

EORTC

**Quality of Life Unit Functions and
Research: A focus for the Quality of Life
Group**

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Management of the EORTC QLQ-C30 and Modules

- QLQ-C30 (QLU started admin management in 1993)
 - Most frequently cited/used measure in cancer
 - Main workload of QLU is admin of the QLQ-C30 (Ken)
 - ◆ 2002 = 200 enquiries of any sort per month (phone, email)
 - ◆ 2004 = 500 enquiries of any sort per month (phone, email)
 - Last six months = 660 **signed academic users**. Approx. 1200 **signed users a year**
 - 8500 user's agreements signed since records began
 - Demand + but less staff resources - system under pressure

Requests for Technical Support

Academic Users

- QLU historically attempted to provide this support
- Greater use/publication of modules = more demand
- FAQ web page (20 people per week)
- Specific module developers will be proposed as contact for technical questions regarding modules

Industry users

- QLU provides this service quickly within a couple of days
- Feedback from industry welcome central resource at the Data Center

Translation Program

- Large and important part of non research work for the QLG is coordinated by Karen West in Brussels Data Center
- A QLG translation committee has been established lead by Dr. Michael Koller
- Key issues are ensuring high quality is maintained
- Karen West is supporting this committee

Recent translations – 71 new or ongoing

QLQ-C30

New: Punjabi

Ongoing: Burmese, Indonesian, Malay, Sinhali, Tagalog & Telegu, Pushto, Vietnamese & Icelandic

Validated Modules

H&N: New: Greek

Phase III / IV Modules

BLS24: Greek **New:** Gujarathi, Hindi & Marathi

BLM30: Chinese & Greek **New:** Arabic, Gujarathi, Hindi & Marathi

BN20: Arabic, Czech & Korean **New:** Finnish, Hungarian, Polish & Russian

CR38: Turkish **New:** Afrikaans, Russian & Zulu

INFO30: Korean

LMC21: **New:** Dutch

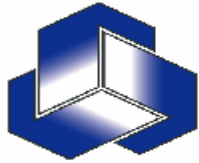
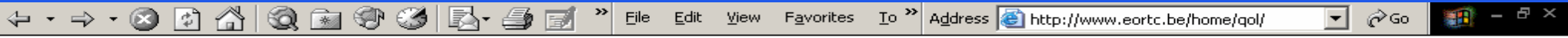
NET35: French, German, Italian, Norwegian, Spanish & Swedish **New:** Bulgarian, Czech, Croatian, French Canadian, Finnish, Hungarian, Norwegian, Polish, Portuguese Brazilian, Romanian & Russian

PR25: **New:** Gujarathi, Hindi & Marathi

SAT32: Icelandic **New:** Lithuanian, Turkish

STO22: **New:** Russian

Web Site



Welcome to the EORTC Quality of Life website



EORTC Quality of Life Group

- [History](#)
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EORTC Quality of Life Unit

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Questionnaires

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Documentation

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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.

As Quality of Life has become increasingly important within the EORTC, it has become necessary to develop a website to highlight this area of research within the EORTC. These pages aim to give an overview of the activities of the Quality of Life Group and the Quality of Life Unit.

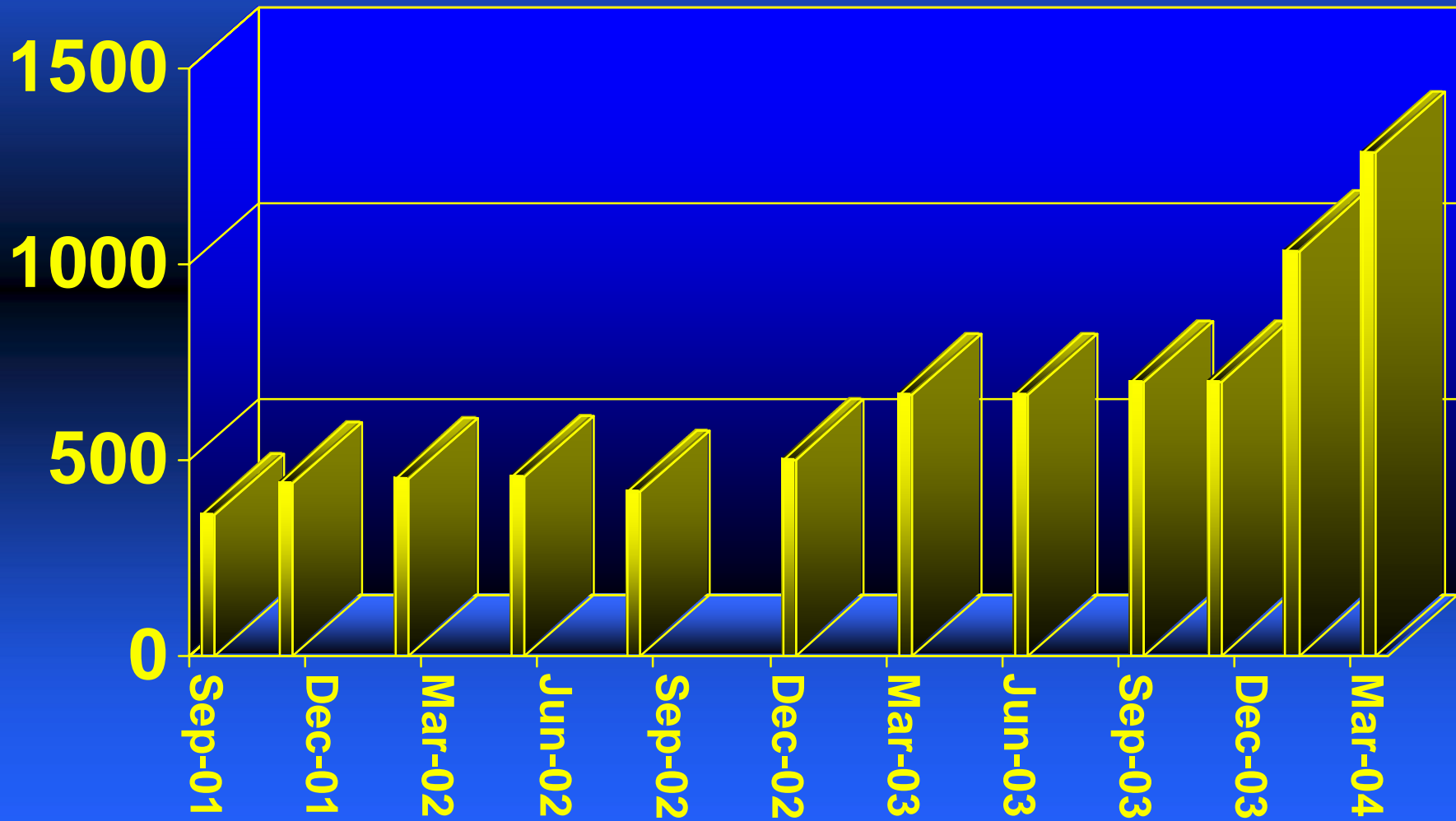
For comments / suggestions about the web site, send a mail to [webmaster](#)

Last updated: 31 March 2004

Download QLQ-C30 & modules

[Programme Quality of Life Group Meeting, Brussels, 23 - 24 April 2004](#)

Average monthly visits to the QOL home web page (2001-2004)



QLQ-C30 downloading statistics

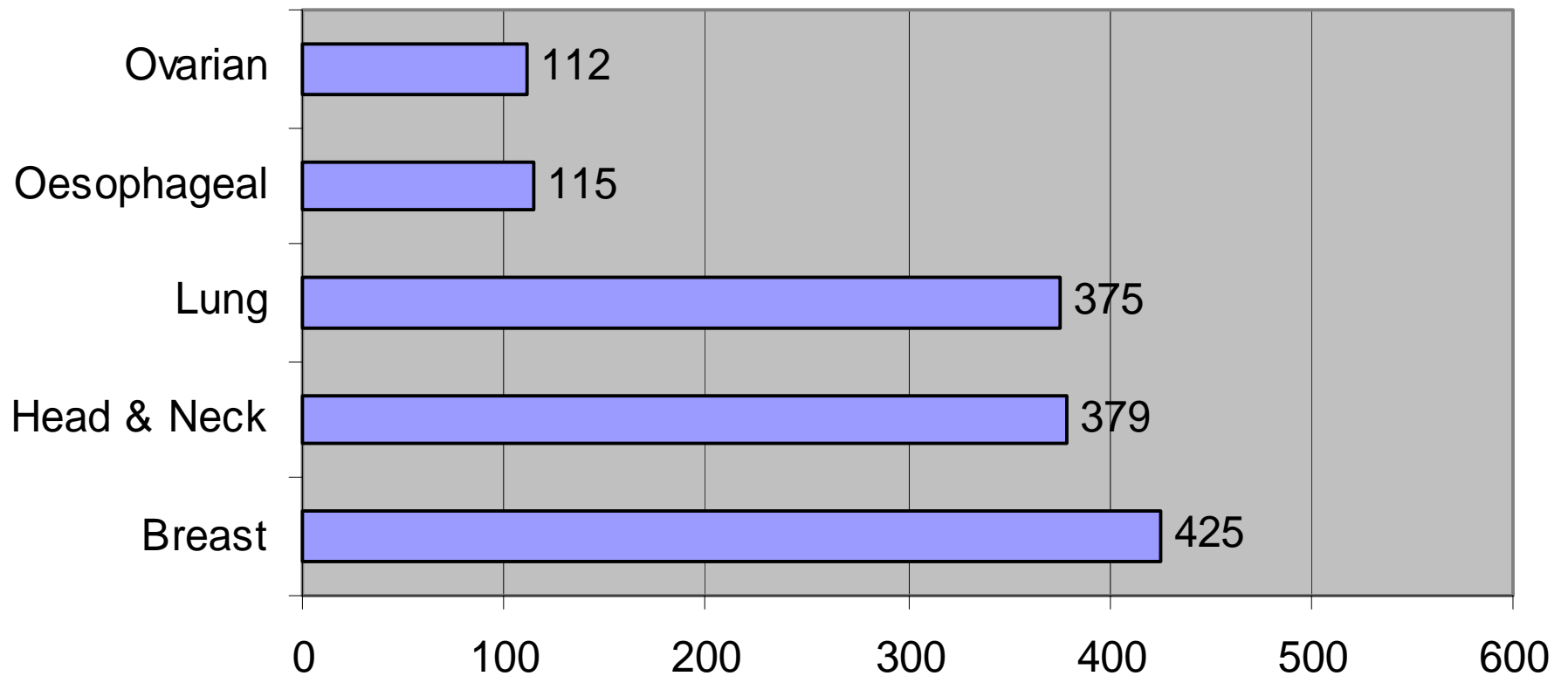
“Where did you hear about the EORTC QLQ-C30?”

640 records from the 1st October - 1st April 2004

- Literature 310 (49%)
- Academic colleague 161 (25%)
- Internet 81 (13%)
- Conferences 57 (8%)
- QLQ-C30 CD 32 (5%)

Which phase 4 module is downloaded the most often (one year data 2003)

Modules requested



Item Bank


Web based database of over 400 QLG questionnaire items

Login to the Item Bank - BETA Version - Microsoft Internet Explorer provided by EORTC

File Edit View Favorites Tools Help

Back Forward Stop Home Search Favorites Media Print Mail

Address <http://www.eortc.be/itembank/> Go Links

 **EORTC**
Quality of Life Group
ITEM BANK

Version [1.0]

The Item Bank is a database including all items from EORTC Quality of Life modules from Phase II to Phase IV. This program allows you to conduct a search on the various existing items. It provides information on item development, translations, bibliography, and other essential details.

To enter the database, please click [here](#)

If you have any problem, please click on [help](#)

Found a bug ? Click [here](#)

Internet



You are now in the Item Bank program.

To conduct a new search, please click on

If you would like to create a new Item List :

New Item List Name Version

Item List first number

Click 'new' to open a new item list

If you would like to open an item List you had previously created, please choose the name here:

Existing Item Lists

Would you like to :

To rename an existing Item List, please specify its name and version, enter the new name and click "rename". If you just want to change the Version or first number, proceed the same way.

To make a copy of an existing Item List, please specify its name and version, enter the name of the copy and click "copy"

Existing item list

New Item List name New version

New item List first number

If you have any problem, please click ["HELP"](#)

To change your password, click [here](#)

[Log off](#)

**QLG research based
activities in the Quality of
Life Unit**

=

**3 EORTC QLG Field
Studies**

**Designed and then conducted from the EORTC
Quality of Life Unit with QLG SC in Brussels**

QLG Recently Closed Field Study

QLQ-STO22

Jane Blazeby et al

**Activated
March 2001**

**Total patients recruited =
267 (estimated 253)**

**Analyzed in
Jan/Feb 2004**

Paper in draft

QLG Ongoing Field Studies

QLQ-PR25

Activated
21 March 2002

Total patients recruited =
573 (estimated 625)

Recruitment closed to
selected groups

Closing summer
2004

**Neil Aaronson/
George van Andel
et al**

**Recruitment mainly by
GU members (>80%)**

QLG Ongoing Field Studies

Anne Brédart et al

QLQ-SAT32

Activated
14 Feb 2002

Total patients recruited = 616,
Recruiting at selected centers only,
(estimated 768)

Expected completion
Summer 2004

Summary

QLG/QLU related non research based functions

- Increased demand for QLQ-C30 is challenging, admin is increasing as users increase

QLG/QLU scientific functions

- Two ongoing field studies. Good progress, closing in two months. Awaiting concrete plans for new research/field studies