

EORTC

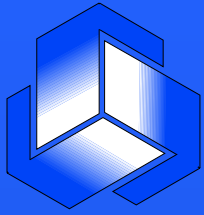
Update on the activities of the Quality of Life Department

Andrew Bottomley Ph.D

Assistant Director, EORTC

Head, Quality of Life Department, Brussels

April 2008



EORTC Headquarters

- **Recent internal re-organization (ongoing)**
 - **Major changes in management and structure**
 - **Fundamentally changing to adapt to the current CT environment, which includes increased 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 (eg. New analysis, time windows, etc)
- 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 QL Department in 2008

Research

Administration

Head of Department
A. Bottomley

HRQOL Specialist
Chantal Quinten

HRQOL Fellow
Francesca Martinelli

HRQOL Fellow
Lily Claassens

Murielle Mauer

HRQOL Statistician
Cornel Coens

HRQOL Fellow
Pending

Research Assistant
Irina Ghislain

Research & Scientific

Translation Coordinator
Linda Dewolf

Secretary/QLG-C30 Admin
Ken Cornelissen

Translation Assistant
Wendy

Administration & Support

Pharma - contracts
Sarah Williams

Clinical Trials Assistant
Sheila Sanderson

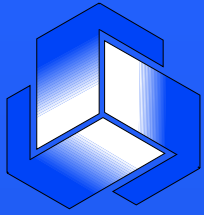
Funded by

Funded by

■ Funded by independent research NCI or independent foundation grants = 7.4 FTE

■ QLG funded position = 3.2 FTE

EORTC



Scientific research activities funded by EORTC Headquarters

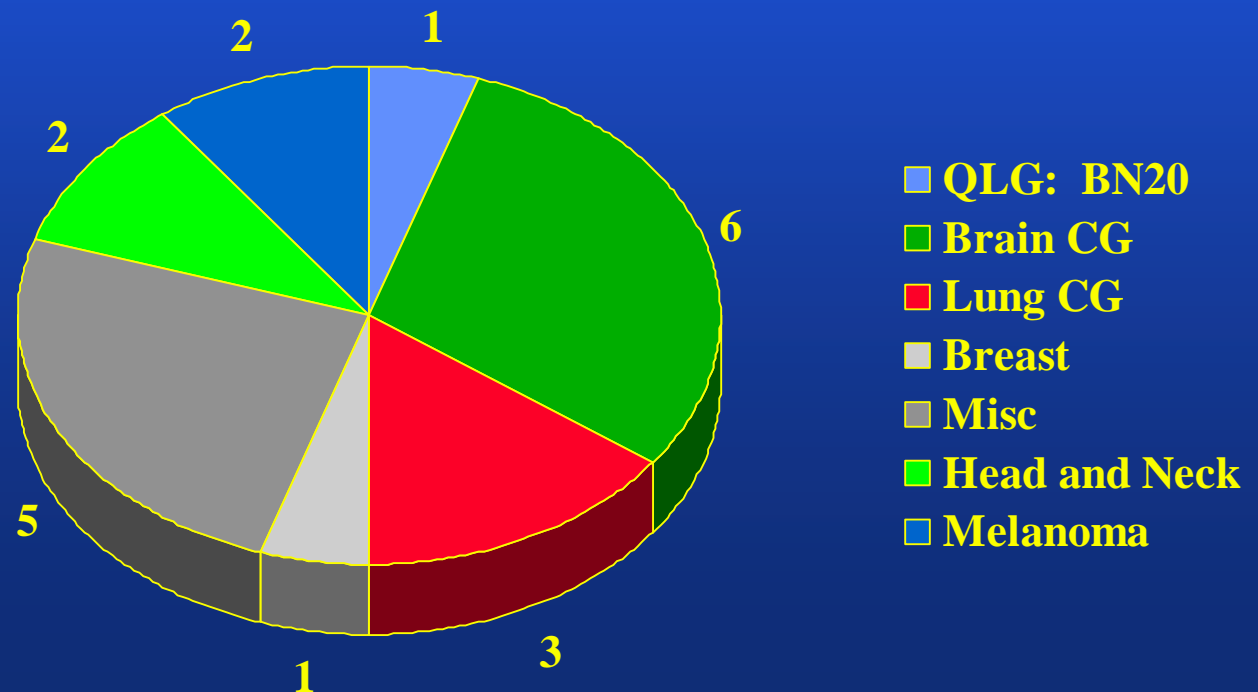
- **Fundamentally now with clinical trials groups in EORTC on trial results**
- **Prognostic factor analysis program**
- **Other methodological analysis and QOL research of limited focus on module development prospective studies**

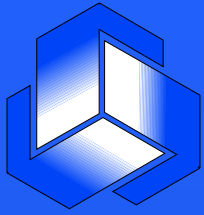
QLD scientific functions: New studies, analysis and preparation of trials and projects

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

+

* **Existing studies** = 20 under pre-analysis/report preparation and discussion in 2007

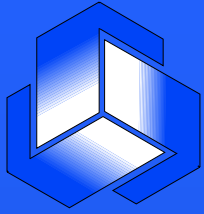




Collaboration with the QLG

- Translations are managed from the department
- Administrative and financial management is done from the department. The department is the front end of the business side
- Management of requests from academia within the department
- Website requests and central coordination and update within the department
- Collaboration on modules and Item Bank – lead from the department
- Support, print and distributed newsletter and other admin tasks by Sheila
- Central depository for module and translation reports
- Help support and coordinate QLG meetings

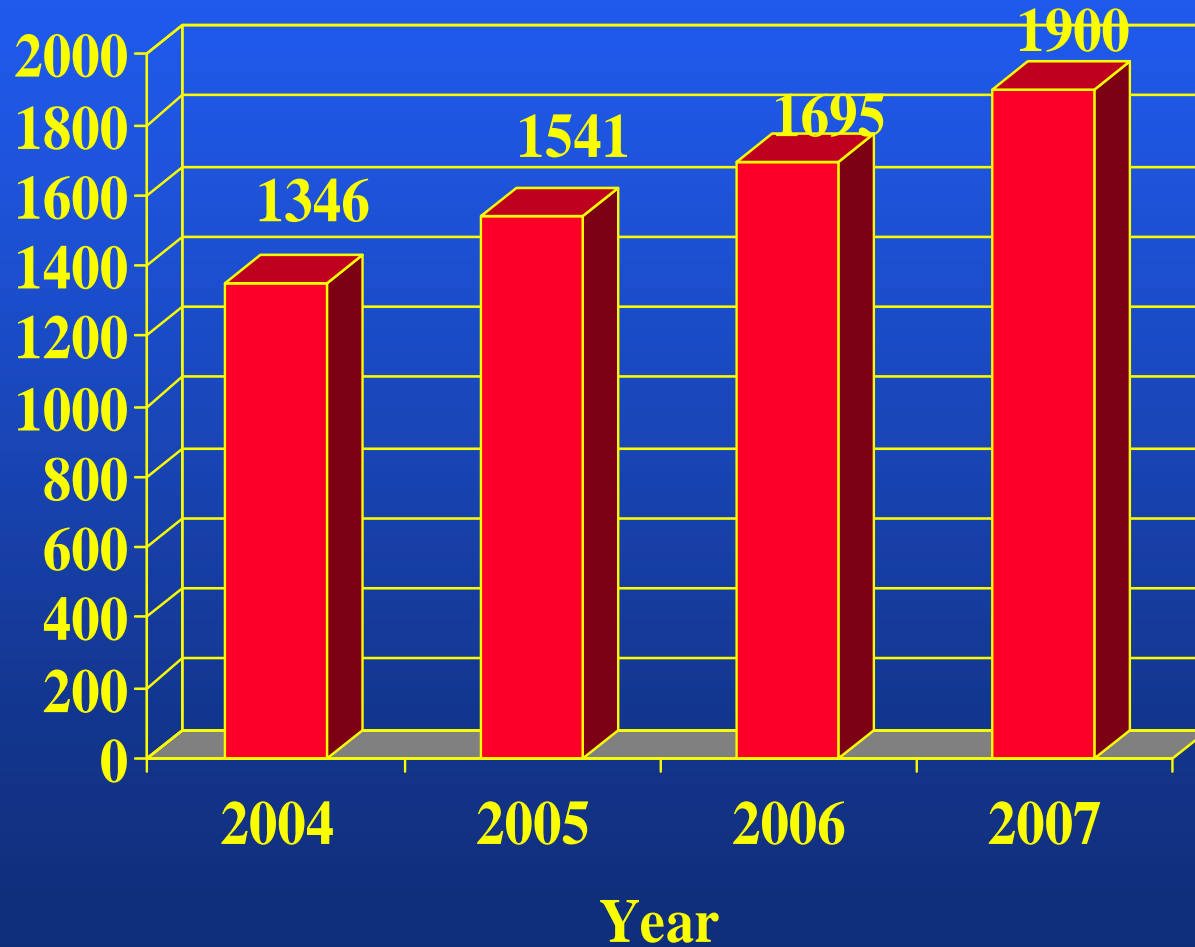
These are significant tasks not to be underestimated. It's like running a business!!!



QLQ-C30 + module administration

Total user's agreements processed

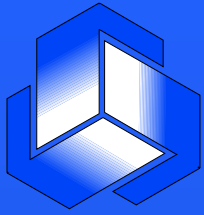
Number of
user's
agreements
processed



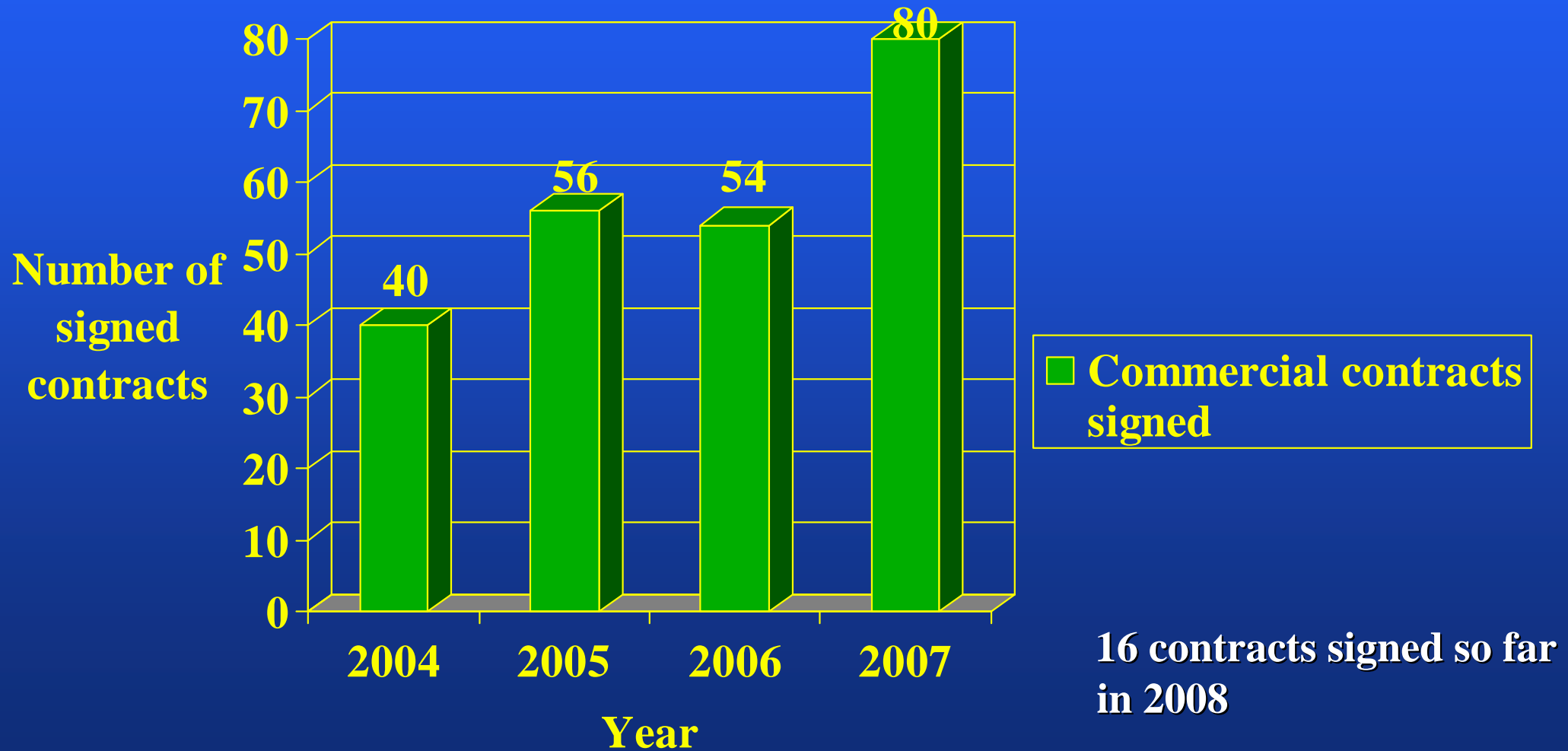
■ QLQ-C30 Academic
Download requests

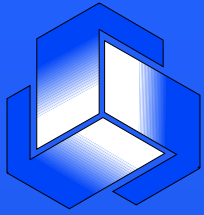
E-mail enquiries per
month 800

EORTC

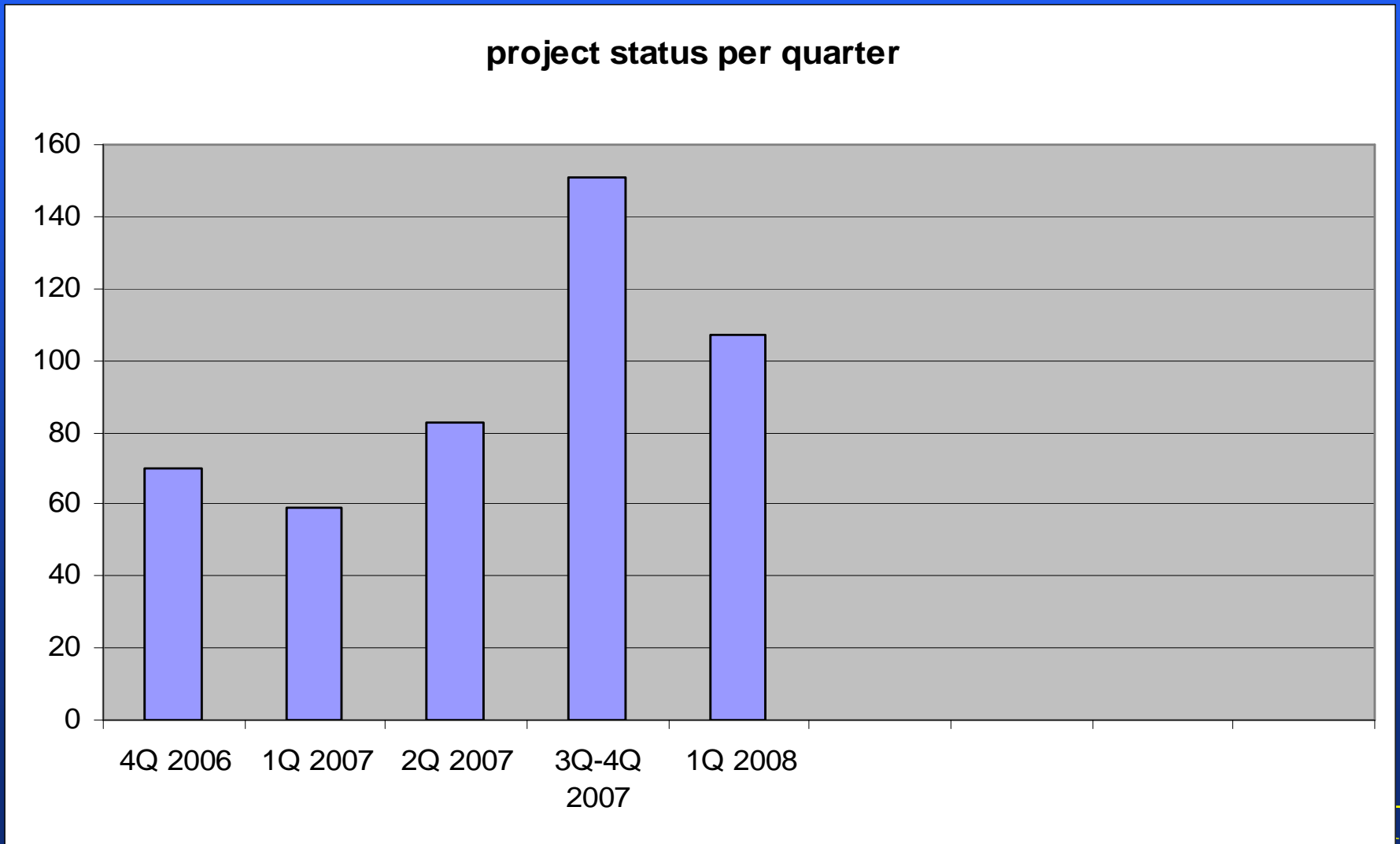


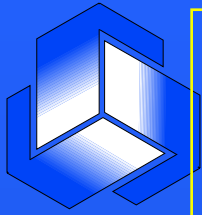
Number of QLQ-C30 contracts signed for commercial studies





QLQ Translations Evolution





Translation programme at the QL Department

- **35** new translations undertaken during the 3 months
- **58** translations ongoing launched in 2006 - 2007
- **14** translations completed during Jan-March 2008
- Translation Quality Assessment process ongoing
- Translation funding implemented as from January for any new contract with the industry - starting to yield good revenue
- Translation manual updating, out soon.....

Production and distribution of QLG manuals, etc.

- **Annual Newsletter, Dr. Martin Taphoorn is the Editor. Local production is done by Sheila Sanderson and Andrew Bottomley with Brief Ink publishers in Brussels. 1000 published last week.**
- **QOL CDs and newsletters still being distributed at various meetings (e.g.: ASCO, ECCO, etc). Only 100 CDS remain.....**
- **Blue books/guidance manuals: All now pending updating, printing and distribution: Most will be electronic only?**
- **All of this distribution is excellent visibility for the QLG**


Website

EORTC Quality Of Life - Microsoft Internet Explorer

File Edit View Favorites Tools Help


Back Forward Stop Home Search Favorites Refresh Mail Print

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

07/05/2007
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

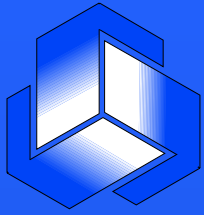
EORTC QLQ-C30
EORTC Modules

- 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

Please help us keep this up to date- if you have an abstract accepted or paper published inform Ken ASAP



Item Bank Version 2

- Version 1 still active and usable
- Revised version 2 developed and tested in November 2006
- Data entry ongoing: outsourced since agreement with QLG - March 2007
- 1st phase completed: all core (65) QLQ-C30 translations incorporated
2nd step: (216) translations of the 10 validated modules

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

- 3rd step: remaining translations to be imported: all translations of 20 modules under development - postponed because of delay in 2nd step
- Managed by Dr. Linda Dewolf at the QL Department and involvement of Teresa Young as QLG ad hoc representative with my occasional input
- Expect all system up and running within a matter of weeks

Ongoing scientific work with QLG

- EORTC PR25 – Draft paper in press, etc.
- BN20 – Draft analysis lead by Martin Taphoorn with others. Draft paper being written
- Support on some module development (ad hoc)
- Joint work on the CCA project

Ongoing independent funded scientific work with other bodies

(approx grants totalling 2 million dollars)

- **EU- Policy making and research**
- **PROBE (Patient reported outcomes and behavioural evidence)**
- **PFA with BGC, Head and Neck, Lung, Melanoma**
- **Other studies on analysis techniques and modeling**
- **Several large research grants under review (ERC/BCS)**
- **Major work with several journals**
- **None submitted to the QLG**

Summary

- **QL Department has a major workload/administrative with the QLG**
- **Major challenge presently is to manage this workload and maintain the quality. With the appointment of ½ time person this will ease things**
- **QL Department scientific focus is on managing clinical trial design, implementation which is also becoming more labour intense and with quicker response times expected**
- **QL Department has an active independent research program (5 other independent research grants) over 2 million dollars of funding so busy with these ventures (eg. PROBE, PFA)**