

Provisional Guidelines on National and Regional Chapters of ISOQOL
Effective from January 2007

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1. Overview

This document provides guidelines for the creation, approval and operation of national and regional chapters of ISOQOL. There are many issues to consider, and because this is ISOQOL's first experience with establishing and operating chapters, the optimal approach is not clear. It is therefore envisaged that these guidelines will be reviewed annually and revised in the light of experience both of the chapters and the Board until such time as the guidelines match the needs and requirements of all concerned.

In this document, "region" refers to a geographical region consisting of a number of countries and the term "chapter" may refer to either a national or regional chapter of ISOQOL. The ISOQOL Board of Directors is referred to simply as the Board hereafter.

1.1. Why have National and Regional Chapters?

ISOQOL supports the development of national and regional chapters as a means of fostering the field of health-related quality of life (HRQL) research in countries and regions beyond ISOQOL's traditional membership base in North America and Western Europe. It is hoped that the development and growth of such chapters will not only increase ISOQOL's membership and foster a more truly international network of HRQL research and researchers, but also promote understanding and use of HRQL measures in a wider and more culturally and geographically diverse range of countries and regions. This in turn will promote more cultural and geographical balance in the field of HRQL research.

2. Establishing a chapter

To form a chapter, a group of ISOQOL members from a particular country or region (the chapter's **founding members**) should be willing and able to meet a set of **minimum requirements** (see Section 3).

In addition to these requirements, and as part of the approval process, a prospective chapter must come to an agreement with the ISOQOL Board about:

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- 2.1. the **relationship** between the ISOQOL parent body and the ISOQOL chapter;
 - 2.2. the **benefits and support** provided by the ISOQOL parent body;
 - 2.3. the **mode of operation** of the chapter, including the **financial** arrangements.
- 2.4. An initial **letter of intention** should be submitted to Board Chapters Liaison Delegate, listing the **names and countries** of the **founding members**, and stating the **national/regional scope** of the proposed chapter and the preferred **mode of operation**.
3. **Minimum requirements for chapters**
- 3.1. A **national chapter** will comprise a minimum of 5 members.
 - 3.2. A **regional chapter** will comprise a minimum of 10 members.
 - 3.3. A chapter should assure that all chapter members are ISOQOL members.
 - 3.4. A chapter will hold an election to select a leadership infrastructure of at least one or two officers; such as a Chair and Co-chair or a President.
 - 3.5. The **mission** of the chapter will be the same as that of ISOQOL.
 - 3.6. The **objectives** of the chapter should be specific to the local needs of its members.
 - 3.7. A chapter will hold one scientific meeting at least every two years.
 - 3.8. A chapter will maintain communication with its members through mechanisms such as meetings, emails and newsletters.
 - 3.9. A chapter will prepare an annual report each year for the Board's information and review;
 - 3.10. A chapter will comply with the general policies of ISOQOL except in cases where prior approval is obtained from the Board.
 - 3.11. A Chapter will provide evidence of its ability to sustain itself.
4. **Relationship between ISOQOL and a chapter**
- 4.1. A chapter is an integral part of ISOQOL and shares the same mission.
 - 4.2. Members of ISOQOL in a specific region/country will automatically become members of the chapter unless they opt not to be.
 - 4.3. When appropriate, a representative of a chapter will be invited to attend that portion of an ISOQOL Board meeting dedicated to chapters to report on the Chapter's activities, to enhance communication between the Board and the chapter. ISOQOL will not pay for the travel expenses of that representative.
 - 4.4. The **financial relationship** between ISOQOL and the chapter will vary with mode of operation. The founding members of a prospective chapter will elect one of two available modes of operation, as specified below, when applying to the Board to establish the chapter. As the chapter becomes established, its leadership may apply to the Board to change its elected mode of operation.
 - 4.5. Regardless of mode of operation, **membership dues** will be as set by ISOQOL; there will be no additional chapter membership dues. All membership dues will be paid via the ISOQOL website to the ISOQOL (parent) bank account, as ordinary ISOQOL members.
5. **Benefits and support provided by ISOQOL**
- The following types of support from the ISOQOL parent body will be available regardless of the mode of operation of the chapter:
- 5.1. ISOQOL will assist the chapter in the election process and endeavor to ensure an open and fair election. To this end, ISOQOL will send out ballot notifications and information to eligible chapter members and receive the votes electronically.
 - 5.2. ISOQOL will create a web page for the chapter at the ISOQOL web site, using content provided by chapter members.

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- 5.3. All chapter members will have full member access to the ISOQOL website.
- 5.4. Chapters will use the ISOQOL logo on their promotional materials and any other official communications and presentations.
- 5.5. Chapters may seek the support of high-profile ISOQOL members who have recognized expertise in particular topics to attend chapter meetings to give talks and workshops, etc. Requests for such support should be made to the Board via the Board Chapters Liaison Delegate. These will be considered on a case-by-case basis.

The degree of access to the services and infrastructure support of the ISOQOL Secretariat for organizing the chapter's activities will vary depending on the mode of operation of the chapter, as specified below.

6. Operation of chapters, including financial arrangements

Aspects of the mode of operation of chapters will vary among chapters according to the preferences, needs and context of each chapter. Two general models are currently available: the so-called "franchise" and "subsidiary" models. We have borrowed these terms from the business world, but we adapt their meaning to our context – ie, the not-for-profit professional society. The key distinction between the two approaches is the amount of autonomy - a chapter in the subsidiary model has less financial autonomy than in the franchise model. The subsidiary model does not retain any of its financial surplus but it has access to more infrastructure support from ISOQOL.

General aspects of chapter operation are:

- 6.1. A chapter will meet all the minimum requirements for chapters, as specified above;
- 6.2. A chapter operates fairly independently of ISOQOL in planning its activities to meet specific local needs of the members; the Board will be involved in planning and approval only to ensure that the activities and their content meet the standards set by the ISOQOL parent body and do not damage or otherwise deleteriously affect ISOQOL's standing and reputation.
- 6.3. A chapter determines what its leadership infrastructure will look like, including the executive positions available and the period of tenure.

7. Franchise model

Operating a chapter as a franchise of ISOQOL involves considerable operational and financial independence from the parent body. In the franchise model, a fee is paid for the use of the parent ISOQOL's "brand name" and logo and limited use of its infrastructure; these payments could involve a share of net revenues and/or periodic lump sum payments

Essential aspects of the franchise model:

- 7.1. The chapter maintains an independent financial account, and it provides an audited financial report as part of its annual report;
- 7.2. The chapter opens and operates an independent bank account;
- 7.3. The chapter registers as an independent legal entity in the respective region or country where appropriate;
- 7.4. ISOQOL will provide an initial financial subsidy to a new Chapter, being 50% of the ISOQOL membership dues for the number of founding members of the new Chapter. Founding members can use this as seeding fund for any costs incurred in the establishment of their chapter, such as registering their chapter within their region &/or country. The founding members will need to initiate this transaction by applying

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for the seeding subsidy.

- 7.5. After the chapter is established, ISOQOL will continue to reimburse 50% of the chapter members' membership dues annually into the chapter's bank account towards the operating cost of the chapter.
- 7.6. The chapter will seek sponsorship for its activities, and any monies granted will be paid into the chapter's bank account.
- 7.7. The chapter will not seek additional financial assistance from the ISOQOL parent body, beyond the seeding subsidy for its routine operations, but it may seek assistance for a special event or for guest speakers at its annual meeting. These will be considered by the Board on a case-by-case basis.
- 7.8. At the end of each financial year, the chapter will transfer 20% of its net revenues (or an agreed annual lump-sum fee) to the ISOQOL parent organization; this fee is in payment for the use of ISOQOL's reputation and "brand", logo, policies, website and infrastructure (including election support), and in recognition of any other administrative, managerial, financial and professional support provided by ISOQOL.

8. Subsidiary model

Operating a chapter as a subsidiary of ISOQOL involves little operational and financial independence from the ISOQOL parent body.

Essential aspects of the subsidiary model are:

- 8.1. The chapter does not maintain an independent financial account, although it provides a financial report as part of its annual report;
- 8.2. The chapter does not open or operate an independent bank account;
- 8.3. The chapter does not register as an independent legal entity;
- 8.4. ISOQOL will not provide an initial financial subsidy to a new Chapter, but it will consider requests from the chapter for any set-up costs encountered by founding members, on a case-by-case basis.
- 8.5. The chapter will seek sponsorship for its activities from various sources (not ISOQOL), and any monies granted will be paid to the ISOQOL (parent) bank account;
- 8.6. The ISOQOL Secretariat may provide some assistance in organizing the chapter's activities; this will be negotiated via the ISOQOL Board Chapters Liaison Delegate and will require Board approval;
- 8.7. The chapter may seek interim financial support from ISOQOL for activities such as securing venues for meetings, but it will commit to recouping costs from registrations and sponsorship and return these to ISOQOL, plus any profits.
- 8.8. All net revenues will go to the ISOQOL parent organization; this is in payment for the use of ISOQOL's reputation and "brand", logo, policies, website and infrastructure (including election support), and in recognition of any other administrative, managerial, financial and professional support provided by ISOQOL.

9. Application for a proposed chapter

The founding members of a chapter should prepare an application which outlines its **Proposed Chapter Establishment Plan**.

9.1. The **Proposed Chapter Establishment Plan** will:

- 9.1.1. give the proposed **name** and **geographical range** of the chapter;
- 9.1.2. outline how the **minimum requirements** have been, or will be, met by the chapter

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and its founding members;

9.1.3. elect a **mode of operation** from the two available modes: franchise or subsidiary.

This application should be submitted to the Board in time for its mid-year meeting, where it will be given full consideration.

10. Approval of a proposed chapter

10.1. Approval

Approval of the Proposed Chapter Establishment Plan will proceed as with other Board decisions - by majority vote. Approval of this plan by the Board constitutes official recognition of the nascent chapter's existence. The founding members of the chapter are then charged with the responsibility of establishing the chapter according to their Proposed Chapter Establishment Plan. The chapter's progress will be monitored annually via the annual report and review process described below.

10.2. Provisional Approval

The Board may grant provisional approval for the formation of a chapter when the number of ISOQOL members is below the minimum requirement, in the expectation that the number of members will increase over time and come into compliance with the minimum requirement within a few years.

10.3. Non-approval, revision and reapplication

If the Board has any concerns about aspects of a proposed chapter's establishment plan, it may not approve the application initially. In that case, the Board will provide feedback to the founding members of the chapter about these concerns and how they may be met. The founding members may choose to revise and resubmit the application accordingly.

Reapplication need not wait for the next mid-year Board meeting; it may occur at any time, facilitated by the Board Chapters Liaison Delegate. Communications to and within the Board can proceed by email until the next approval decision (for or against) is made.

11. Annual report and review

A chapter is required to submit an annual report to the Board. This report should provide an update on the chapter's current membership, leadership, activities in the past year, plans for the coming year(s) and a financial statement (with an audited financial report where applicable). Chapters may also wish to include suggestions to the Board about revision of these guidelines to better meeting their local needs and circumstances. The annual report should be prepared and submitted in time for the Board to review at its mid-year Board meeting.

The Board will review the annual report of each chapter to judge whether the chapter has met the minimum requirements, and will consider any suggested revisions to the guidelines.

12. Termination of chapters

ISOQOL reserves the right to terminate a chapter if it persistently fails to comply with the minimum requirements.

13. Alternatives to forming a chapter

Establishing and maintaining a chapter will require substantial commitment and effort from the founding members and the chapter's elected leadership. Such an effort may not seem necessary or realistic for some geographical clusters of ISOQOL members. These groups may consider the following two options, either as an alternative to formally establishing a regional

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or national chapter or with the intention of becoming a chapter at a later date. They may consider operating in the form of an ISOQOL Special Interest Group (SIG), such as a SIG on region/culture-specific QOL issues, eg the IberoAmerican HRQL SIG. Another approach would be to form on an *ad hoc* project group, such as for the purpose of organizing a one-off ISOQOL regional conference.

14. Roles and responsibilities

Three sets of people are involved in the establishment and maintenance of ISOQOL chapters.

14.1. The Chapter Leadership will:

- 14.1.1.** Ensure that its chapter complies with all the minimum requirements.
- 14.1.2.** Prepare the chapter's annual report.
- 14.1.3.** Maintain an updated list of the chapter's membership for the purpose of communication among members and election of the leadership structure.

14.2. The Board Chapters Liaison Delegate will:

- 14.2.1.** Liaise with the leadership of each chapter to ensure annual reports are submitted in a timely fashion.
- 14.2.2.** Co-ordinate the annual reports of all chapters to ensure they are included in the Board Book for each mid-year Board meeting, and present them to the Board for review and discussion.
- 14.2.3.** Provide feedback from the Board to the chapter leadership.
- 14.2.4.** Update the guidelines in response to ISOQOL's experience with chapters and the recommendations and decisions of the Board.

14.3. The ISOQOL Board will:

- 14.3.1.** Provide due consideration of the chapter reports, with particular view to whether minimum requirements are met;
- 14.3.2.** Review these guidelines in the light of experience both of the chapters and make recommendations on revisions to better meet the needs and requirements of all concerned.