

and the patient's self-rating are viewed as being equally important and used as complementary methods. When selecting or developing instruments, the individual rating of the different dimensions must be taken into account as well as the time frame of the evaluation protocol. The selected method of assessment is generally one of the following: questionnaire, interview or diary.

When selecting tests to be completed by experts or patients, it is important that the psychometric properties, the validity and the reliability, are known. A critical problem in assessing quality of life is the responsiveness of the measure and its ability to respond to changes over time. Global measures may lack the ability to detect small but important clinical changes in specific patient samples. Therefore it is highly recommended to use an instrument with documented psychometric properties and one which is known to apply to the specific research question and to encourage the development of specific oncological quality of life instruments through interdisciplinary co-operation.

The basic sociodemographic characteristics should be assessed in a standardised way for descriptive or comparative purposes.

#### 4. Study design

The objective of assessing the influence of therapy on quality of life can only be achieved by longitudinal studies. Patients should be assessed prior to beginning treatment if responses are to be monitored over time. Given the present state of knowledge, cross-sectional studies, as pilot studies, may be desirable and useful.

The initial evaluation point and the intervals between assessments are to be planned *a priori*, according to the specific questions of the study. It is important to differentiate between short, medium and long-term effects and side-effects of a given therapy. Therefore the assessment protocol should have a meaningful relation to the therapeutic intervention and its outcomes (responsiveness of the tumour, toxicity and other side-effects). Other essential measures of supportive care should be described.

#### 5. Data collection

The first step of data collection is to obtain informed consent from the subject after the objectives and procedures have been explained. Further, the primary physician, if he or she is not conducting the study, must be involved in the consent process. The routines of data collection (time, location, and who does it) must be clearly defined. Reasons for missing data and protocol deviances should be well documented. Generally it is recommended that data collection takes place during active treatment and follow-up.

#### 6. Data analysis and interpretation

It is essential that a biostatistician/methodologist be involved in the planning and execution of the study and not only consulted when the data are ready for analysis. The assessment of quality of life must be an integral part of the whole study protocol. Appropriate statistical procedures must be selected and employed according to the purpose and design of the study and the available data.

The assessment of changes in quality of life parameters should be analysed both in terms of individual patient responses and between groups. According to existing information, extensive intra- and interindividual variance is to be anticipated and must be taken into account when making group comparisons.

Quality of life data are to be analysed and interpreted within the context of medical data and statistically significant differences are to be examined in relation to clinical relevance. Missing or incomplete data must be described and accounted for when performing the analyses and interpreting the results.

#### 7. Conclusion

Research in quality of life in oncology has become a top priority. The examination of relevant clinical questions and the development of appropriate methods can only be done in a meaningful way if participating individuals work in the spirit of interdisciplinary co-operation.

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#### ECL Fundraising Survey 1989

The Association of European Cancer Leagues (ECL) has updated its European Fundraising Survey. The 1989 survey describes the development of the fundraising activities within 18 cancer leagues from 17 European countries, including additionally the American and the Canadian Cancer Societies.

In 1989, the ECL members raised a total of US\$432.7 million. The American Cancer Society raised US\$358.1 million, and the Canadian Cancer Society raised US\$65.4 million. The funds raised per inhabitant were US\$1.2, 1.4 and 2.5 respectively.

The survey uncovers rather extreme differences between the ECL countries, from US\$0.2 to 10.4 per inhabitant (Figs 1 and 2); and the development from 1985 to 1989 (Fig. 3)—although indicating a steady overall growth in funds raised—also shows that the growth is very unevenly distributed. This is illustrated by the growth span described by the three fastest and slowest growing societies respectively.

To some extent, the differences described in the survey is of course explained by the different socioeconomic structures of the ECL countries. Also, some countries have cancer leagues which were not covered in the survey. Still, however, the differences are surprisingly large between countries where the basis for fundraising should be very much the same. This then can only be explained by the national cancer leagues' different approaches to fundraising, that is, by the differences in the principles and practices applied in building professional fundraising organisations within each league.

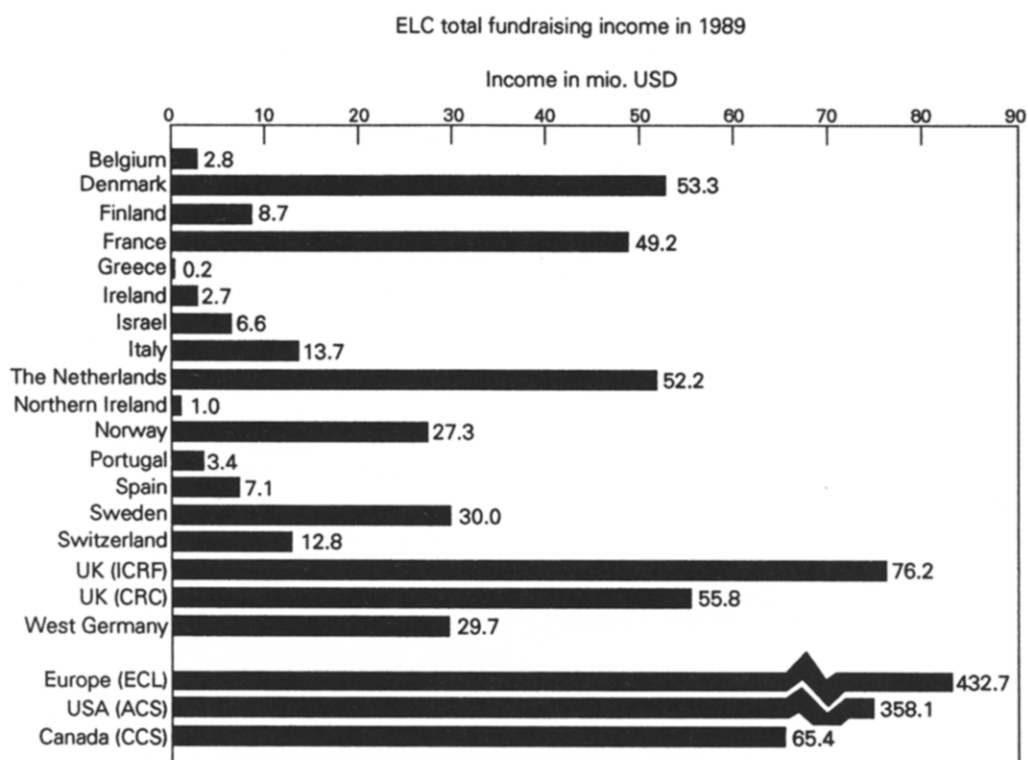


Fig. 1. ECL total fundraising income in 1989 (income in US\$ million).

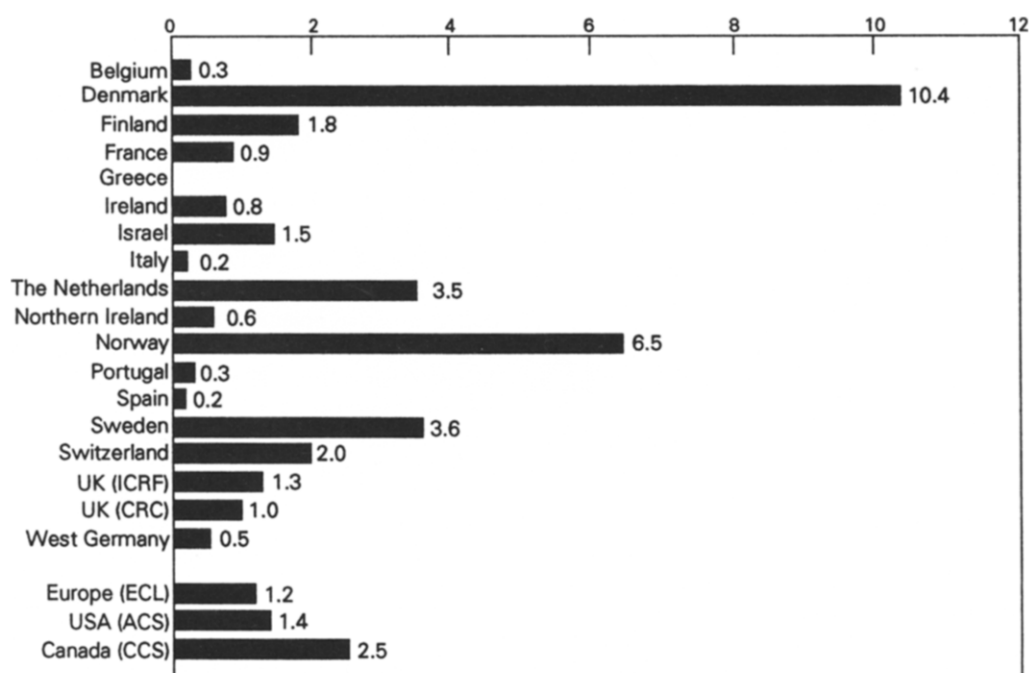


Fig. 2. ECL fundraising income per inhabitant in 1989 (income per inhabitant in US\$).

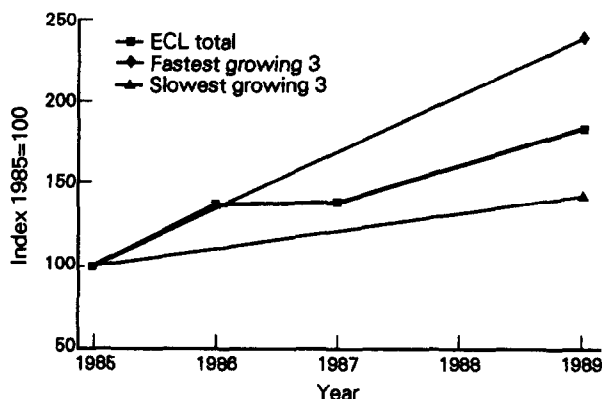


Fig. 3. ECL income index span 1985–1989 (current prices).

Indirectly, the Fundraising Survey thus uncovers unexploited possibilities for fundraising, and also the need for a closer cooperation between the ECL members in this field of activity.

Tor Øyan  
Head of Analysing Section  
Danish Cancer Society

### More Members and More Activities in ECL

At the General Assembly of the Association of European Cancer Leagues (ECL), 28 October 1990 in Amsterdam, five more cancer leagues became members of the Association, including the newly established cancer leagues in Czechoslovakia, Hungary and Poland. The ECL comprises now 23 national cancer leagues from 21 European countries.

The ECL will in 1991 create the framework for a number of joint project and programmes such as:

- an ECL meeting in January on strategies of the national cancer leagues in the EC in connection with the EC "Europe against Cancer" programme
- an ECL workshop in April for telephone help lines
- a specialised professional ECL workshop on fundraising
- an ECL conference in October on "The role of the cancer league dealing with unproven methods"
- a revised agreement regarding the exchange of new information between the national cancer leagues
- an ECL short-term staff fellowship programme
- bilateral agreements between national cancer leagues for the transfer of experiences and technology.

Bilateral agreements have so far been established between the following leagues: the Polish Committee for the Fight against Cancer and the Dutch Cancer Society, the Czechoslovakian League against Cancer and the Norwegian Cancer Society, and the Hungarian Cancer League and the Danish Cancer Society. Further bilateral agreements are under negotiations.

Ole Bang  
President  
The Association of European Cancer Leagues

### Cytokines in the 1990s

A meeting entitled Cytokine Use in the 1990s: Past, Present and Future will be held on 15 February 1991, at the San Diego Le Meridien Hotel at Coronado San Diego, California. The meeting is sponsored by the Department of Medicine University of California, San Diego. For further details, contact Meeting Management, 5665 Oberlin Drive, Suite 110, San Diego, CA 92121, U.S.A. Tel (619) 453-6222, fax (619) 535-3880.

### Retirement of Professor Maurice J. Staquet

31 December 1990 marked the departure of Professor Maurice J. Staquet as Director of the EORTC Data Center and EORTC Coordinator for EUROCODE.

Dr Staquet received his MD degree from the University of Brussels where he also obtained a postgraduate degree in Cardiology. He completed a Master of Science Degree in Biostatistics at the School of Public Health, Columbia University, New York.

Dr Staquet held various posts in teaching, research and medicine with the Hôpital St Pierre, the Institut Jules Bordet, the University of Brussels, the New York Medical College, the Amsterdam School of Tropical Medicine, the National Cancer Institute in Bethesda, and the National Center for Polar Research. He was also Visiting Professor at the Stanford School of Medicine in California for five consecutive years. In recognition of his work in Antarctica, he was honoured with the Decoration of the Chevalier de l'Ordre de Léopold II.

He is the founder of the International Society of Clinical Biostatistics and a member of the Society of Clinical Trials and other societies. Dr Staquet has published more than 200 articles in the field of medicine. He is also member of the editorial board of both medical and statistical journals. He is presently the executive editor of *Melanoma Research*.

In 1969 Dr Staquet became the EORTC Coordinator for Clinical Trials and a member of the Council and the Board of Directors of the EORTC. In 1976 he became the Director of the Data Center. Under his leadership the Data Center has grown 5 fold and has become an internationally respected centre for cancer clinical trial design and analysis. In 1983 Dr Staquet received the Medal of the Académie Royale de Médecine de Belgique on behalf of the EORTC.

On the occasion of the departure of Dr Staquet, the EORTC Data Center staff organised an Open House in his honour in the new Data Center premises. This occasion was attended by more than 300 visitors from all over the world and was concluded by a private evening reception where all the Data Center personnel expressed their thanks to Dr Staquet and wished him the best of luck in his future endeavours.

Dr Staquet will continue his activity of Professor of Medical Ecology at the Brussels Free University and as the coordinator of the European Collaborative Group for Pain Research ("Europain").

Richard Sylvester  
Acting Director  
EORTC Data Center