

Update on the activities of the Quality of Life Department

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EORTC Headquarters



1992



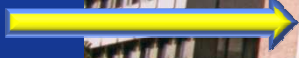
1998



2010



2000



EORTC Staff

From 28 in 1991 to 185 in 2011



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 policy QOL in EORTC trials with all clinical trial groups
- 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**, **item bank**, **academic users** and all **pharmaceutical contracts**

EORTC Headquarters in 2011

- **Key tasks designing clinical trials with 19 clinical groups**
- **Increased registration trials with FDA and EMEA, always with QOL**
- **Continue to adapt to the current CT environment, which includes increased quality standards and participation with industry for clinical trials, but reduced patient recruitment significantly (as across EU);**
- **EORTC HQ continues to evolve over the coming year, we now have 190 staff, some 20 nationalities, network of 2000 clinicians**

Structure of the QOL Department in 2011

Collaborate with QLG and the 19 other EORTC clinical groups

Head of Department
A Bottomley 

Secretary /
Academic Admin
Rossella Guzzo 100% 

Collaborate with MDC Chair

Research
Unit

Admin Unit

Fellow
Francesca Martinelli 

Research
Administrator
Irina Ghislain 

Statistician
Corneel Coens 

Fellow
Efsthathios Zikos 

Fellow
Divine Ewane Ediebah 


Scientific staff funded by
independent research
foundation grants and
core support


Total QLD Research
FTE= 7

Translation
Unit

Translation Team
Leader
Dagmara Kulis 100% 

Communication to
Translation
Committee

Translation Officer
Petra Jeglíková 50% 

Junior Translation
Officer
Maria Arnott 50% 

Commercial
Contracts
Erika Carroll 50% 

Collaborate with QLG treasurer

Clinical Trials Assistant
Sheila Sanderson 

Collaborate with MDC Chair

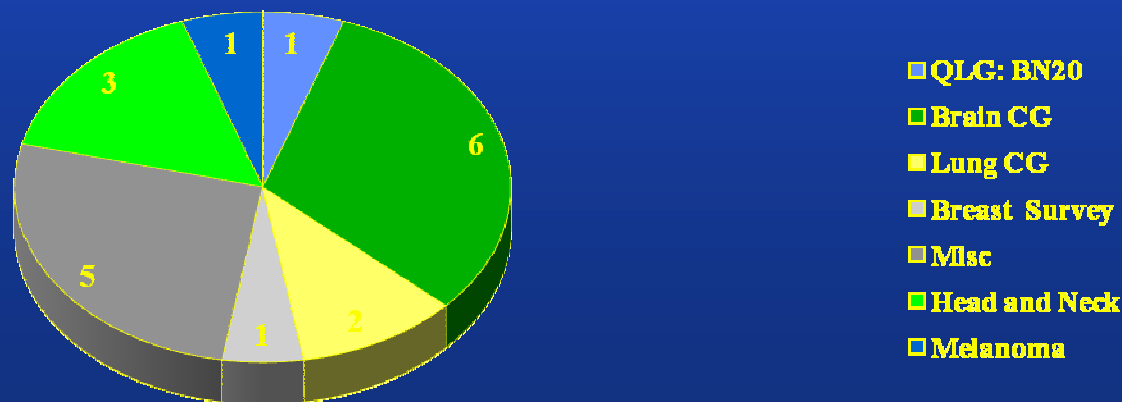
QLG funded
positions Total QLG
FTE= 3.6

Clinical trials

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

* **New Studies** = 7 new RCT's with QOL in 2010 (including 5 registration/fully sponsored).

* **Existing studies** = under pre-analysis/report preparation and discussion in 2010 over 70% of trials sponsord by industry but to EORTC SOPS and regulations



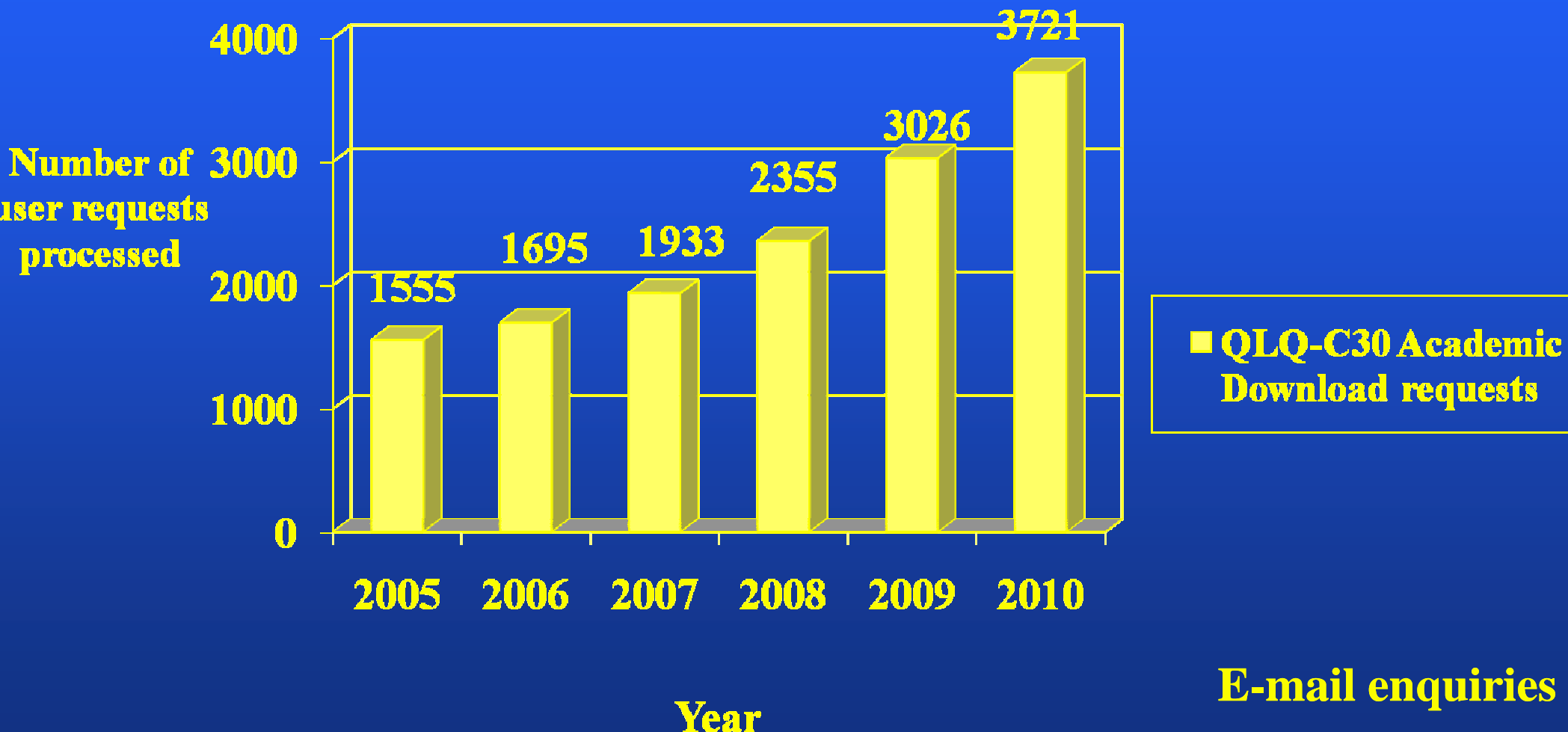
Research on PROBE PROGRAM

- 25 peer review abstracts (17 at ASCO, 5 ESMO, 3 ISOQOL)
- 2 young investigator awards at MASCC (Chantal and Francesca)
- 2 papers published and 10 drafted and in press
- International conference in Brussels, Nov 2009 : invited to China to present this with EORTC STAFF and David Collingridge (editor) of TLO - special session in July 2010
- Great collaborations with other groups such as MRC, NCIC, AGO, and others
- Excellent collaboration with EORTC clinical groups
- Visit our website to see conference as we do it bi-annually – www.eortc.be/probe
- PROBE will continue as we have had funding for this, so major effort and interest and funding and core support

Collaboration with the QLQ

- **Administrative and financial management (over 16 years). The QLD manages over one million Euros per year in income that passes through the department for the QLQ**
- **Translations (new fees generated 103,000 Euros in 2009): on track for 2010.**
- **Management of requests of academia = always increasing**
- **Website requests and central coordination**
- **Collaboration on modules and Item Bank**
- **Support for newsletter and other admin tasks such as meeting organisation**

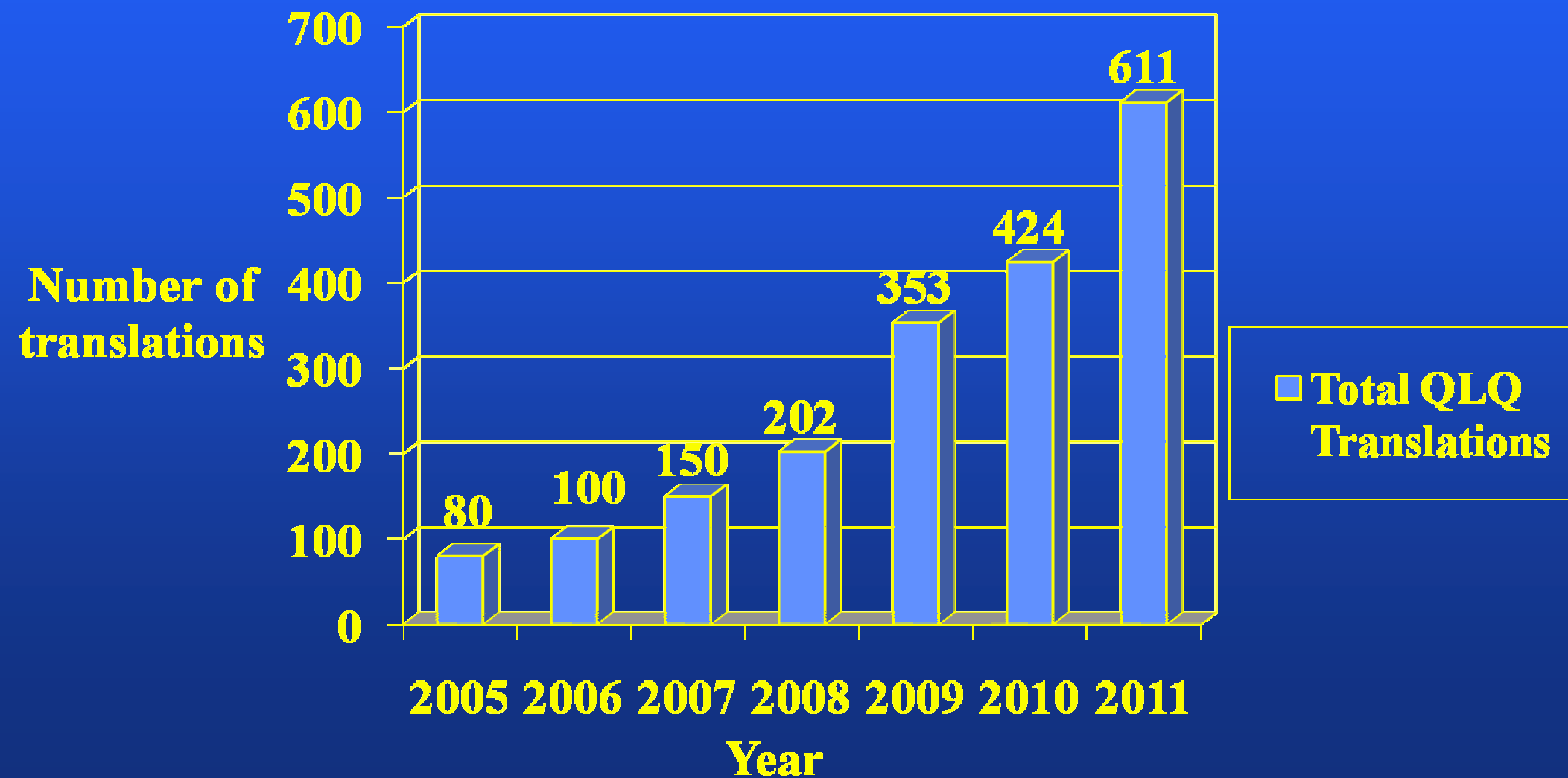
QLQ-C30 + module administration Total user's requests processed



E-mail enquiries
per month 800

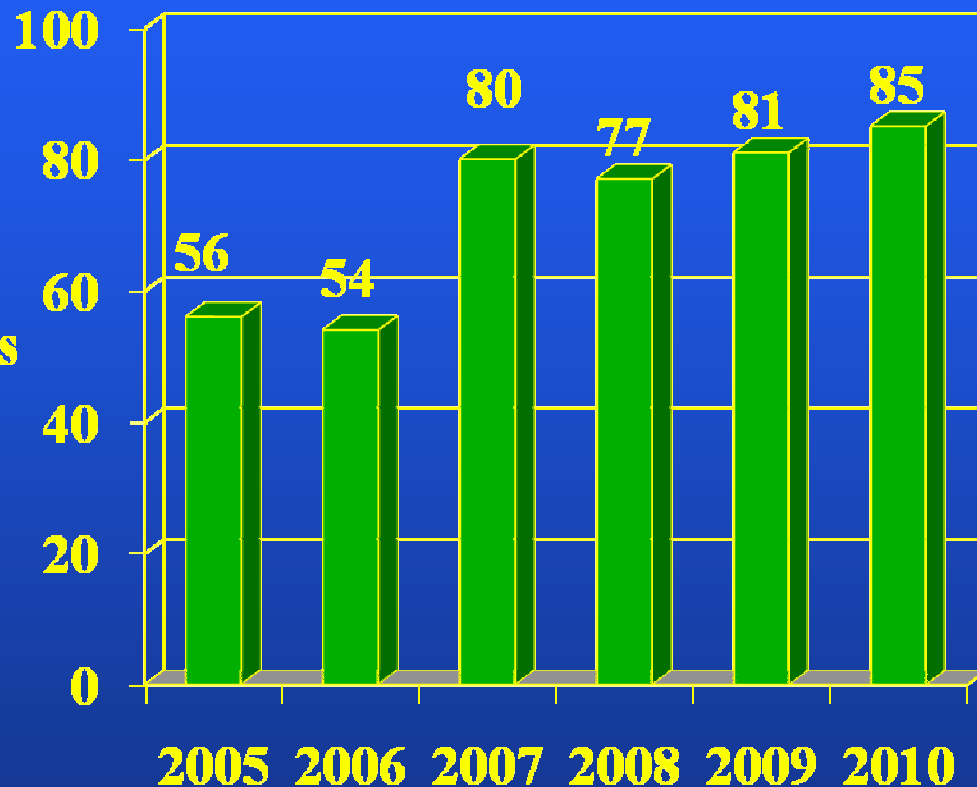
QLQ Translations Evolution

712 including cultural adaptations



Contracts for commercial studies (for using the QLQ-C30)

Number of
signed contracts



■ Pharma contracts -
signed

Year

Highlights:

- **Quality and formatting projects**
- **Presentations and papers about methodology**
- **Addressing the continuously growing number of requests for new translations from pharmaceutical / commercial industry.**

Activities undertaken by the QOL Department for the QLG newsletter (2011)

- Liaison with QLG newsletter editor - proposing and agreeing timetable of what has to be done by when, in order for the newsletter to be ready in time for EGAM. Sending nearly finalized version to QLG newsletter editor for comments and approval.
- Proofreading of all articles following their review by the QLG newsletter editor.
- Liaison with all authors: asking for clarification on article if necessary, asking authors for missing or replacement photos where necessary, sending each author the final version for approval;
- Reviewing quote from graphic designer and requesting approval for budget from QLG Treasurer. Reviewing amendments to quote if necessary.
- Liaison with the Group Secretaries on updating the publications section.
- Liaison with the graphic designer: accepting or rejecting all layout drafts, checking and proposing all amendments, checking changes to all draft versions (eight in total); checking text is all there. Selecting quotes to be part of articles. Making sure contact details of the Group and the Department are as up to date as possible. Giving final approval for printing.

Recent EORTC Clinical Trials

- van Herpen C M L, Mauer ME, Mesia R, Degardin M, Jelic S, Coens C, Betka J, Bernier J, Remenar E, Stewart JS, Preiss JH, van den Weyngaert D, Bottomley A, Vermorken JB. Short-term health-related quality of life and symptom control with docetaxel, cisplatin, 5-fluorouracil and cisplatin (TPF), 5-fluorouracil (PF) for induction in unresectable locoregionally advanced head and neck cancer patients (EORTC 24971/TAX 323), *British Journal of Cancer* 103, 1173-1181, doi:10.1038/sj.bjc.6605860 2010.
- Taphoorn MJ, Claassens L, Aaronson NK, Coens C, Mauer M, Osoba D, Stupp R, Mirimanoff RO, van den Bent MJ, Bottomley A on behalf of the EORTC Quality of Life Group, and Brain Cancer, NCIC and Radiotherapy Groups An international validation study of the EORTC brain cancer module (EORTC QLQ-BN20) for assessing health-related quality of life and symptoms in brain cancer patients. *European Journal of Cancer*. 2010;46:1033-1040.

Quality of Life, Symptom Research and Patient Reported Outcomes in Cancer Clinical Trials

To be held at the European Parliament

7 – 9 September 2011

Brussels - Belgium

Aim of the Symposium

Covering a broad range of topics in HRQOL

Addressing recent developments of EORTC tools for use in clinical trial

Discussing international developments and research oncology

Making EU legislators interact with EU patient groups to foster a greater collaboration

PROBE



The Symposium organisation is a priority for PROBE following the success of the previous edition in 2009

Registration to attend the Symposium is available on Probe website www.eortc.be/probe

The Patient's FACE

Forum Against Cancer Europe promotes the collaboration between the European Cancer community and European Parliamentarians.

It has been set up by the European Cancer Coalition (ECC) representing more than 300 cancer patient groups across 42 countries

- **International Faculty**
- **European Parliament**
- **European Parliamentary Group GUE/NGL**
- **Cancer Patient Representatives**

Thank you