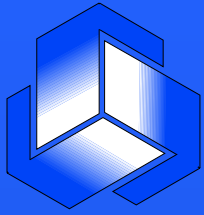


**EORTC**  
**Update on the activities of the Quality  
of Life Department**

**Andrew Bottomley Ph.D**

**EORTC Quality of Life Department, Brussels**

**November 2007**



# EORTC Headquarters

- **Recent internal re-organization (ongoing)**
  - **Major changes in management and structure**
  - **Fundamentally changing to adapt to the current CT environment, which include increase quality standards and participation with industry for clinical trials**
  - **EORTC will continue to evolve over the coming year**

# EORTC Quality of life Department: Key Tasks

- To supervise the design, conduct and evaluation of QOL in selected cancer clinical trials
- Develop scientific research to help implement QOL in EORTC trials
- To collaborate with the QLG on **joint scientific** initiatives to develop tools (direct and indirect)

## WITH THE QLG KEY TASKS ARE:

- Manage the **translation programmes, academic users** and all **pharmaceutical contracts**

# Structure of the Quality of Life Department

**Head of Department**  
A.Bottomley

**QOL Specialist**  
Chantal Quinten

**QOL Fellow**  
Lily Claassens

**Translation Coordinator**  
Linda Dewolf, PhD

**Secretary/QLQ-C30 Admin**  
Ken Cornelissen

**Research & Scientific**

**Administration & Support**

**QOL Statistician**  
Corneel Coens  
PhD

**Statistician / Research Fellow**  
Murielle Mauer  
PhD

**Pharma - contracts**  
Sarah Williams  
50%

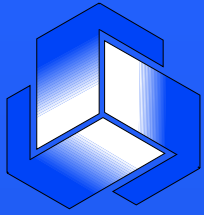
**Admin Assistant**  
Sheila Sanderson  
20% + 20% voluntary

**Funding source**

**Funded by**

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

 QLG funded position  
2.7 FTE



## **Scientific activities funded by EORTC Headquarters**

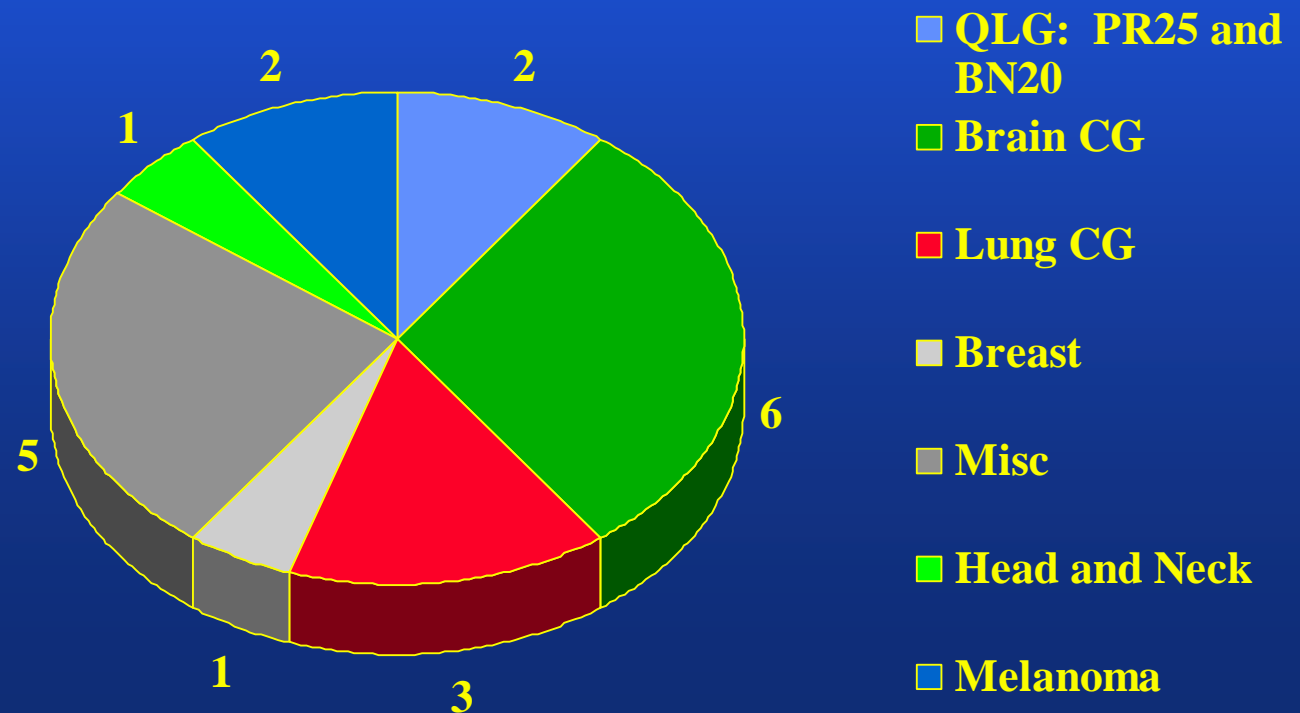
- **Fundamentally now with clinical trials groups in EORTC on trial results**
- **Prognostic factor analysis**
- **Other methodological analysis and QOL research but of limited focus on module development prospective studies**

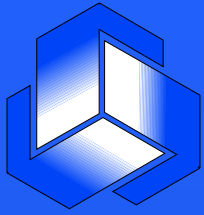
# QLD scientific functions: New studies, analysis and preparation of trials and projects

\* **New Studies** = Six new RCT's with QOL in 2007 (including 2 registration/fully sponsored).



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





# Collaboration with the QLG

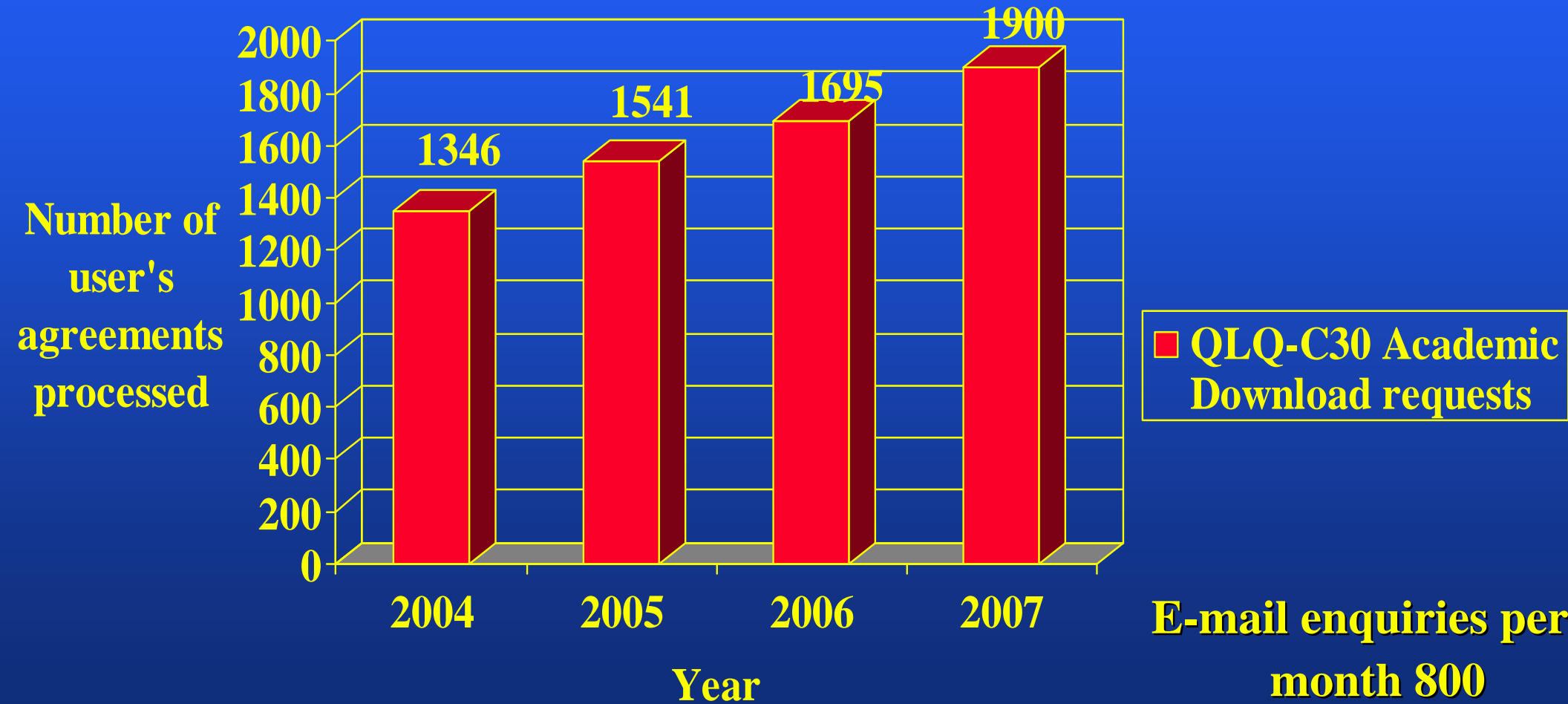
- **Translations**
- **Administrative and financial management**
- **Management of requests of academia**
- **Website requests and central coordination**
- **Collaboration on modules and items bank**
- **Ad hoc analysis of modules (BN 20)**
- **Ad hoc support on some module development**
- **Support for newsletter and other admin tasks**

# **Recent QLQ Validation analyses coordinated from the QLD**

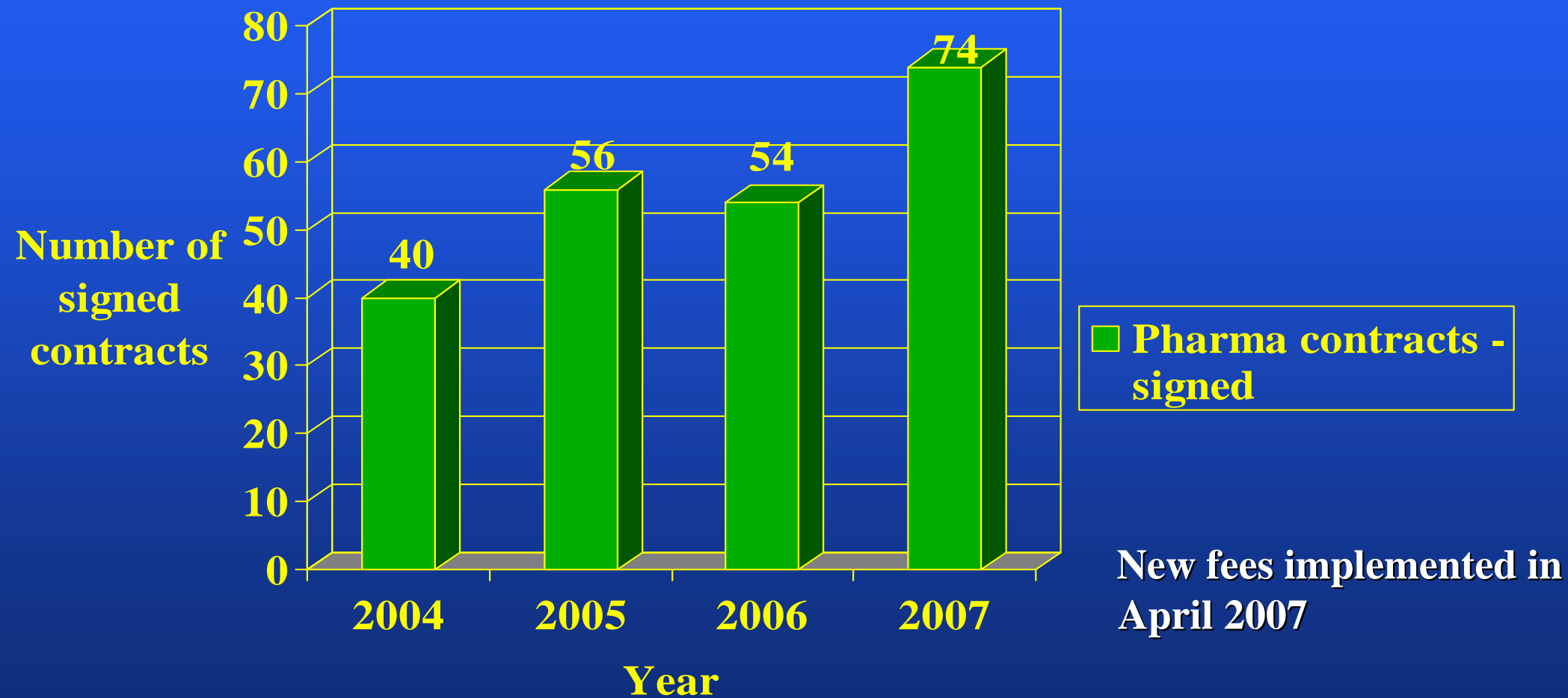
- **PR25 – Draft paper with Neil Aaronson and George van Andel**
- **BN20 – Draft analysis lead by Martin Taphoorn**

# QLQ-C30 + module administration

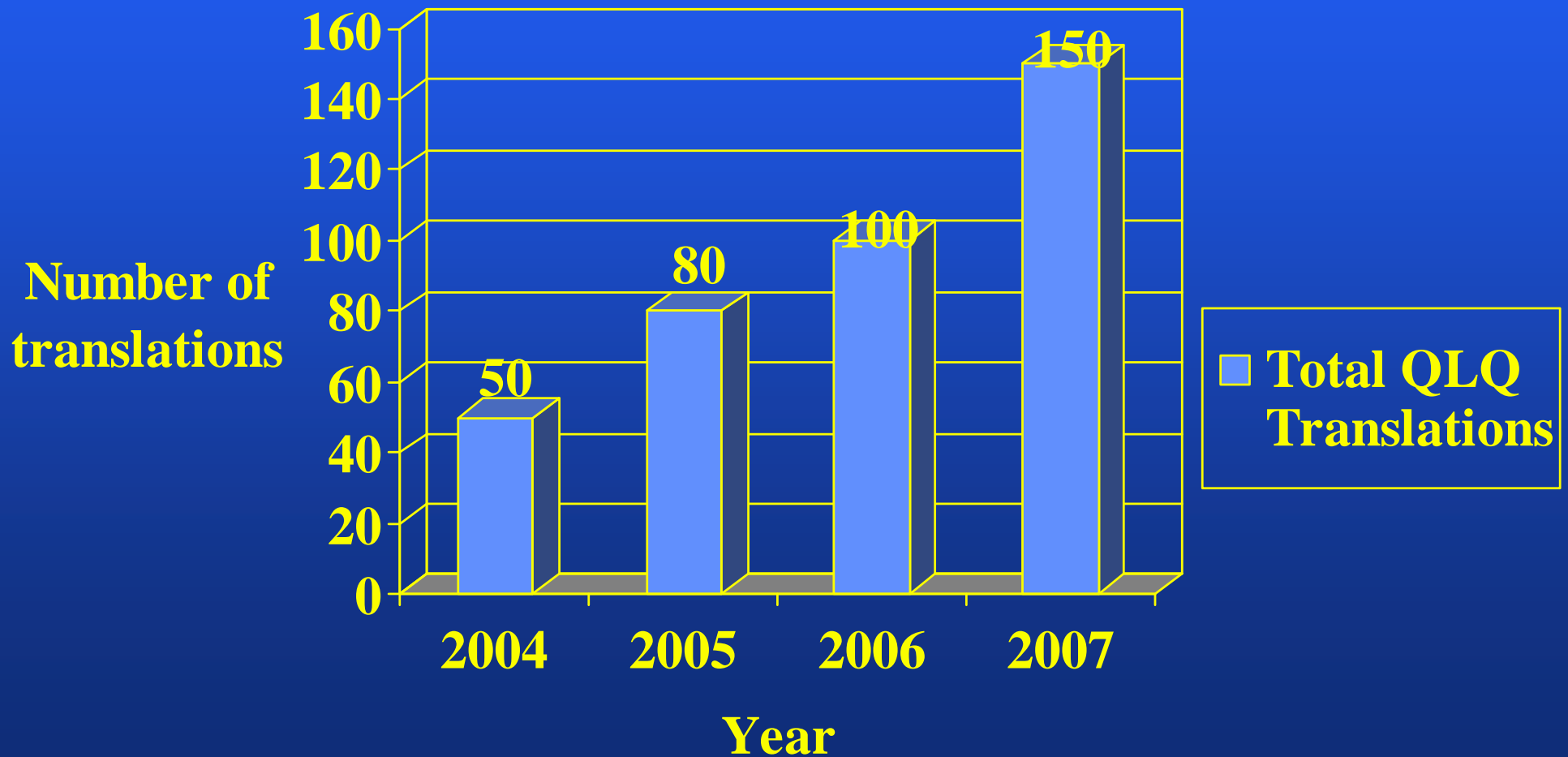
## Total user's agreements processed



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



# QLQ Translations Evolution



# Translation programme

- **80** translations undertaken in 2005
- **150** translation projects undertaken in 2007 – The concern is to keep the workload manageable given that there are currently more than 480 validated translations and 180 translations in progress or ready to be pilot tested
- Major initiatives began in 2007 to improve quality and standardisation (see the translation committee – report)

## **Production and distribution of QLG manuals, etc.**

- **Annual Newsletters, Dr. Martin Taphoorn is the Editor. Local production is done by Sarah Williams, Sheila Sanderson Andrew Bottomley with Brief Ink publishers in Brussels**
- **QOL CDs still being distributed at various meetings (eg: ASCO, ECCO, etc)**
- **Blue books/guidance manuals: All now pending updating, printing and distribution  
Translation Manual update near to completion and ready for circulation to co-authors**

# Website

# 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 Stop

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

Links Full Schedule Intranet HR Information Windows

## 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

<a href="#">Sitemap</a>	<a href="#">News</a>	<a href="#">FAQ</a>	<a href="#">Itembank</a>	<a href="#">Links</a>	<a href="#">EORTC homepage</a>
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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

EORTC Quality Of Life - Microsoft Internet Explorer

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Back Forward Stop Home Search Favorites

Address http://groups.eortc.be/qol/ Go Links

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

EORTC group for research into Quality of Life

Home Quality of Life Group Quality of Life Unit Questionnaires Glossary Documentation Education Links Contact Us



## 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

22-23/11/2007  
**Autumn 2007 QLG Meeting**  
22 - 23 November 2007  
Belfast, Northern Ireland, UK

24-25/04/2008  
**Spring 2008 QLG Meeting**  
24 - 25 April 2008  
Stockholm, Sweden

### News

07/09/2007  
The date and location of the Spring 2008 QLG meeting have been set. The meeting will take place on 24 - 25 April in Stockholm, Sweden.

25/07/2007  
As you can see, the EORTC Quality of Life Group has a new website... The new website is more user friendly and it truly reflects all aspects of quality of life.

### Questionnaires

**EORTC QLQ-C30**  
*EORTC Modules*

- EORTC QLQ-LC13 (Lung)
- EORTC QLQ-BR23 (Breast)
- EORTC QLQ-H&N35 (Head & Neck)
- EORTC QLQ-OES18 (Oesophageal)
- EORTC QLQ-OV28 (Ovarian)
- EORTC QLQ-MY20 (Multiple Myeloma)
- EORTC QLQ-CX24 (Cervical)

**EORTC QLQ-C15-PAL**  
**EORTC IN-PATSAT32**

Local intranet

## **Item Bank Version 2**

- **New version developed and tested in autumn 2006**
- **Data entry ongoing outsourced since agreement with QLQ -March 2007**
- **1<sup>st</sup> phase completed: all core (65) QLQ-C30 translations incorporated**
- **2<sup>nd</sup> step: (216) translations of the 10 validated modules**

**Delay on EMakina' side due to reformatting in Indian languages (Tamil, Sinhala) and some translations of BR23 and HN35**

- **3<sup>rd</sup> step: remaining translations to be imported: all translations of 20 modules under development - postponed because of delay in 2<sup>nd</sup> step**
- **Managed by Dr. Linda Dewolf at the QL Department and oversight by Teresa Young as QLQ representative**

# Summary

- **QL Department still faces the same marked increase in the projects/administrative tasks with the QLG as reported in March**
- **Major challenge presently is to manage this workload and maintain the quality. This is under review**
- **QL Department 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!**