclusion of the conference. Special considerations will be given for health or family emergencies if requested in writing no later than 15 days after the last day of the event.

Cancellation notices should be directed to the ISOQOL Executive Office at info@isoqol.org.

Reimbursement

General Reimbursement Policies/Limitations

ISOQOL requires original receipts for all reimbursements and reserves the right to withhold reimbursements without receipts. ISOQOL will not pay for early departure fees, upgrades, movie rental at hotel, long distance phone calls, meals for individuals other than Participants, transportation ticket change or cancellation fees, limousine service or rental car service. Any expenses other than what is listed or amounts greater than the approved budget must be pre-approved by ISOQOL Board of Directors and Executive Director prior to the meeting.

1. Annual Program Conference Faculty

Co-Chairs

- Complimentary Meeting Registration

Speakers - Members

- No compensation should be paid to members of the society for speaking at scientific meetings (either plenary or other presentations at the ISOQOL annual conference) with the exception of patient partners, students and special member types.

Speakers - (Non-Member)

(Reimbursement is presented to Executive Committee by Program Committee for approval)

- Compensation may be paid to plenary and other invited speakers, who are not members of the society with the recommendation of the Program Chair and approval by the Executive Committee. Compensation may include registration and expenses for travel and accommodation expenses that have been agreed in advance.
- Workshop presenters may be offered one night's lodging for up to two presenters (registration fee is not waived)

2. Meetings Outside of the Annual Conference – ISOQOL may develop additional educational meetings outside of the Annual Conference. These conferences are specific in nature and may enlist member participation and non-member invited speakers. Reimbursement for these events include:

Co-Chairs

- Complimentary Meeting Registration
- Up to two nights at conference hotel, room and tax at single room conference rate only

Speakers (Members)

- Complimentary Meeting Registration
- Up to two nights at conference hotel, room and tax at single room conference rate only

Speakers (Non-Member):

- Complimentary Meeting Registration
- Up to two nights at conference hotel, room and tax at single room conference rate only
- Reasonable travel expenses up to \$500 for domestic or up to \$1,500 for international travel

3. Educational Courses

Faculty

Compensation may be paid to two (2) faculty members presenting an ISOQOL educational course. Reimbursement for each faculty member includes:

- One night at the conference hotel, room and tax in single room only
- Honorarium of \$800
- Reasonable travel expenses up to \$500 for domestic or up to \$1,500 for international travel will be paid on regional & requested courses (not in conjunction with the Annual Conference)

4. Board of Directors

Spring Meeting

- Two nights' room and tax at single room conference rate only will be charged to the ISOQOL master account. All incidentals will be the responsibility of the member. The ISOQOL office will reserve your hotel room and forward your room confirmation via email after receiving your Travel Form.

- Air Travel (coach/economy) will be reimbursed for round trip. Airfare arrangements should be made on your own or through the ISOQOL Travel Agent.
- Ground Transportation costs if you are not using air transportation.
- For meal reimbursement, the meal must be during dates specifically related to the program. Original receipts are required.
- Other expenses directly related to the meeting - parking, tips, etc.

Fall Meeting - For attendance at the ISOQOL Board of Directors Fall Meeting held in conjunction with the ISOQOL Annual Conference:

- One night prior to the board meeting at the conference hotel, room and tax at single room conference rate. Note: only current board members are eligible.

NOTE: Reimbursement dollars are subject to change due to availability of funding or industry costs.

Research

ISOQOL is highly supportive of research activities led by Special Interest Group (SIG) and Taskforces that align with the societal strategic plan. This research policy covers any research conducted internally as an officially approved ISOQOL activity by ISOQOL members, for example member surveys, focus groups or member-initiated research projects. ISOQOL does not support *ad hoc* research undertaken at ISOQOL-sponsored activities as the society is concerned about the welfare and the rights of all individuals who participate at any sponsored activity and *ad hoc* research may not permit ISOQOL to adequately vet research with participants at these sponsored activities and ensure adequate protections of participants as research subjects.

Any research conducted by parties **external** to ISOQOL that requires ISOQOL resources (i.e. conducted during the ISOQOL annual meeting or another ISOQOL-sponsored meeting, or involving other ISOQOL resources, such as administrative support for external online surveys) is regulated by the corresponding policies, such as Endorsement policy (for endorsement of meetings or letters of support for research projects), Collaborations policy (for projects involving ISOQOL representation) or Communications policy (for intersociety collaborations).

Any human subject research, as defined by the World Medical Association Declaration of Helsinki (<http://www.wma.net/en/30publications/10policies/b3/>), which is undertaken with or by ISOQOL members must adhere to the following principles:

1. Voluntary participation by the subjects must be assured, indicated by free and informed consent;
2. An appropriate balance exists between the potential benefits of the research to the individual and/or the ISOQOL and the risks assumed by the individual;
3. Fair procedures and outcomes in the selection of the research individuals;
4. The proposed work must be reviewed and approved by an appropriate ethical committee prior to the event (e.g., an institution ethics or internal review board). Note: ISOQOL encourages the joint partnership between investigators not affiliated with institutions that conduct human subjects' research and academic members affiliated with universities or other research organizations to facilitate ethical review and approval from recognized regulatory organizations.
5. The participants must be advised that the primary purpose of the event is to conduct research. As part of the consent process the researchers must describe the goals of the research, methods, materials to be collected, the planned use/storage of the data and how participants will be acknowledged for their contribution. Any fees that may be charged to participants attending the event or alternatively that may be paid to the participants must be clearly stated.
6. The investigators undertaking the research activity retain responsibility for maintaining all research materials for a period of no less than seven years.
7. If publication of results is anticipated, please see the [ISOQOL Policy Manual - Authorship of ISOQOL Publications](#). Research participants should be advised of the publication policy at the time of consent.

Application for ISOQOL approval

The following steps are required to obtain ISOQOL approval for any internal research project. Investigators are strongly encouraged to contact ISOQOL management staff early in the planning phase of any project to ensure compliance with policies.

1. The [CONCEPT PROPOSAL APPLICATION](#) (located on the ISOQOL Members Only webpage) must be completed.
2. If involving human subjects, the proposed work must be reviewed and approved by an appropriate independent ethics committee (e.g., a university, hospital or private institutional review board). Please submit a one page summary of the project and the letter of ethics committee approval (or letter of exemption where appropriate). In some cases (where ISOQOL members may be directly engaged as research participants) it may be appropriate to include the informed consent form as part of the application. ISOQOL reserves the right to request additional documentation.
3. Complete documentation must be submitted to the ISOQOL at least 30 days prior to the event.

Qualifications

ISOQOL will use the following guidelines when considering a research project.

7. ISOQOL will only approve research applications that are in keeping with its mission and principles. The Executive Committee (EC) leadership will evaluate the relevance of the matter to the ISOQOL mission, and may seek input from the Board or other ISOQOL members with relevant expertise. The EC will then vote (majority rule*) if ISOQOL should respond and in what manner, taking into account the urgency of the response.
8. ISOQOL will not endorse programs that are for-profit entities.
9. You must be an active ISOQOL member to apply for research projects covered by this policy.

Agreement

The applicants agree to:

4. Credit the International Society for Quality of Life Research for its support of the project.
5. If relevant (for projects of longer duration) provide the Executive Director with a summary report on an annual basis.
6. Submit a final brief summary report stating what the key conclusions are and include any publications resulting from the project. ISOQOL reserves the right to request additional documentation.

Reserves

Every attempt will be made through sound fiduciary controls, to ensure that ISOQOL's yearly revenues equal or surpass yearly expenditures in operating budgets approved by the Board of Directors. The surplus funds are to be used to provide contingency funds, fund capital improvement projects and/or to develop new programs.

It is the goal of the Board of Directors to maintain a reserve equal to or greater than 50% of the current year's operating expense budget displayed in the Financial Statement on the Summary of Activities. The reserve is defined as equivalent to the Net Assets displayed in the Financial Statement on the Balance Sheet.

Social Media

ISOQOL uses social media to build relationships with the health care field, the media and the public as part of our efforts to fulfill the society's mission. The use of social media enables dialogue with various audiences about health care issues and trends as they affect health-related quality of life (HRQL) and related patient-centered outcomes (PCO) research.

Because ISOQOL's use of social media is closely tied to its mission, it is critical that ISOQOL's use of social media properly reflects the association's views and positions. Therefore, ISOQOL staff will be the sole responsible party for using social media on behalf of the association, but may also for a general or for a specific purpose or time period specifically designate, appoint, authorize and/or otherwise approve, as appropriate, members of leadership to serve non-admin roles on specific social media platforms (for example, SIG leaders could be appointed as managers on an ISOQOL LinkedIn subgroup under the official ISOQOL LinkedIn account).

All ISOQOL members are encouraged to call to the attention of ISOQOL staff and/or leadership any issues, concerns or problems that might interfere with the association's responsible use of social media. Bringing the issue to the attention of the association immediately will enable ISOQOL to work toward an appropriate and timely resolution of the issue, concern or problem.

Social Media is about Civil Discourse

- ISOQOL accepts responsibility for the content it posts on its social media sites and will not impersonate, mislead or purposely obscure the association's identity when using social media. Social media is about enhancing the association's credibility and reputation. ISOQOL also expects participants in dialogue on our social media sites to refrain from impersonating, misleading or purposely obscuring their identities.
- ISOQOL protects its own intellectual property and respects the intellectual property of others. We will not intentionally use copyrighted material without permission or use others' company or business name, logo or other trademark-protected materials in a manner that may mislead or confuse others with regard to the company's brand or business affiliation. ISOQOL also expects that participants in dialogue on our social media sites to display the same respect for the intellectual property of ISOQOL and others. We will respond to clear and complete notices of alleged copyright or trademark infringement.
- ISOQOL accepts differences and differing opinions about health care issues affecting the field of HRQL and related PCO research. We strive to maintain a courteous, polite and professional dialogue about these issues even when we might disagree with opinions expressed by others. ISOQOL expects that participants in dialogue on the association's social media sites will also accept differences and differing opinions by responding in a respectful way when they disagree or have a difference of opinion.
- ISOQOL does not use social media to bully, intimidate or threaten others and we expect participants in dialogues on the association's social media sites to refrain from bullying, intimidation and threatening harm or violence to anyone, including threats directed to the association or any of its staff.
- ISOQOL does not use social media to defame the reputation of others and we will not tolerate the use of the association's social media sites by any dialogue participants in order to defame the reputation of the association, any individuals or groups of individuals, or any organization or business entity.
- ISOQOL does not publish or post profanity or obscene or pornographic communication on its social media sites. We do not tolerate the use of profanity or posting obscene or pornographic images by any participants in the dialogue on the association's social media sites, whether in a user profile or background or in a response, comment, or message posting or response.
- ISOQOL intends that social media serve as an effective communications tool for the association and will refrain from spamming and other abusive uses of the social media technology/capability. We expect that participants in dialogue on the association's social media sites will properly use the technology/capabilities as an effective communications tool and will not engage in spam or other misuse of communications technologies/capabilities.

ISOQOL will take appropriate steps to ensure that dialogue on the association's social media sites conform to the behavioral standards outlined above. Such steps may include blocking any user and ending any communication with the blocked user or involving proper law enforcement authorities, including when the association feels that an actual violent threats have been made.

Special Interest Group (SIG)

SIGs are specialized communities within ISOQOL based on shared interests in advancing health-related quality of life (HRQL) for specific populations (i.e., patients, children, etc.), geographic demographics (developing nations, United Kingdom, etc.) and fields of science (statistics, psychometrics, etc.), as well as your career (new investigators, clinical practice, etc.). These communities facilitate opportunities for members to network and collaborate, as well as to influence the work of the society through project proposals.

Membership

Any current member of ISOQOL may elect to become a member of a SIG with no limit to the number of SIGs they can join.

In the event that a current ISOQOL member wishes to become a member of a SIG prior to the annual renewal of his/her ISOQOL membership, he/she may do so by updating his/her online ISOQOL member profile.

Membership is automatically renewed on an annual basis so long as ISOQOL membership is current and the SIG member has not opted to withdraw from the SIG.

- A SIG Initiative application will be forwarded to the ISOQOL Office for review. **All initiatives must be approved by the ISOQOL Executive Committee. In each instance, the SIG may not enter into any formal agreement or contract with any outside individual or organization using the name of ISOQOL without the express written permission of the ISOQOL Executive Committee.** For all approved activities, the ISOQOL Office can assist with administration, including serving as the sponsoring organization for grant proposals. All contract negotiations will be managed by the ISOQOL Office. Workshops and projects must be included in the annual budget provided to the ISOQOL Board (see "Financials"). SIG Initiative applications are reviewed and a response is forwarded to the SIG Chair within a 30-day period.

SIG Leadership

SIG Governance

There are two governance structures available to the SIG.

1. Chair, Chair-Elect/Immediate Past-Chair
The Chair-Elect position will be for a one-year term. Upon completion of their term, the Chair-Elect will then serve a two-year term as Chair, followed by a one-year term as Immediate Past-Chair. The leadership team will, at any one time, have either a Chair-Elect or Immediate Past-Chair.
2. Co-Chairs
If there are two (2) Chairs, the terms will be staggered such that one Chair is in their first year while the second Chair is in their second year.

SIGs may also choose to add a Secretary-Treasurer position. This position would follow the election process with a term of three years.

Any SIG leadership vacancies that occur between elections shall be filled by appointment of the remaining SIG leadership. Any individual so appointed shall serve for the remainder of the replaced officer's term.

Officer Responsibilities

SIG leaders are responsible for leading and overseeing the activities of their SIG in accordance with procedures outlined during the SIG Leader Orientation Program and ISOQOL policies.

These responsibilities include, but are not limited to:

- Coordinating with the ISOQOL Office and Board Liaison as needed
- Executing the decisions and recommendations of the SIG
- Facilitating SIG conference calls
- Overseeing all SIG projects and ensuring project proposals are submitted to Leadership for approval in a timely manner
- Organizing or designating leadership for SIG activities (e.g., submission of symposium for annual meeting, writing newsletter articles)
- Developing project budgets, if applicable

- Designating someone to record meeting and teleconference minutes
- Providing a formal report to the ISOQOL Board of Directors' spring meeting using the standard SIG report template supplied by the ISOQOL Office.
- Other duties as outlined in the ISOQOL SIG Orientation Documents

Elections and Officer Terms

SIGs will hold elections for SIG Chairs every year or every other year depending on the number of SIG Chairs. Chairs may not succeed themselves and are limited to two terms within a SIG.

1. Chair, Chair-Elect/Immediate Past-Chair
In this structure, the election will occur every other year electing a Chair-Elect (prior to the start of the second year term of the Chair);
2. If there are two Co-Chairs, the terms will be staggered such that one Chair is in their first year while the second Chair is in their second year, and the SIG will hold elections every year for the new Co-Chair.

If the SIG includes a Secretary-Treasurer position, this position would be elected every three years. The Secretary-Treasurer is limited to one term within a SIG. This does not count towards the two term Chair limit.

Candidates for SIG leadership positions can self-nominate. The election process will open on or before April 1 and end May 15 or the next business day. Election information including candidates' names, institutions, and bios are due to the ISOQOL Office no later than March 15. All candidates for SIG Officers must be current members of that SIG and ISOQOL before the April 1 deadline. Any SIG wishing to conduct their election at the ISOQOL Annual Meeting will be responsible for notifying the ISOQOL Office of this event no later than March 15, and will notify the ISOQOL Office of the result of the election immediately following the conclusion of the Annual Conference. Only current SIG members who have paid their ISOQOL dues are eligible to vote in the election.

In the event that a SIG is of such a size and function that only one candidate is willing to serve if elected for a given SIG Officer position, the election will proceed as uncontested, and the candidate will be considered as having been elected to the office if he/she receives the majority of the votes cast by SIG members in an election that allows for a choice between the nominee and a "vote withheld" category.

Elections will be held electronically and administered by the ISOQOL Office. Paper ballots will not be distributed by the ISOQOL Office.

All terms of office begin at the end of the ISOQOL Annual Conference.

Financials

The ISOQOL Board of Directors is the sole fiduciary for all ISOQOL funds. Limited funds are included in the ISOQOL operating budget to support routine SIG activities (e.g., conference calls, webpage updates, etc.). While ISOQOL encourages SIGs to undertake projects beyond routine activities, funding for such activities will need to be identified beyond the ISOQOL operating budget. The ISOQOL Office can assist SIGs in applying for grants via ISOQOL. Activities requiring funding beyond the standard budget should be submitted by October 1 to be reviewed by the Board during their Annual Budget Meeting.

SIG Operating Policy Addenda and Bylaws – Optional for SIG

The ISOQOL SIG Operating Policies presented in this document are to be considered the main principles and policies by which all SIGs operate. For some SIGs this document will be the sole set of principles and policies that guide the operation of a SIG. However, when it fosters the achievement of a SIG's mission, a SIG may elect to addend operating procedures or policies to the core ISOQOL SIG Operating Policies so long as they do not alter or substitute for the policies delineated in this document. Such addenda will be reviewed and are subject to approval by the ISOQOL Board of Directors. From the standpoint of any SIG's interactions with the ISOQOL Board of Directors and the ISOQOL Office, it is only the policies in the current ISOQOL SIG Operating Policies document that will be formally recognized as governing the operation of a SIG, and any policy addenda by SIGs will be viewed as strictly internal to the operation of the SIGs.

The ISOQOL SIG Operating Policies, together with any SIG-specific policy addenda appended to the ISOQOL SIG Operating Policies, will constitute the full set of operating principles governing the operation of a SIG. SIGs will not maintain, nor have any need for, a separate By Laws document.

SIG Operating Policy Amendments – Optional for SIG

Suggested amendments to the ISOQOL SIG Operating Policies can be initiated by the leadership of any SIG by communicating suggestions to the ISOQOL Executive Director. All suggestions will be accorded due consideration by the ISOQOL Board of Directors, and a decision to amend the Operating Policies will depend on the ISOQOL Board of Directors' assessment of the collective benefit of the amendment to all SIGs of the ISOQOL.

The ISOQOL Board of Directors can initiate consideration of amendments to the Operating Policies based on its perception of benefit to the SIGs of the ISOQOL. A decision to amend or not will be made by the Board only after SIG leadership has been fully consulted regarding the impacts that any policy change would have on the operation of SIGs, and only after the advice of the SIG leadership has been given due consideration.

SIG Project Proposals

All initiatives must be approved by ISOQOL Leadership via the project proposal form (this process is outlined in the SIG Leadership Orientation documents). In each instance, the SIG may not enter into any formal agreement or contract with any outside individual or organization using the name of ISOQOL without the express written permission of ISOQOL Leadership. For all approved activities, the ISOQOL Office can assist with administration, including serving as the sponsoring organization for grant proposals. All contract negotiations will be managed by the ISOQOL Office. Any budget considerations must be included in the original project proposal. SIG project proposals are reviewed and a response is forwarded to the SIG Chair within a 30-day period. Exceptions to this process are outlined in the SIG Leadership Orientation documents.

SIG Reporting to the ISOQOL Office

Each SIG will be asked to complete the following items:

1. Annual report using the reporting template, for review at the Spring Board of Directors meeting.
2. Participation in the SIG Council meeting held at the Annual Conference.
3. Business Plan and Budget for the next year's initiatives forwarded to the Board of Directors in early Fall, if applicable.
4. Elections every year or every other year depending on leadership structure.
5. Other items as described in the SIG Leader Orientation documents.

Services provided by the ISOQOL Office

The ISOQOL Office is available to assist SIGs. The services provided by the ISOQOL Office include, but are not limited to:

- Assist with development of new SIG
- Manage budgets for SIG initiatives
- Track membership
- Assist with workshops or project logistics
- Contract negotiation
- Conduct elections (electronic)
- SIG Project Marketing
- Update webpage
- Distribution of surveys
- Board Liaison – ISOQOL Executive Committee assigns each SIG a liaison chosen from the current ISOQOL board members. The board liaison is an advisory ex-officio role to support, connect and guide the SIG. Each liaison can determine how/when to interact with their SIG chair(s), at a minimum the following 3 (three) annual touch-point meetings should be arranged:
 - SIG Leadership Orientation Call: to serve as a post-annual conference debrief of the activities occurred up to, during and, if applicable, following the annual conference.
 - Annual Report Submission: to serve as a pre-annual board meeting (which occurs in April) debrief to review and provide the liaison with an update on current and proposed activities prior to their review of the SIG annual report at the board meeting.
 - SIG Council Meeting: to serve as a face-to-face meeting at the Annual Conference for quick updates.

Requirements to Form a Provisional SIG

Any five (5) Society members in good standing may organize a SIG of the Society by requesting authorization in a signed petition addressed to the ISOQOL Board of Directors. The petition shall include the proposed name, the specific area of interest, the scope and purpose of the proposed SIG, and CVs for the founding members.

Any group that is considering basing their SIG off a geographic region is encouraged to demarcate their SIG as the largest possible meaningful area defined geographic region, culture, and/or language.

An application to form a SIG should also address two questions:

- What is the need for this SIG that is currently not being met by the existing ISOQOL organization?
- What is the new opportunity for addressing the mission of ISOQOL through the creation of this SIG?

The petition shall be sent to the Executive Director for review. The request will be reviewed to determine if the area of interest or geographic network could be identified within an existing SIG/Geographic Network as a project or subgroup. If found to be in proper form, the request shall be forwarded to the Board of Directors for approval or disapproval of provisional status for a period not to exceed 2 years. The ISOQOL Office may assist in organizing the SIG. During the provisional period, the SIG shall perform activities as described above for Full SIGs.

Change of Status from Provisional to Full SIG

The organizers of the approved provisional SIG shall operate according to the ISOQOL SIG Operating Policies. The provisional SIG will develop a mission statement, elect officers, secure a minimum of ten (10) Society members and provide a report of its scientific activity and future plans. Individual SIG supplementary operating policies consistent with the ISOQOL SIG Operating Policies may be appended as amendments. The amendments specify member eligibility criteria and the purpose and goals of the SIG. The amendments will be consistent with and support the Society's mission and the ISOQOL Operating Policies.

The SIG Chair(s) shall submit the SIG's mission statement, list of officers and members, the scientific activity report and optional supplementary operating policies to the Executive Director of the Society for approval by the Board of Directors. The Board of Directors may approve establishment of the SIG at any time during the provisional period.

SIG Dissolution

The ISOQOL Executive Director is responsible for monitoring the performance of SIGs over time to ensure that the minimum membership of ten (10) is maintained and that it operates in a manner consistent with the Society's mission and operating policies, and submits the required reports during the year. When a SIG fails to do so for two (2) consecutive years, the Executive Director will inform the SIG officers and the ISOQOL Board of Directors. After consultation with the SIG leadership and due consideration of remedies, the ISOQOL Board of Directors may elect to decommission the SIG, and will necessarily do so if issues persist through the third year of consideration.

Staff Performance Evaluation

(For all EDI Staff)

The evaluation is on an annual basis. Job factors that are reviewed include: job knowledge, quality of work, problem solving skills, time management/organizational skills, communication skills, external relations, dependability, professionalism, and adaptability.

Support

It shall be the ISOQOL policy to accept funding to support and further ISOQOL's mission to advance the scientific study of health-related quality of life and other patient-centered outcomes to identify effective interventions, enhance the quality of health care and promote the health of populations. Any funding or support given to ISOQOL will in no way dictate or influence ISOQOL's scientific mission, publications, educational or institutional programs.

ISOQOL will work in partnership with various entities to secure donations, marketing options, advertising, industry support, exhibits, grants and general society support. This would also include unrestricted educational grants offered by various institutes and/or industry partners.

All support efforts will be a collaborative effort with membership administered through the ISOQOL office. Funding options will be published by the ISOQOL office through various documents including but not limited to the Exhibitor Prospectus, Advertising Opportunities, Support Opportunities Guide, and Membership Donation Drive

ISOQOL reserves the right to decline funding from entities that do not align with the mission.

Translation Policy & Process

ISOQOL alone shall hold all ownership and other proprietary rights (including, without limitation, any and all copyrights) and sales for all translated versions of ISOQOL documents. The following process will be followed for all translations:

1. Branding, Title and Acknowledgements will be designated as such:
 - a. Cover –
 - i. Branding will remain consistent with original document
 - ii. Title will remain the same
 - iii. Edition will read – First Edition of “*Language*” Translation
 - iv. Translation entity will be acknowledged – Translated by: _____
 - b. Original edition will be reference on inside page
 - c. Acknowledgement – original Editor, Team and Funding will be acknowledged along with translational editor, contributors, and/or funding entity. The translational team will be designated as:
 - i. Translational Editor – “*Language*” Translational Editor
 - ii. Translational Contributors – “*Language*” Translational Contributors
 - iii. Funding Entity – “*Language*” Translational Funding
2. Local translation/back translation will include two teams (translators and back translators) that operate under one director, but otherwise are independent of each other.
3. For each team, at least one person who is fluent in English and the native language and is a quality of life researcher is required. Other specialists (professional translator, linguist, cultural expert, etc., are optional).
4. The translation and back translation will be submitted to the ISOQOL office, who will identify an independent project manager that will review the translation and back translation and work with the translational team to determine a final draft of the product. The primary aim of this review and determination is to be based on the evidence of conceptual equivalency in the key concepts presented in the document. This independent person will submit a report addressing the degree of achievement of this aim to the ISOQOL office.
5. ISOQOL leadership will review the report and approve the translational version of the document.
6. The ISOQOL office will produce and publish the translation version through its current outlets.

Translation Policy & Process – ISOQOL Dictionary

ISOQOL alone shall hold all ownership and other proprietary rights (including, without limitation, any and all copyrights) and sales for all translated versions of the dictionary. Any translation of the ISOQOL dictionary will remain an internal ISOQOL procedure. The following process will be followed for all translations:

1. Branding, Title and Acknowledgements will be designated as such:
 - a. Cover –
 - i. Branding will remain consistent with original dictionary
 - ii. Title will remain the same
 - iii. Edition will read – First Edition of “*Language*” Translation
 - iv. Translation entity will be acknowledged – Translated by: _____
 - b. Original edition will be reference on inside page (dictionary with individual ISBN)
 - c. Acknowledgement – original Editor, Team and Funding will be acknowledged along with translation editor, contributors, and/or funding entity. The translation team will be designated as:
 - i. Translation Editor – “*Language*” Translation Editor
 - ii. Translation Contributors – “*Language*” Translation Contributors
 - iii. Funding Entity – “*Language*” Translation Funding
2. Local translation will include one team (consisting of the following roles: translator, editor and proofreader) that operate under one coordinator. Collaboration is encouraged as much as possible in order to efficiently discuss any arising issues and reach consensus. Each step must be documented in a translation report.
3. Within the team, the first translator should be fluent in English and be a native speaker of the target language, and is a quality of life researcher. The editor is also fluent in English and native speaker of the target language, with experience translating the subject matter terminology. Lastly, the proofreader should be a professional linguist, fluent in English and native speaker of the target language; subject matter expertise is desirable but not required. Other specialists (professional translator, linguist, cultural expert, etc.) are optional. Each role may be performed by one or more individuals as decided by the coordinator.
4. After the translation team has resolved all issues and finalized the translation, a methodology report, covering all the steps of the translation process and summarizing the discussions, will be submitted to the ISOQOL office for endorsement by the Board.
5. ISOQOL leadership will review the translation methodology report and approve the translation of the dictionary.
6. The ISOQOL office will produce and publish the translation version through its current outlets.

Whistleblower **(Policy Maintained by EDI)**

General

The International Society for Quality of Life Research (ISOQOL) Code of Ethics (Code), Board of Directors, Executive Committee, committee chairs and members, representatives, employees and management company employees to observe high standards of business and personal ethics in the conduct of their duties and responsibilities. As employees and representatives of ISOQOL, we must practice honesty and integrity in fulfilling our responsibilities and comply with all applicable laws and regulations.

Reporting Responsibility

It is the responsibility of all Board of Directors, Executive Committee, committee chairs and members, representatives and employees to comply with the Code and to report violations or suspected violations in accordance with this Whistleblower Policy.

No Retaliation

No Board of Directors, Executive Committee, committee chairs and members, representatives, employees and management company employees who in good faith reports a violation of the Code shall suffer harassment, retaliation or adverse employment consequence. An employee who retaliates against someone who has reported a violation in good faith is subject to discipline up to and including termination of employment. This Whistleblower Policy is intended to encourage and enable employees and others to raise serious concerns within ISOQOL prior to seeking resolution outside the organization.

Compliance Officer

The ISOQOL Consulting Partner is responsible for investigating and resolving all reported complaints and allegations concerning violations of the Code and, at her discretion, shall advise the other EDI partners. The Consulting Partner has direct access to the other EDI Partners and is required to report to the Board of Directors at least annually on compliance activity.

Reporting Violations

The ISOQOL encourages an open door policy and suggests that volunteers or employees share their questions, concerns, suggestions or complaints with someone who can address them properly. In most cases, an employee's supervisor is in the best position to address an area of concern. However, if someone is not satisfied with the supervisor's response, the individual is encouraged to speak with the Executive Director or the EDI Consulting Partner. If the reporting party is not satisfied with the executive director or EDI Consulting Partner response, the individual may go to the EDI President or Chief Operating Officer.

Supervisors and managers are required to report suspected violations of the Code of Conduct to ISOQOL's Consulting Partner, who has specific and exclusive responsibility to investigate all reported violations. For suspected fraud, or when someone is not satisfied or is uncomfortable with following ISOQOL's open door policy, individuals should contact ISOQOL's consulting partner directly.

Accounting and Auditing Matters

The Consulting Partner shall immediately notify the other EDI Partners and the Audit Committee of any complaints regarding accounting practices, internal controls or auditing and work with the other EDI Partners until the matter is resolved. The Board of Directors shall be notified of reported concerns or complaints regarding such issues.

Acting in Good Faith

Anyone filing a complaint concerning a violation or suspected violation of the Code must be acting in good faith and have reasonable grounds for believing the information disclosed indicates a violation of the Code. Any allegations that prove not to be substantiated and which prove to have been made maliciously or knowingly to be false will be viewed as a serious disciplinary offense.

Confidentiality

Violations or suspected violations may be submitted on a confidential basis by the complainant or may be submitted anonymously. Reports of violations or suspected violations will be kept confidential to the extent possible, consistent with the need to conduct an adequate investigation.

Handling of Reported Violations

The Consulting Partner will notify the sender and acknowledge receipt of the reported violation or suspected violation within five business days. All reports will be promptly investigated and appropriate corrective action will be taken if warranted by the investigation.

Policy Manual Revisions

Revision 10 – April 2020

Revision 9 – October 2019

Revision 8 – October 2018

Revision 7 – April 2018

Revision 6 – August 2016

Revision 5 – June 2016

Revision 4 – April 2016

Revision 3 – March 2016

Revision 2 – January 2016

Revision 1 – June 2015

Original – May 11, 2015