CALL FOR EUROPEAN RESEARCH CENTERS INTERESTED IN RECEIVING A FELLOW FROM ANOTHER EUROPEAN COUNTRY

Name of the Institution: Agence de la biomédecine. REIN Registry
Contact person: Dr. Cécile Couchoud
Address: 1 avenue du stade de France
Postal code: 93212
City: Saint Denis La Plaine
Country: FRANCE
Phone: 00 33 1 55 93 64 67
Fax: 00 33 1 55 93 69 36
E-mail: cecile.couchoud@biomedecine.fr
Synopsis on research programme in Nephrology/ Dialysis/ Transplantation

The French Renal Epidemiology and Information Network (REIN - Réseau Epidémiologie et Information en Néphrologie) registry was founded in 2001 to provide a tool for public health decision support, evaluation and research related to renal replacement therapies for end-stage renal disease (ESRD) [1]. It has five goals: (1) to provide estimates of the total ESRD patient population, to report on incidence, prevalence, mortality rates, and trends over time at both the regional and the national levels and to describe patient condition, (2) to follow up the cohort of ESRD patients and evaluate access to and outcome of dialysis and transplantation, (3) to assess quality of care, (4) to promote the development of clinical, epidemiological, evaluation and economic research on chronic kidney disease, and (5) to contribute to the ERA-EDTA registry and to international studies.

The REIN registry is intended to include all ESRD patients on RRT ― either dialysis or transplantation ― living in metropolitan France or in overseas districts. To reach the registry purposes of both surveillance and evaluation, a set of basic items, including fixed and annually updated items, was defined for all patients. Seven types of events are reported to the registry as soon as they occur: recovery of renal function, changes in dialysis setting, changes in type of dialysis, registration on the waiting list for a kidney transplantation, renal transplantation, graft failure and death. The REIN guide defines all items to be recorded, includes coding instructions, and serves as a standard for all participating regions (http://www.agence-biomedecine.fr/article/142).

REIN information system takes advantage from the new Technologies of Information and Communication. Its overall architecture is that of a Decisional Information System combining Datawharehousing and Geographical Information techniques.

REIN is a social, informational and scientific network where nephrologists, epidemiologists, patients and public health representatives collaborate according to a set of functional, financial and informational agreements. The national level comprises a coordinating office, a steering committee and a scientific council. The key-organizational units are regions whose inclusion requires the participation of all centres and the notification of all ESRD cases. Regional REIN units comprise a coordinating nephrologist and an epidemiological support ensuring data quality control and regional analysis. REIN registry is a shared research infrastructure: data are accessible to clinical and epidemiological researchers for study protocols validated by the Scientific Council. A yearly Call for Research Project is organised since 2008.

In 2009, 9 700 patients with end-stage renal disease started renal replacement therapy (dialysis or preemptive graft): crude annual incidence rate of renal replacement therapy for end-stage renal disease 150 per million population. On December 31, 2009, 37 500 patients were on dialysis (prevalence 585 pmh), 33 000 patients were living with a functioning graft (prevalence 509 pmh). It offers a complete view on ESRD patients in France linking records on dialysis patients with those of transplanted ones. One of its specificity is to record a large set of comorbidities.

Current lines of research.
REIN supports many working groups with various lines of research. Different biostatistician skills are used as needed: logistic regression, Cox model, Poisson regression, Markov chain model, Data mining, bootstrap…

Elderly patients
Savoye et al. Transplantation. 2007. 84(12):1618-24

Diabetes

Peritoneal dialysis

Access to transplantation

Clinical performance indicators

Geographical epidemiology

New Technologies of Information and Communication and Data exchange
Jacquelinet & al. AMIA 2006 Conf Proc: Nov; 374-378

Research/es in which the Fellow will be involved.
During his stay at the REIN registry, the fellow could be trained in epidemiological and statistical skills. It can be also an opportunity to participate to a study and a publication. He will be integrated in a multidisciplinary group.
Cécile Couchoud, Christian Jacquelinet, Bénédicte Stengel: epidemiologists
Mathilde Lassalle, Emilie Savoye: biostatisticians
Geneviève Bernède, Antonio Sequeira : engineer in informatics

Please consider that by submitting this Application you accept that it will be published in ERA-EDTA website. This means that your e-mail address will be posted, too.

Please, return this form, as an attachment, to the following e-mail address:

fellowships@era-edta.org