

EORTC

Update on the activities of the Quality of Life Unit

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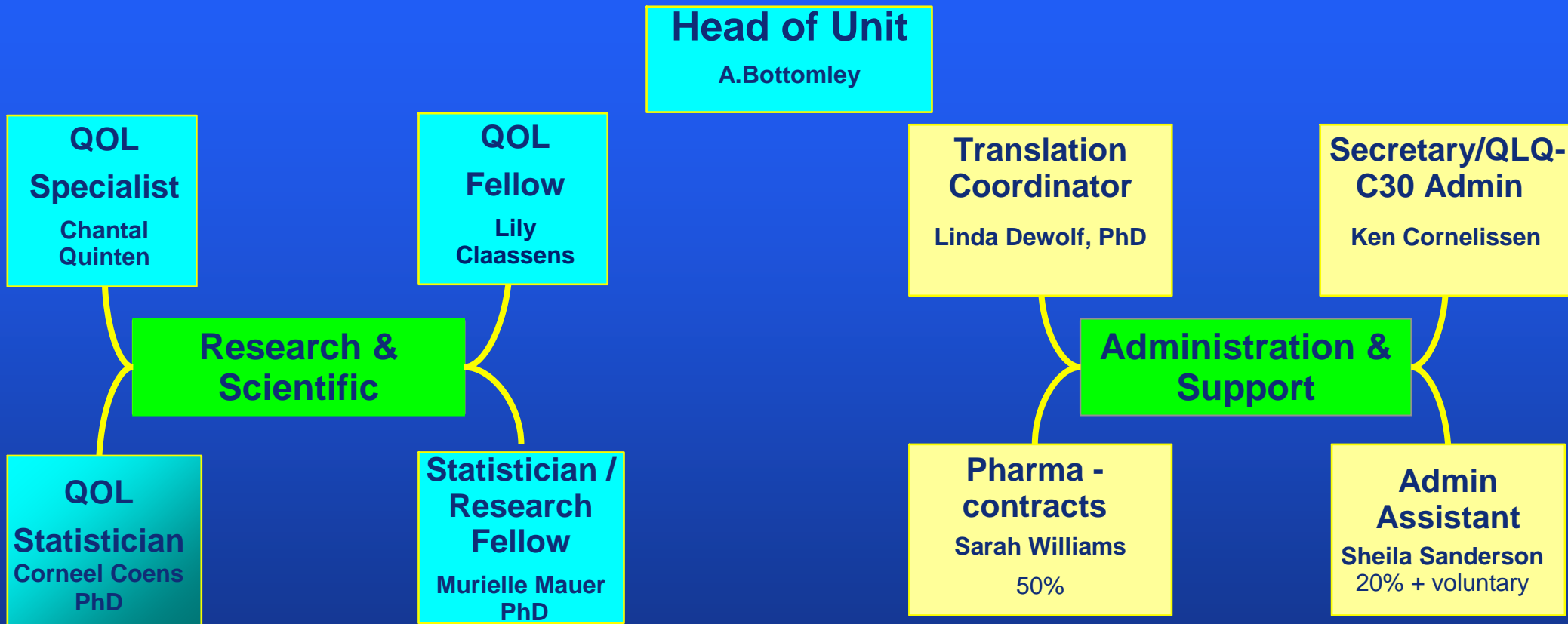
EORTC Quality of Life Unit, Brussels

7th March 2007

EORTC Quality of life Unit: Key Tasks

- To supervise the design, conduct and evaluation of QOL in selected cancer clinical trials
- To collaborate with the QLG on **joint scientific** initiatives to develop tools (direct and indirect e.g. Bone, information and fatigue modules)
- **To manage the translation programmes, academic users and all pharmaceutical contracts with the QLG**

Structure of the Quality of Life Unit in 2007



Funded by

 Data Center/ Pharma grants/ EORTC
BCG/US ABBC and academic grants

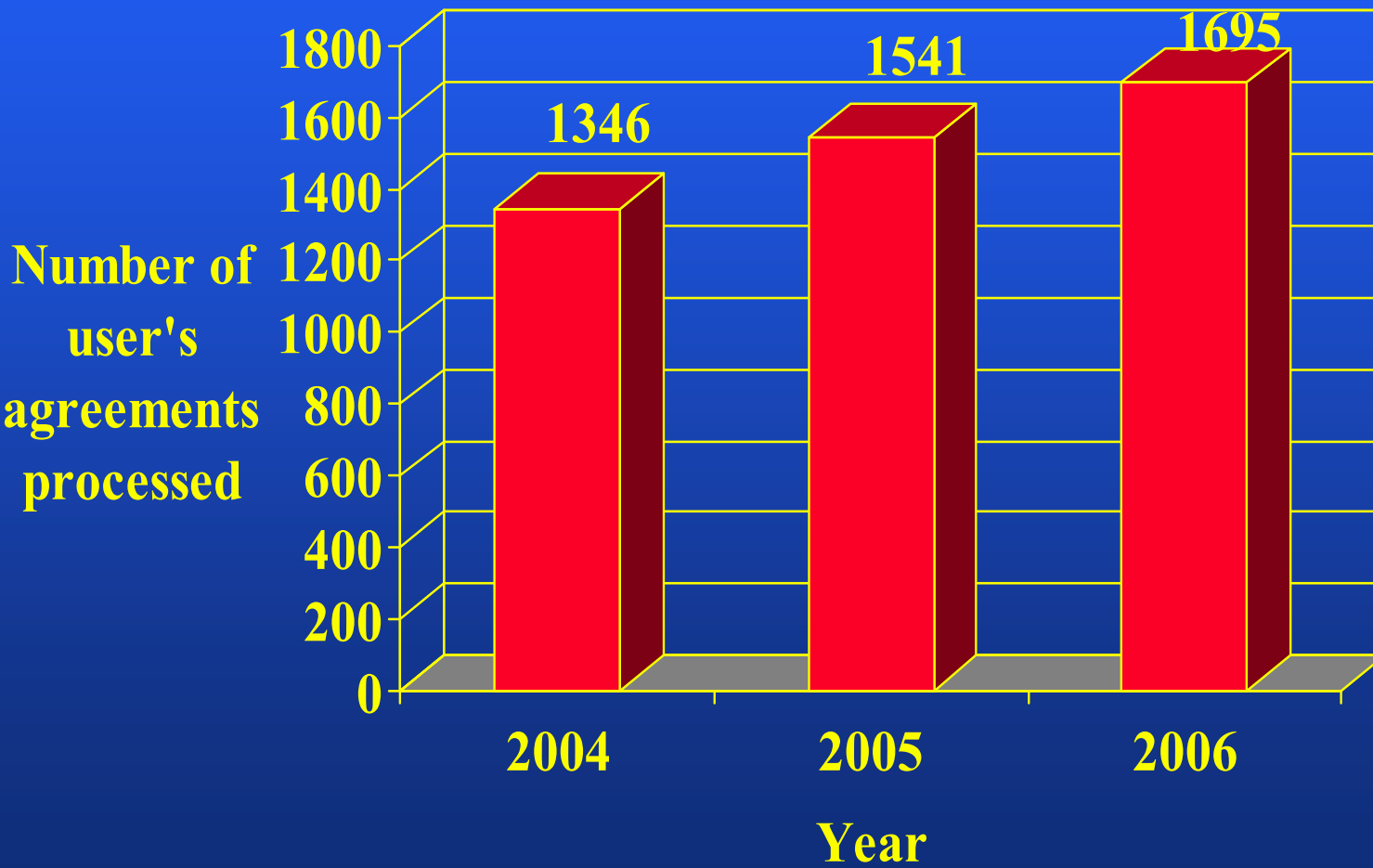
Funded by

 QLG funded position
2.7 FTE

Users demand for the QLQ-C30 + modules

Total user's agreements signed

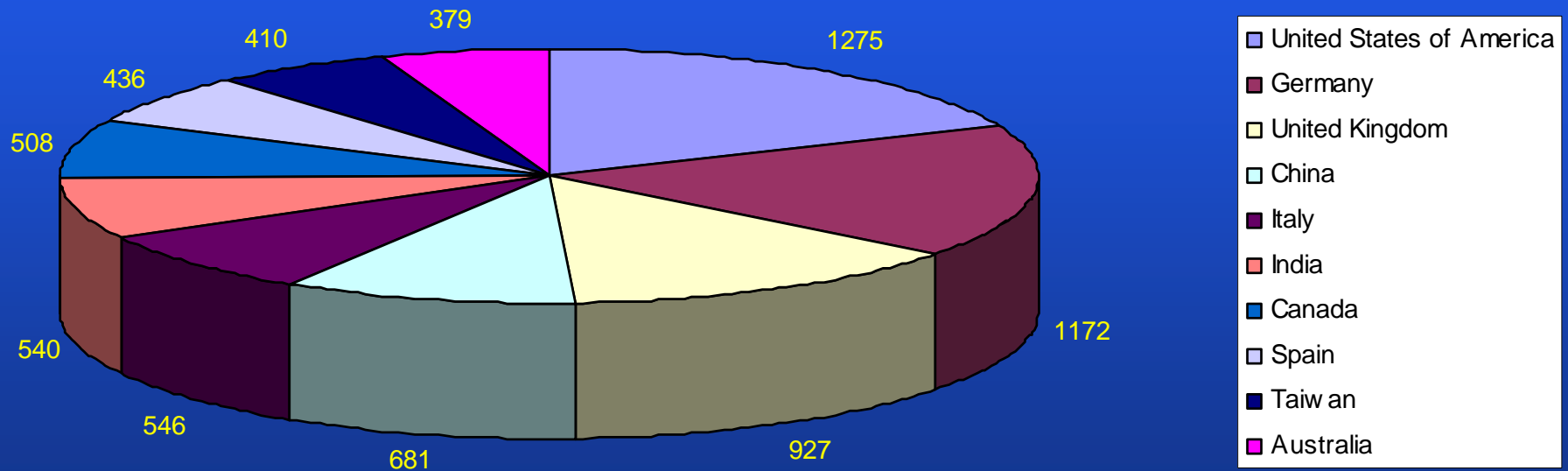
**25%
increase
in users
since
2004**



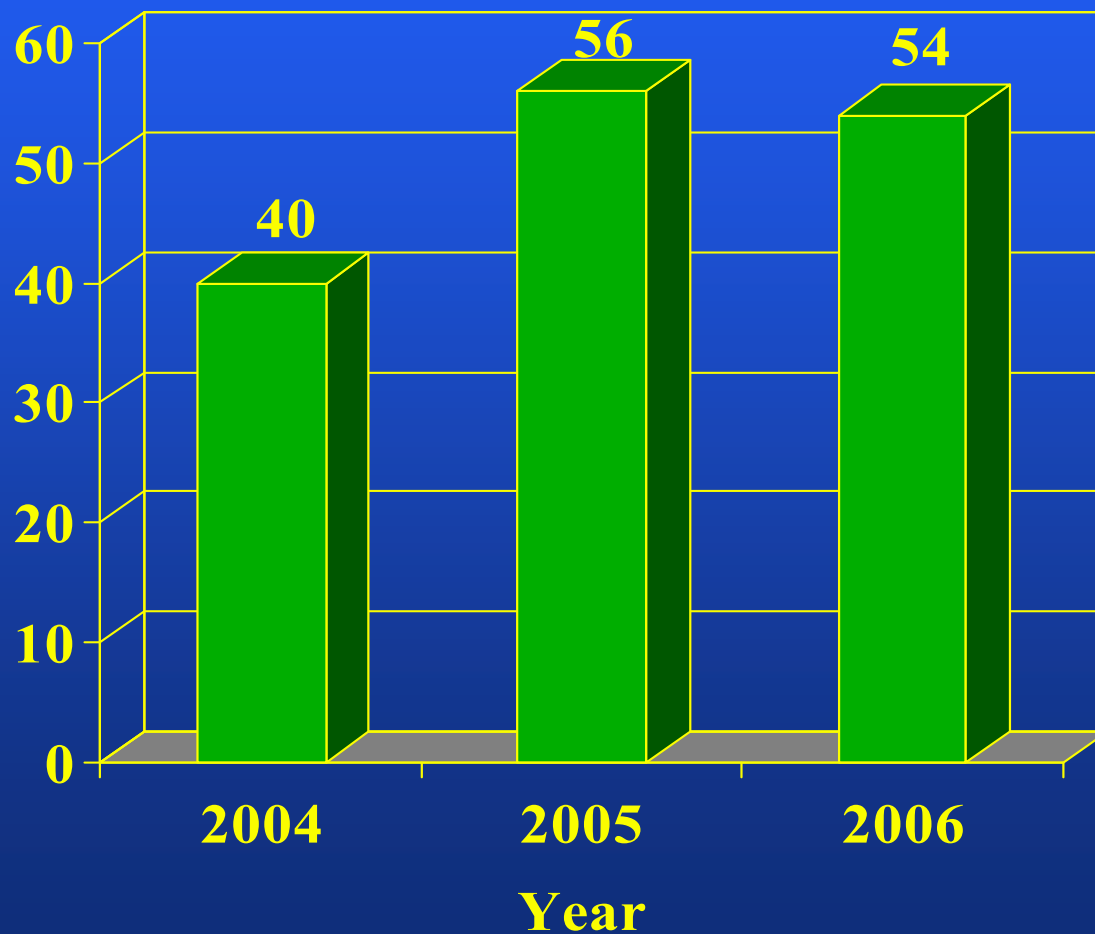
**QLQ-C30 Academic
Download requests**

**800 e-mail
enquiries
per month**

Top 10 Countries requesting the QLQ-C30: 2004 - 2006



Contracts with pharmaceutical companies and CROs (for using the QLQ-C30)

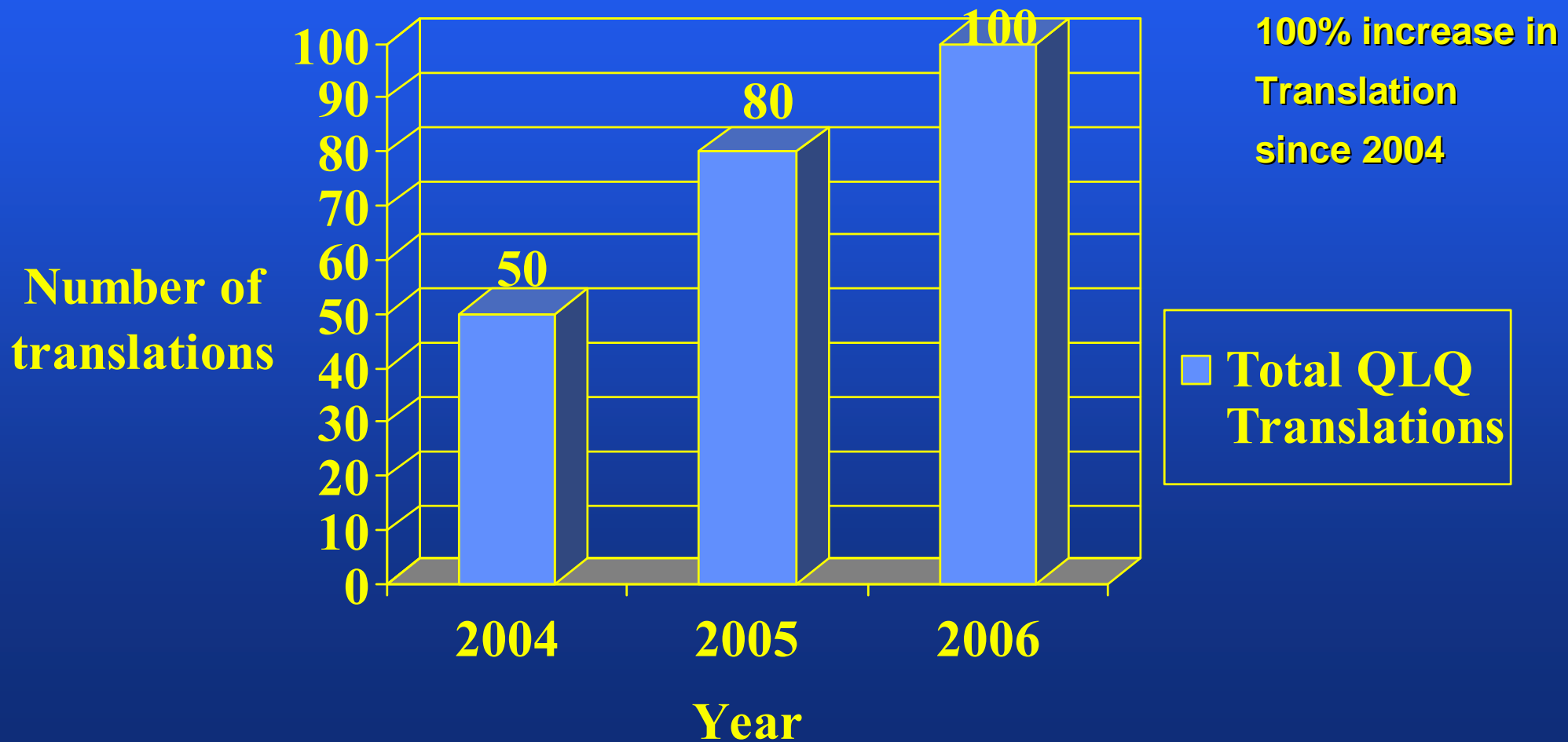


■ Pharma contracts - signed

Major effort spent in chasing delayed payers in Nov/Dec 2006 by Sarah Williams

Review of fees conducted in 2007

QLQ Translations Evolution – 2004 - 2006



Translation programme

- **100** translations in 2007 – Why such an increase?

More modules; changing modules; more demand from industry (often with rapid deadlines); better funding from industry; increased collaboration with translation agencies; more languages required in other non EU locations and perhaps the FDA draft PRO guidance

- Given this increase the major concern is to keep the workload manageable and also ensure the quality within the limited resources we have available
- Major initiatives began in 2007 to improve quality and standardisation (see translation committee – report)

Production and distribution of QLG manuals, etc.

- **New newsletter this week, Martin Taphoorn is the Editor**
- **Local production is done by Sarah Williams, Sheila Sanderson with Brief Ink publishers in Brussels.**
- **2000 printed, 850 distributed at EGAM, plus copies to ASCO (June), ECCO (September) and to recent academic and industry users**
- **QOL CDs still being distributed at various meetings (e.g. ASCO, ECCO, etc)**
- **Blue books/guidance manuals: All now pending updating (e.g. translation manual, scoring manual, reference values manual, and new manual on analysis) and printing and distribution**

Website

- Due to the website success, in November the QLG agreed to invest in a new look web page, with an external web designer, based in Brussels
- New website development was kindly coordinated by Ken (QLU Secretary), with Bernhard and Ian Martin (web consultant) with Neil Aaronson and myself
- Expect it to be running within the next week

Before...

Welcome to the EORTC Quality of Life website - Microsoft Internet Explorer

File Edit View Favorites Tools Help

Back Forward Stop Home Search Favorites Refresh Print View Source Links Full Schedule Intranet HR Information Windows

Address http://www.eortc.be/home/qol/ Go



Welcome to the EORTC Quality of Life Group

EUROPEAN ORGANISATION FOR RESEARCH AND TREATMENT OF CANCER
Group for research in Quality of Life

February 14, 2007

Sitemap	News	FAQ	Itembank	Links	EORTC homepage
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EORTC Quality of life Group

- History
- Function
- Activities
- Projects
- Executive
- Membership
- Future meetings
- Presentations of past meetings

EORTC Quality of Life Unit

- History
- Activities
- Personnel

Questionnaires

QLQ-C30

Frequently Asked Questions

Please read this for the answer to our most common questions

Download Quality of Life Questionnaires

Introduction

In recent years much interest has been focused on integrating quality of life as an endpoint for cancer clinical trials within the EORTC. The general purpose of Quality of Life assessment in clinical trials is to provide a more accurate evaluation of the well-being of individuals or groups of patients and of the benefits and side-effects that may result from medical intervention.

Applet fphover started Local intranet

... After

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Address <http://www.muzique.be/eortc/index.htm> Go

EORTC European Organisation for Research and Treatment of Cancer *QoL*

EORTC group for research into Quality of Life

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Quality of Life



Quality of Life assessment in cancer clinical trials provides a more accurate evaluation of the well-being of individuals or groups of patients and of the benefits and side-effects that may result from medical intervention.

These pages aim to give an overview of the activities of the EORTC Quality of Life Group and the Quality of Life Unit.

Events

22/12/06
Spring 2007 QLG Meeting (EGAM)
7 - 10 March 2007 (QLG 9 - 10 March) Brussels, Belgium

22-23/11/07
Autumn 2007 QLG Meeting
7 - 10 March 2007 Belfast, Northern Ireland, UK

News

22/12/06
The QLG and the QLU wish you a Merry Christmas and a Happy New Year.

During the holidays there will be intermittent coverage, so please expect a delay in receiving replies. Thank you for your unders

Questionnaires

QLQ-C30
Modules
QLQ-C15-PAL
EORTC-IN-PATSAT32

Internet

Item Bank Version 2

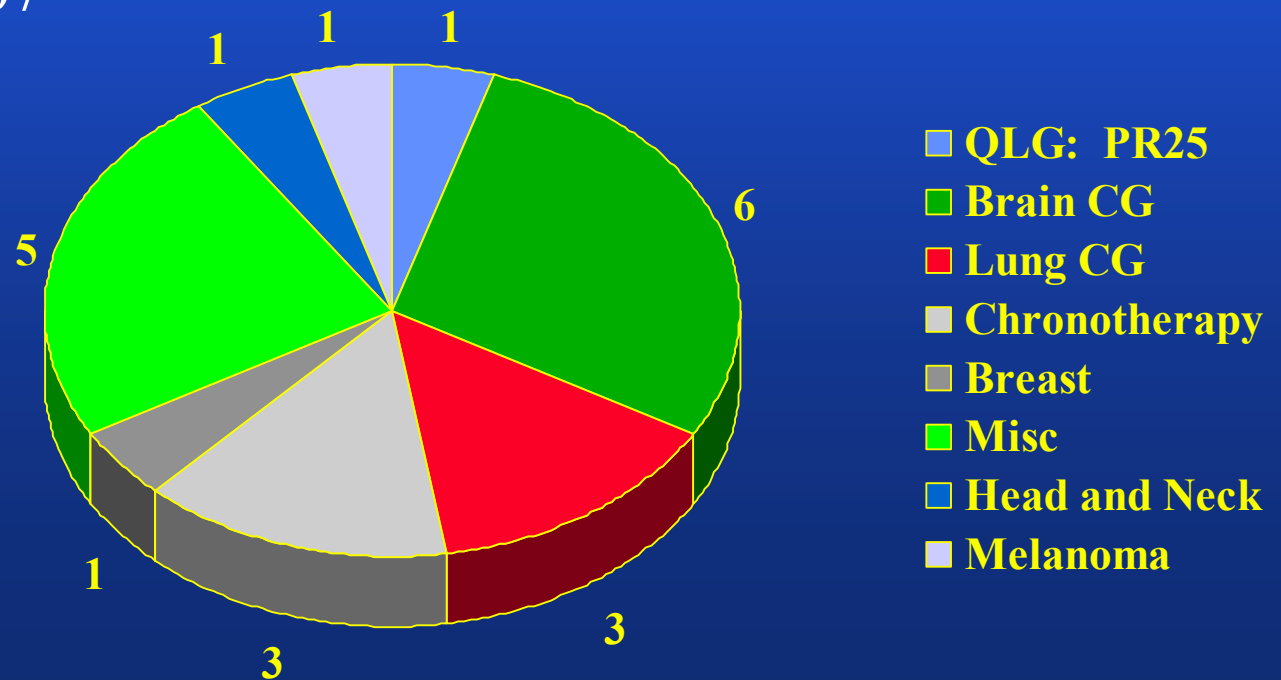
- New version developed and tested in autumn 2006
- **Data entry pending** – QLG asked to fund a one year post at EORTC for data entry – EORTC has hire freeze pending, QLU exploring outsourcing and **a bid is now pending**
- Managed by Linda Dewolf at the QLU and oversight by Teresa Young
- Care needs to be taken as not to overload QLU with new projects given we could see quality reduce

QLU scientific functions : New studies, analysis and preparation of trials and projects

* **New Studies** = Five new RCT's with QOL per year (including registration/fully sponsored). In 1x Lung, 1x Breast, 3 Brain



* **Existing studies** = Under pre-analysis/report preparation and discussion in 2007



Summary

- QLU is a major administrative/logistic support centre for the QLG, but we face an marked increase in the projects/administrative tasks
- Major challenge presently is to manage this workload and maintain the quality. This is under review
- QLU scientific focus is on managing clinical trial design, implementation which is also becoming more labour intense and with quicker response times expected
- New ideas for collaboration are always welcome!