



Carmine Zoccali

ERA-EDTA President
Jorge Cannata-Andía
Oviedo, Spain

Registry Committee

Carmine Zoccali (Chairman)
Reggio di Calabria, Italy

David Ansell
Bristol, United Kingdom

Christian Combe
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Staff

Kitty Jager
Managing Director

Paul van Dijk
Medical Information scientist

Ronald Cornet
Senior IT Specialist

Friedo Dekker
Senior Epidemiologist

Vianda Stel
Epidemiologist

Anneke Kramer
Medical Information scientist

Annick van den Broek
Datamanager

Gita Guggenheim
Secretary

QUEST Project approved by PHEA (Public Health Executive Agency of the European Union)

From Carmine Zoccali, ERA-EDTA Registry Chairman and Kitty Jager, ERA-EDTA Registry Managing Director

In general, renal registries in Europe collect very basic patient data. A number of National or Regional Renal Societies have successfully extended the scope of their Registries or are in the process of doing so, but until recently the information included in these databases was mainly used for dialysis centres planning and to produce information on patient outcomes. On average, EU countries spend about 3% of their overall health budget on renal replacement therapies. Therefore monitoring the quality of care is fundamental for professional, financial and ethical reasons. In fact, the European scenario is rapidly changing and patients, health authorities and doctors now increasingly demand information on the quality of care of dialysis and transplant patients.



Kitty Jager

The European Renal Association-European Dialysis and Transplant Association (ERA-EDTA) has made major efforts to produce and promote evidence-based clinical practice guidelines for dialysis and transplant patients, the European Best Practice Guidelines (EBPG). These well conceived guidelines have been widely "disseminated", but their actual impact upon clinical practice still remains a black box in the majority of EU countries. Producing solid databases allowing direct comparisons of EBPG goals with actual clinical achievements is the basis for quality improvement programs. There is a widely perceived need of a gradual transition of Registries toward systems capable of sustaining these programs and a few registries have already successfully extended the breadth of their data collection to start quality improvement programs.

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A Summary of the QUEST Calcium-Phosphate-Bone Working Group

From Dimitrios Memmos, on behalf of the Working Group

The task of the first QUEST Convention, in Toledo, was to set up a large clinical database, including the most important parameters in the area of calcium and phosphate metabolism and to formulate new research protocols. Our proposed clinical performance measures (what to collect, how and when) on calcium and phosphate were: A. Demographic data, B. Clinical information, events and outcomes. C. Biochemical data and D. Management data. There was a separation of these data to (a): Basic essential (b): More complete-expanded data. The parameters of (b) were not included in the present study.



P. Messa, C. Tielemans and D. Memmos

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Expanding the evidence base, a call from 150 years ago

From David Ansell, ERA-EDTA Registry Committee Member



In the 1850s Florence Nightingale argued strongly that only by collecting and analysing pertinent data was it possible to determine the extent to which hospitals and other public institutions were effective in serving those who relied on their help.

“In attempting to arrive at the truth, I have applied everywhere for information, but in scarcely an instance have I been able to obtain hospital records fit for any purpose of comparison. If they could be obtained, they would enable us to decide many other questions... They would show [the taxpayers] how their money was being spent [and] what amount of good was really being done with it...” (Florence Nightingale - Notes on Hospitals, 1859)



Florence Nightingale

Her father was an expert in statistics and one of the pioneers in the embryonic field of epidemiology. Florence shared his interest in statistics and made extensive use of statistical analysis in the compilation, analysis and presentation of data on medical care and public health. She was also insistent that the knowledge gained from the analyses must then be the basis for effective action. Today, after 150 years, the same motivation is the basis for evidence-based approaches in Medicine, in Public Health, in Nursing, in Nephrology and the ERA-EDTA Quest initiative.

The international renal community has established many standards that we should achieve in patients under

the care of nephrologists. In some countries, governments are legally mandating a requirement to achieve these standards even though practical methods to achieve the standards are poorly documented.

When the UK Renal Registry was set up to collect comparative data relating to quality of care, the consensus in the UK, as in many other countries, was that physicians were all doing the best possible for our patients and there was probably little difference between centres. The UK Renal Registry has been collecting quarterly data on dialysis and transplant patients for almost 8 years and has demonstrated that this may not be the case. The latest Report continues to show statistically significant differences in the achievement of haemoglobin, ferritin, PTH, phosphate, calcium, albumin (BCP or BCG assays), blood pressure, Urea Reduction Ratio, and bicarbonate between centres (X2 $p < 0.001$), which are not readily explained through case-mix and local circumstances. While these differences are no doubt multifactorial the question of how to reduce them and reliably achieve outcomes in line with Clinical Practice Guidelines remains.

Since the 1970s quality control methodology in industry has produced huge improvement in the quality of manufactured goods. Do we have anything to learn from their example, in addition to the lesson that monitoring quality control takes time and carries financial cost?

In the USA the ‘100,000 Lives’ Campaign, a nationwide initiative of the Institute for Healthcare Improvement to significantly reduce morbidity and mortality in American health care, has been a considerable success. The campaign was the first national effort to promote saving a specified number of lives by a certain date (June 14, 2006) through engaging US hospitals in a commitment to changes that were known to improve patient care and prevent avoidable deaths.

In Nephrology, much of the data we have is observational and the neg-



David Ansell

ative all cause mortality results from recent interventional studies (Hemo, 4D, CARE, ALERT, DCORR) have not been helpful in indicating the direction we should be taking. If we are achieving the current standards, increasing dialysis dose further, decreasing serum cholesterol or serum phosphate will not be the nephrology ‘100,000 lives’ equivalent. We need to first monitor the standards, to show what is being achieved, and then investigate the methodologies of centres who are doing better than average. Other targets for the nephrology ‘100,000 lives’ would be improving vascular access (reducing lines and line sepsis) and reducing late referral. In 2005, the UKRR reported nationally on the large variation in provision of vascular access between the centres within the UK. A similar international survey under iDOPPs has highlighted similar large variations between different countries.

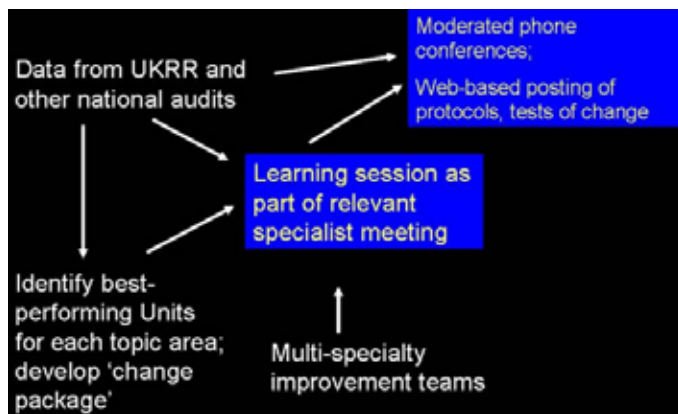
The UK has been a leader in the publication of our data analyses, with each centre being clearly identified. This data has also been made openly available on the web for both the patients and general public. In spite of this easy accessibility in comparing data, there has been no systematic use of the data to study the underlying differences in unit management processes or to attempt a reduction in centre variation. This year, the UK renal community has negotiated funding from the Government, to establish Quality Initiative teams to moderate discussion groups and to teach im-



provement methodology. A much more active quality assurance culture is in prospect, which the figure illustrates.

As a parallel development the ERA-EDTA Quest initiative will extend the ERA-EDTA dataset collection, through development of a European standard for transmission of data between renal IT systems. This will promote quality control activity and

the comparison of data between renal units, nationally and internationally. There is inevitably some apprehension by nephrologists around centre identification in reporting data, and the UK experience should help alleviate some of this concern. And point to ways for effective implementation of the evidence base.



Contributions to the ERA-EDTA Registry as of July 1, 2006

- registries contributing individual patient data to the ERA-EDTA Registry database
- registries sending selected aggregated data to be included in the annual report
- no registry/no contribution/data not eligible for analysis



A Summary of the QUEST Calcium-Phosphate-Bone Working Group

From Dimitrios Memmos, on behalf of the Working Group

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Possible research protocols are: Collection of calcium and phosphate metabolism parameters in patients on haemodialysis or CAPD, in patients with stage 3 and 4 chronic kidney disease and in the transplant population.

The task of the second QUEST Convention in Istanbul was to assign priority (numbers) to each parameter and to prepare a list of properties of parameters to be collected. The priority list of data of calcium and phosphate is: 1) calcium (total), 2) phosphate, 3) PTH, 4) phosphate binders, 5) active vitamin D analogs, 6) calcimimetics, 7) albumin, 8) dialysate calcium, 9) parathyroidectomy, 10) hospitalisations, 11) height, 12) dry weight, 13)

bone fractures, 14) calcifications, 15) aluminum.

In Vienna, additional data for paediatric patients were added to the priority list of parameters. These were pubertal status, bone mineral density and growth hormone therapy.

The **ESBONET Study: European Study of Bone and Mineral Metabolic Disorders in Renal Transplantation** has been proposed by Jorge Cannata-Andia. The aim is to survey bone and mineral disorders after renal transplantation in Europe. There was a lot of discussion about this European multicenter, open, observational, prospective cohort study. About 3500 incident renal transplant patients with a functional graft, at 3 months after

transplantation, will be included. The duration of the study will be 5 years. Patient data will be recorded every 3 or 6 months and gathered in the data base of the ERA-EDTA Registry.

Parameters of this study are: demographic data, medical history, life style, weight and height, creatinine, GFR, calcium, phosphate, PTH, 25(OH) and 1,25(OH)2D, albumin, glucose, haemoglobin and lipids, DEXA, fractures, bone status, hospitalizations, mortality, diabetes, blood pressure, transplant rejections and treatment with steroids, immunosuppressive drugs, calcium, diphosphonates and statins.

QUEST Project approved by PHEA (Public Health Executive Agency of the European Union)

From Carmine Zoccali, ERA-EDTA Registry Chairman and Kitty Jager, ERA-EDTA Registry Managing Director

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In 2004 the ERA-EDTA Registry put these problems at central stage in the ongoing collaboration with national Registries and the QUality European STudies (QUEST) initiative is an important result of this interaction. An essential step of this last initiative is that of establishing standards for high quality data collection. This is a tantalising task which requires important investment in human and financial resources.

To fund this part of the QUEST initiative, the ERA-EDTA submitted a specific project to the European Com-

mission in 2005. This first project was much appreciated, but it did not receive a score sufficiently high to be financially awarded. We have built upon this useful experience and submitted another grant application in 2006 with a project named Nephro-QUEST to clearly point out the renal aspect of the project.

To our great satisfaction Nephro-QUEST has been selected for funding by the European Commission. Currently, we are in the process of negotiations with the EC, but we feel that receiving a high score and being se-

lected for funding is a great achievement for the ERA-EDTA Registry and all national and regional registries participating in this grant application.

The recognition of the importance of our work by external experts is an extra boost to further strengthen our collaboration at the European level. We feel this is undoubtedly a big step forward for the QUEST initiative and we are determined to further set the stage for the quality improvement programs that European nephrologists dream of.

The Sixth ERA-EDTA Epidemiology Course will be held in Thessaloniki (Greece) on February 10-12, 2007

On February 10-12, 2007 the ERA-EDTA Registry organises the sixth ERA-EDTA Epidemiology Course in Thessaloniki, Greece. Dimitri Tsakiris is the host of this course. The first five editions were held in Rome, Italy (September 2004), Toledo, Spain (March 2005), Würzburg, Germany (October 2005), Salzburg, Austria (March 2006) and Stockholm (September 2006).

On the basis of surveys among course participants these courses can be considered to be a true success.

THE COURSE IS FULLY BOOKED

More information on this course are available on <http://www.ndt-educational.org/thessaloniki2007.asp>



The seventh ERA-EDTA Epidemiology Course will be held in Leiden (The Netherlands) on September 22-24, 2007. The application procedure will start in June 2007. More information will be available soon on the ERA-EDTA Website (see Education and then CME Courses).

Registry activities during the XLIV ERA-EDTA Congress in Barcelona, Spain (June 21-24, 2007)

22 June - 10.30 to 12.00 a.m. - ERA-EDTA Registry Symposium.

23 June - 10.30 to 12.00 a.m. - Compact Primers and Updates for the Nephrologist - Clinical Epidemiology.

More information available at www.eraedta2007.org

ERA-EDTA Registry contact details

Postal address

ERA-EDTA Registry
Academic Medical Center
University of Amsterdam
Dept. of Medical Informatics, J1b-125
P.O.Box 22700
1100 DE Amsterdam
The Netherlands

Visiting address

Meibergdreef 9
1105 AZ Amsterdam
The Netherlands

Phone: +31 20 566 7637

Fax: +31 20 691 9840

E-mail: erareg@amc.uva.nl

Website: www.era-edta-reg.org