

The renal epidemiology and information network (REIN): a new registry for end-stage renal disease in France

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Abstract

The French Renal Epidemiology and Information Network (REIN) registry began in 2002 to provide a tool for public health decision support, evaluation and research related to renal replacement therapies (RRT) for end-stage renal disease (ESRD). It relies on a network of nephrologists, epidemiologists, patients and public health representatives, coordinated regionally and nationally. Continuous registration covers all dialysis and transplanted patients. In 2003, 2070 patients started RRT, 7854 were on dialysis and 7294 lived with a functioning graft in seven regions (with a population of 16.5 million people). The overall crude annual incidence rate of RRT for ESRD was 123 per million population (p.m.p.) with significant differences in age-adjusted rates across regions, from 84 [95% confidence interval (CI): 74–94] to 155 [138–172] p.m.p. The principal causes of ESRD were hypertension (21%) and diabetic (20%) nephropathies. Initial treatment for ESRD was peritoneal dialysis for 15% of patients and a pre-emptive graft for 3%. The one-year survival rate was 81% [79–83] in the cohort of 2002–2003 incident patients. As of December 31, 2003, the overall crude prevalence was 898 [884–913] p.m.p., with 5% of patients receiving peritoneal

dialysis, 47% on haemodialysis and 48% with a functioning graft. The experience in these seven regions over these two years clearly shows the feasibility of the REIN registry, which is progressively expanding to cover the entire country.

Keywords: end-stage renal disease registry; epidemiology; network; renal replacement therapy; public health decisional support systems; quality control

Introduction

France has contributed to the European Dialysis and Transplant Association (EDTA) registry for more than 30 years, reporting on trends and outcome in end-stage renal disease (ESRD) therapies [1]. Only a few regional surveys have been conducted in France since 1994 [2–4] and one national survey on dialysis in 2003 [5], while other European countries were setting up national registries [6–8]. In the late 1990s, the increasing burden of ESRD led the Ministry of Health and the National Health Insurance Funds to work together with representatives of nephrologists, nurses, health care facilities and patients to develop new policies. These consultations led to the enactment of new regulations on RRT in 2002. One major change in RRT policy was that planning of the offer of care

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was related to population needs, assessed at the regional level. Moreover, two of the objectives of the 2004 national public health programme specifically concerned kidney diseases: to stabilize ESRD incidence by 2008 and to improve the quality of life for dialysis patients. The REIN project, developed by a group of experts as an initiative of the French Society of Nephrology, provided the renal data system required to implement these two governmental measures.

The 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. 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 international studies.

Organizational principles

The REIN network includes nephrologists, nurses, patients, public health representatives and epidemiologists coordinated within regional and national steering committees (Appendix 1). To facilitate the links with the existing transplant database (CRISTAL), the French Transplant Agency (now called *Agence de la biomédecine*) was chosen as the coordinating centre. In each region, it signs a funding agreement with a department providing methodological support to the regional committee to pay clinical research assistants. The REIN registry is supported by the National Health Insurance Funds (Caisse Nationale d'Assurance Maladie), the Ministry of Health, the National Institute of Public Health Surveillance (InVS), University Descartes-Paris 5, and the National Institute of Health and Medical Research (Inserm). It also receives additional grants from the regions. Although participation in the registry is not mandatory, dialysis centres are strongly encouraged to do so. The financial support for data management and quality control furnishes one incentive. Moreover, the new regulations on RRT require the regular provision of data to administrative agencies. The registry is progressively spreading throughout the country and is aiming for nationwide coverage (that is, all 22 regions and 4 overseas districts) by the end of 2006. In 2003, the REIN included seven regions covering more than one fourth of the overall French population: Auvergne (1.3 million population), Bretagne (2.9), Champagne-Ardenne (1.3), Languedoc-Roussillon (2.4), Limousin (0.7), Lorraine (2.3) and Rhône-Alpes (5.6).

Population and information

The REIN registry is intended to include all ESRD patients on RRT – either dialysis or transplantation – living in metropolitan France or in overseas districts. At the start of the registry in a region, all (prevalent) dialysis patients in that region are registered. New (incident) patients are reported from the first day of RRT. Patients with a diagnosis of acute renal failure are excluded, i.e. those who recover all or some renal function within 45 days or are considered as such by experts when they die before 45 days. Patients with pre-emptive grafts and those living with a functioning graft are identified from the transplant database.

To further the registry purposes of both surveillance and evaluation, a set of basic items, including fixed and annually updateable items, was defined for all dialysis patients (Appendix 2). Five types of events are reported to the registry on occurrence from the first day of any treatment: (1) renal transplantation, (2) changes in dialysis setting, (3) changes in type of dialysis, (4) transient recovery of renal function and (5) death. Patients who died outside dialysis units are actively sought, especially early death in intensive care units.

Primary renal diseases are coded according to the thesaurus of the French-language Society of Nephrology, based upon the 10th revision of the International Classification of Disease (ICD-10) and grouped by the eight ERA-EDTA categories [9]. 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/fr/pro/actu-rein.asp>).

In 2003, data on dialysis were collected through different computer systems [10,11] and aggregated at the national level with those from the national transplant database. As places of residence are not yet updated for all past transplanted patients, some patients with a functioning graft were assigned their region of follow-up in 2003 for place of residence. The National Commission for Information Technology and Privacy (Commission Nationale de l'Informatique et des Libertés) has approved the data collection conducted by the REIN registry.

Quality control

The participation rate of centres in all contributing regions is 100%. A clinical research assistant in each region visits every dialysis centre to verify the completeness of patient and event registration, by comparing reports to the registry with centre administration files. Completeness is also assessed through record linkage with hospital databases, particularly to search for early deaths in non-nephrology departments. Completeness and accuracy are systematically ascertained for items deemed essential, that is, identification, demographics, primary renal disease and date at RRT initiation. Other items, such as comorbid

Table 1. Crude and age-adjusted incidence rates^a

	N	%	Crude incidence p.m.p (95% CI)	Adjusted incidence p.m.p (95% CI)
All	2070	100	122.8 (117.5–128.1)	118.8 (113.6–124.1)
Men	1241	60	151.5 (143.1–159.9)	155.9 (147.1–164.7)
Women	825	40	95.5 (89.0–102.0)	81.8 (76.0–87.5)
0–19 years	34	2	8.3 (5.5–11.1)	7.0 (4.5–9.6)
20–44 years	226	11	39.8 (34.6–45.0)	38.8 (33.7–43.9)
45–64 years	555	27	134.5 (123.4–145.7)	139.4 (127.7–151.1)
65–74 years	576	28	376.8 (346.0–407.5)	386.6 (354.9–418.4)
Over 75 years	676	33	484.2 (447.7–520.7)	545.0 (501.4–588.7)
Auvergne	171	8	131.1 (111.5–150.8)	114.7 (97.0–132.5)
Bretagne	268	13	90.4 (79.6–101.2)	84.0 (73.5–94.4)
Champagne-Ardenne	150	7	112.2 (94.3–130.2)	111.9 (93.6–130.2)
Languedoc-Roussillon	368	18	152.8 (137.1–168.4)	136.0 (121.7–150.2)
Limousin	80	4	113.3 (88.5–138.1)	93.7 (72.3–115.0)
Lorraine	350	17	152.4 (136.5–168.4)	155.4 (138.4–172.4)
Rhône-Alpes	680	33	117.0 (108.2–125.8)	123.9 (114.4–133.4)
Glomerulonephritis/sclerosis	271	13	16.1 (14.2–18.0)	16.2 (14.2–18.2)
Pyelonephritis	91	4	5.4 (4.3–6.5)	5.0 (4.0–6.1)
Polycystic kidneys, adult type	146	7	8.7 (7.3–10.1)	8.3 (6.9–9.6)
Diabetes mellitus	421	20	25.0 (22.6–27.4)	24.0 (21.7–26.4)
Hypertension	438	21	26.0 (23.6–28.5)	25.1 (22.7–27.5)
Renal vascular disease	29	1	1.7 (1.1–2.4)	1.6 (1.0–2.2)
Miscellaneous	391	19	23.2 (20.9–25.5)	22.5 (20.3–24.8)
Unknown	219	11	13.0 (11.3–14.7)	12.6 (10.8–14.3)
Missing data	61	3	3.6 (2.7–4.5)	3.5 (2.6–4.4)

^aThe RRT incidence rate was defined as the number of new patients on dialysis or receiving a pre-emptive graft in 2003 and living in the regions covered; the denominator used the mid-year (30 June 2003) population, estimated from census data.

conditions, are checked through *ad hoc* quality control. Additional validation at the national level is intended to eliminate any duplication across regions. All these procedures are documented in the REIN guide.

Finally, dialysis centres in regions bordering regions of those participating are asked twice a year to provide information about the patients they treat who live in the participating regions. This policy will continue until the registry covers the entire country.

Epidemiology and patient outcome

In all, 2070 ESRD patients in the seven regions started RRT in 2003. The overall crude incidence rate of RRT for ESRD was 122.8 per million population (p.m.p). The overall age-adjusted rate, using the 1995 European population as reference [9], was 118.8 and differed significantly across regions, from 84.0 in Bretagne (western France) to 155.4 Lorraine (eastern France) (Table 1). They were more than 50% higher for men than women. Median age at RRT initiation was 69.6 and ranged from 2 to 100 years. Figure 1 shows that incidence rates increased with age until 85 years in all regions, but with marked differences in levels among the elderly across regions. Hypertensive and diabetic nephropathies were the main causes of ESRD with 51 new patients per million population.

Peritoneal dialysis was the initial modality of treatment for 14.8% of patients (range: 13.1–25.0%,

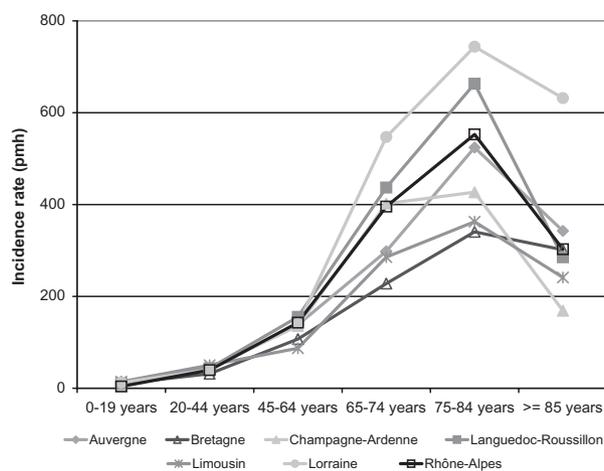


Fig. 1. Crude incidence rates by age and region.

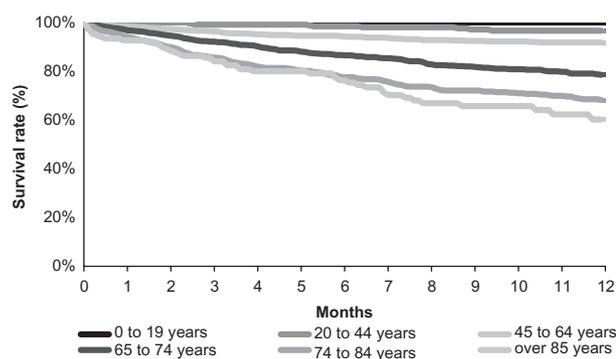
according to region) and pre-emptive graft for 3% (2.0–5.2%) (Table 2).

At RRT initiation, 50% of the patients had cardiovascular disease and 33% diabetes, nearly all (91%) of whom had type 2 non-insulin-dependent diabetes.

Among the incident patients in 2002 and 2003, the overall one-year survival rate, starting from the first day of any treatment, was 81.0% [79.4–82.6]. We used the actuarial method and observations were censored as of 31 December, 2003. The survival probability decreased with age, but remained

Table 2. Crude and age-adjusted incidence rates by first treatment modality, by region

First Treatment modality	N	%	Crude incidence p.m.p (95% CI)	Adjusted incidence p.m.p (95% CI)
Auvergne				
Haemodialysis	141	82.5	108.1 (90.3–126.0)	93.7 (77.7–109.6)
Peritoneal dialysis	23	13.5	17.6 (10.4–24.8)	15.0 (8.6–21.4)
Pre-emptive graft	7	4.1	5.4 (1.4–9.3)	6.0 (1.5–10.5)
Bretagne				
Haemodialysis	214	79.9	72.2 (62.5–81.9)	68.0 (58.6–77.4)
Peritoneal dialysis	40	14.9	13.5 (9.3–17.7)	12.4 (8.3–16.5)
Pre-emptive graft	14	5.2	4.7 (2.2–7.2)	3.6 (1.5–5.7)
Champagne-Ardenne				
Haemodialysis	123	82.0	92.0 (75.8–108.3)	91.1 (74.7–107.5)
Peritoneal dialysis	24	16.0	18.0 (10.8–25.1)	18.3 (10.8–25.8)
Pre-emptive graft	3	2.0	2.2 (0.0–4.8)	2.5 (0.0–5.3)
Languedoc-Roussillon				
Haemodialysis	304	82.6	126.2 (112.0–140.4)	111.9 (99.0–124.8)
Peritoneal dialysis	51	13.9	21.2 (15.4–27.0)	18.6 (13.3–23.9)
Pre-emptive graft	13	3.5	5.4 (2.5–8.3)	5.5 (2.5–8.5)
Limousin				
Haemodialysis	58	72.5	82.1 (61.0–103.3)	69.3 (50.9–87.8)
Peritoneal dialysis	20	25.0	28.3 (15.9–40.7)	20.6 (11.1–30.2)
Pre-emptive graft	2	2.5	2.8 (0.0–6.8)	3.7 (0.0–8.8)
Lorraine				
Haemodialysis	297	84.9	129.3 (114.6–144.0)	130.0 (114.7–145.4)
Peritoneal dialysis	46	13.1	20.0 (14.2–25.8)	22.2 (15.3–29.1)
Pre-emptive graft	7	2.0	3.0 (0.8–5.3)	3.2 (0.8–5.5)
Rhône-Alpes				
Haemodialysis	561	82.5	96.5 (88.5–104.5)	102.2 (93.5–110.8)
Peritoneal dialysis	101	14.9	17.4 (14.0–20.8)	18.5 (14.8–22.2)
Pre-emptive graft	18	2.6	3.1 (1.7–4.5)	3.2 (1.7–4.7)
All				
Haemodialysis	1698	82.1	100.9 (96.1–105.7)	97.4 (92.7–102.2)
Peritoneal dialysis	305	14.8	18.1 (16.1–20.2)	17.7 (15.6–19.7)
Pre-emptive graft	64	3.1	3.8 (2.9–4.7)	3.7 (2.8–4.7)

**Fig. 2.** One-year survival rate by age group in the 2002–2003 incident cohort.

above 60% in patients older than 75 at RRT initiation (Figure 2).

As of 31 December 2003, 7854 patients were on dialysis in these seven regions and 7294 lived with a functioning graft. Age-adjusted prevalence differed significantly across regions (Table 3). Figure 3 illustrates the distribution of dialysis modalities among the prevalent patient population. Treatment modalities for haemodialysis were divided into four categories: haemodialysis centre located in a health facility with physicians always available (in-centre haemodialysis), haemodialysis centre without a physician always

available (out-centre haemodialysis), self-care units and home haemodialysis. Peritoneal dialysis was either continuous ambulatory or automated peritoneal dialysis (including all automated techniques with or without extra exchanges). Only 11% received either continuous or automated peritoneal dialysis and 3% home haemodialysis, but 34% of the patients were treated in out-centre or self-care structures.

Feasibility and strength

Two years after it started, REIN has clearly demonstrated the feasibility of an ESRD registry in France. The strengths of the REIN registry include its network organization, its overview of RRT through dialysis and renal transplantation links, due to its setting within the French Transplant Agency, the development of new informatics tools and the quality control of data. Its design also makes it possible to meet three complementary goals for RTT: planning and monitoring, evaluation and research. Clinicians, patients, administrators and researchers can and do discuss these data, within national and regional steering committees. Finally, the seven contributing regions in 2003 also supplied data to the ERA-EDTA registry and thus made it possible to see RRT in France in its European perspective [9].

Table 3. Crude and age-adjusted prevalence rates by treatment modality, by region, as of 31 December, 2003^a

Treatment modality	N	%	Crude prevalence p.m.p (95% CI)	Adjusted prevalence p.m.p (95% CI)
Auvergne				
Haemodialysis	594	55.6	455.7 (419.0–492.3)	377.5 (345.7–409.4)
Peritoneal dialysis	61	5.7	46.8 (35.1–58.5)	37.9 (27.8–47.9)
Transplantation	413	38.7	316.8 (286.3–347.4)	308.7 (278.5–339.0)
Bretagne				
Haemodialysis	956	43.6	321.8 (301.4–342.2)	281.6 (263.0–300.3)
Peritoneal dialysis	88	4.0	29.6 (23.4–35.8)	22.2 (17.1–27.3)
Transplantation	1147	52.4	386.1 (363.7–408.4)	387.3 (364.6–410.0)
Champagne-Ardenne				
Haemodialysis	534	51.1	399.8 (365.9–433.7)	384.1 (350.5–417.7)
Peritoneal dialysis	64	6.1	47.9 (36.2–59.7)	40.4 (29.6–51.3)
Transplantation	448	42.8	335.4 (0.0–366.4)	340.1 (0.0–371.9)
Languedoc-Roussillon				
Haemodialysis	1332	54.1	550.0 (520.5–579.5)	478.1 (451.6–504.6)
Peritoneal dialysis	133	5.4	54.9 (45.6–64.3)	41.5 (33.8–49.1)
Transplantation	999	40.5	412.5 (386.9–438.1)	411.3 (385.6–437.1)
Limousin				
Haemodialysis	301	47.1	426.5 (378.3–474.7)	342.2 (301.6–382.8)
Peritoneal dialysis	43	6.7	60.9 (42.7–79.1)	40.2 (26.8–53.5)
Transplantation	295	46.2	418.0 (0.0–465.7)	397.1 (0.0–443.4)
Lorraine				
Haemodialysis	974	43.6	424.5 (397.8–451.2)	403.7 (377.4–430.0)
Peritoneal dialysis	151	6.8	65.8 (55.3–76.3)	55.2 (45.5–64.9)
Transplantation	1111	49.7	484.2 (455.7–512.7)	488.3 (459.2–517.3)
Rhône-Alpes				
Haemodialysis	2357	42.8	404.2 (387.8–420.5)	403.5 (386.7–420.3)
Peritoneal dialysis	266	4.8	45.6 (40.1–51.1)	43.7 (38.2–49.2)
Transplantation	2881	52.3	494.0 (476.0–512.0)	501.4 (482.9–519.9)
All				
Haemodialysis	7048	46.5	417.9 (408.2–427.7)	385.8 (376.4–395.1)
Peritoneal dialysis	806	5.3	47.8 (44.5–51.1)	40.0 (37.1–43.0)
Transplantation	7294	48.2	432.5 (422.6–442.4)	432.3 (422.3–442.3)

^aPrevalence was defined as the number of patients alive, living in the regions covered and on RRT as of 31 December, 2003. The denominator for prevalence rates was the population on that date.

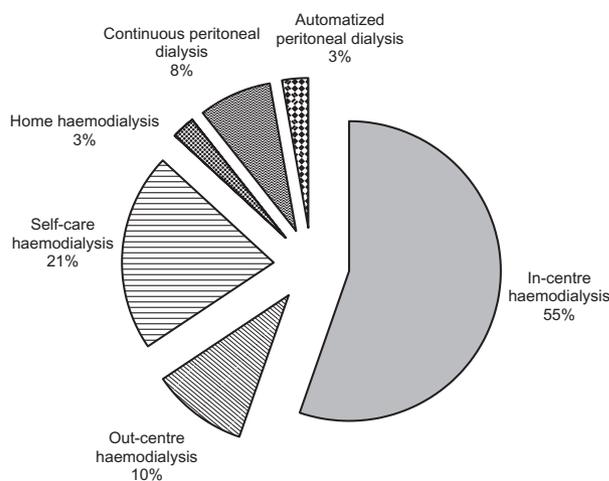


Fig. 3. Distribution of the prevalent patients among dialysis modalities.

International comparisons

Overall, the crude RRT incidence rate in 2003 for these seven regions was 122.8 p.m.p. The mere report of this number is in itself a significant progress for the French

nephrology community, since the last available national estimate of 62 p.m.p dates from 1992 [1]. It is likely that the French incidence rate, like that in other countries, increased over the last ten years in part because of population ageing and the increased prevalence of diabetes, although some of this increase may have resulted from improved registration rates or improved access to RRT [12]. The French 118.8 p.m.p adjusted incidence rate is lower than rates in Dutch-speaking Belgium (160.7 p.m.p) and Spain (147.3 p.m.p in Valencia, 142.5 in Catalonia), but higher than in the UK (96.5 p.m.p in England/Wales, 115.3 in Scotland), the Netherlands (107.9 p.m.p) and the Scandinavian countries (91.1 p.m.p in Finland to 115.3 in Sweden) in 2003 [8]. Since March, the 2003 are now available. Bearing in mind the necessity for caution in comparing data collected in heterogeneous conditions across countries, we note the contrast between the incidence rate calculated from our data and the 259 p.m.p incidence rate reported in the United States for the European-American population [13].

The crude one-year survival rate among incident dialysis patients was 81.0 [79.4–82.6]. Although it is difficult to compare survival rates without adjusting for age and comorbidities, these data are consistent

with those from Europe as a whole, that is, from the 11 countries that contribute data to ERA-EDTA (ERA-EDTA, 1996–2000 cohort: 81.4 [81.2–81.6]) [9]. These initial results do not indicate that French dialysis programmes select younger or healthier patients. Indeed, the proportion of elderly patients (33% of the incident patients are older than 75 years) is higher than anywhere else in Europe except Belgium. In these regions, 50% of the patients had a history of cardiovascular disease at initiation and 33% had diabetes. The one-year survival rate was 79.7 [76.7–82.6] in France for patients with diabetes and 79.6 [79.1–80.1] in Europe.

The crude prevalence for dialysis was 465.7 p.m.p in the seven regions. A recent cross-sectional survey, however, indicated a higher national prevalence rate, i.e. 505 p.m.p in June 2003 [CNAM-TS, personal communication]. Although differences in the distribution of risk factors may explain part of this variation, different historical backgrounds in transplantation activity may also play an important role. As of 31 December 2003, the total number of patients living with a functioning graft in France was 21 982 for a national prevalence rate of 359 p.m.p, while prevalence in the seven regions was 432.5 p.m.p. Thus, the overall prevalence in these regions was 892.2 p.m.p, i.e. 3% higher than the national level of the 864 p.m.p. The seven regions have a lower proportion of patients on peritoneal dialysis than other European countries. A shortage of in-centre dialysis and the long distance between patients' homes and facilities have led these regions to develop various alternatives to in-centre haemodialysis: 38% of the haemodialysis patients were treated in out-centre or self-care structures or at home. Finally, home haemodialysis has definitely dropped in France (from 17% in 1985 to 9% in 1991, and 3% in 2003) [1].

Comorbidities and clinical performance measures

Unlike most existing registries, REIN records updateable data on comorbid conditions, which need to be taken into account because they can affect both the selection of dialysis modality and outcomes [14]. The specificity of the USRDS form for most of these data is excellent, but sensitivity was less good, except for hypertension, diabetes and HIV disease [15]. A concordance study in Languedoc–Roussillon showed fair reliability of coding for comorbid conditions at treatment initiation [16].

The REIN registry also records clinical performance measures and aims to serve as a tool for benchmarking. Such data as timing for referral and vascular access, as well as haemoglobin level, EPO use and dialysis adequacy, are important for assessing the extent to which clinical guidelines are implemented throughout dialysis facilities and thus improving patient care [17,18]. REIN will also be used to evaluate the trends in meeting the objectives of the 2004 public health programme.

Limitations

Information about the patient residence was not recorded for transplants until 1997. Update of this information is in progress. Meanwhile, we assumed that patients with a functioning graft and unknown residence lived in the same region as that of their follow-up centre in 2003. As in other registries, some heterogeneity may exist in the coding of primary renal disease, particularly for hypertension and diabetic nephropathies. In the absence of a well-established standard method for diagnosing non-biopsy-proven nephropathy, coding is primarily based on the opinion of the attending nephrologist and may thus vary, both between and within regions. Improvement and upgrading of REIN's information system continues (Internet, Datawarehouse, Geographical Information System, meta-model, EDI) and in 2006 it will implement a shared information system covering dialysis and transplantation including a terminological server [19,20]. Finally, because of their high levels of transplantation activities and development of out-centre and peritoneal dialysis, dialysis in these seven regions cannot be considered representative of that of France as a whole. Nor are they representative of the overseas territories, where previous studies showed that ESRD prevalence is twice as high as in metropolitan France [21]. At present, international comparisons are also limited by the fact that the French law does not allow one to collect continuous data on ethnicity.

Conclusion

REIN is a national, multi-partner, innovative programme in France. After many years without standard information on RRT in France, the REIN registry provides quality-controlled data about patients with ESRD, their treatments and their outcomes. The REIN network, by promoting data sharing and discussion of the results by the various actors, should improve both the decision-making process and quality of care in health management.

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Conflict of interest statement. None declared.

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Appendix 1. Partners

Regions

Alsace: JF Marichal
 Antilles-Guyane: Cz Hiesse
 Aquitaine: D Alessandri, JL Bouchet
 Auvergne: CH Dabot, B Aublet-Cuvelier, E Cellarier, P Girault
 Basse Normandie: J Potier, P Thibon
 Bourgogne: JS Virot, B Gouyon
 Bretagne: V Joyeux, D Durand, F Le Duff
 Centre: S Baudin, F Von-Ey, CL Berquez, JM Halimi
 Champagne-Ardenne: H Maheut, F Vitry, MD Lorenzi, J Chanard
 Corse: M Basteri
 Franche-Comté: M Chalopin
 Haute Normandie: M Edet, M Godin
 Ile de France: G Bobrie, P Landais, M Ben Saïd, P Chaignot, P Taupin
 Languedoc-Roussillon: F de Cornelissen, JP Daurès, Y Duny
 Limousin: JC Aldigier, F Glaudet, A Vergnenègre
 Lorraine: L Frimat, C Loos-Ayav, V Vogel, M Kessler, S Briançon
 Midi-Pyrénées: P Giraud, TH Lang, C Munzer
 Nord-Pas de Calais: V Lemaitre, CH Noël, S Gomis
 Pays-de Loire: M Hourmant

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 Institut National de la Santé et de la Recherche Médicale

Other

Université Joseph Fourier Grenoble
 Société de Néphrologie
 Société Francophone de Dialyse
 Registre de Dialyse Péritonéale de Langue Française
 Société Française de Transplantation
 Fédération Nationale d'Aide aux Insuffisants Rénaux
 Association Française des Infirmiers de Dialyse, Transplantation et Néphrologie
 Direction de la Recherche des Études de l'Évaluation Statistique

continued

Appendix 1. Continued

Pédiatre: P Niaudet, A Bensman,
 Picardie: B Coevoet
 Poitou-Charente: M Bauwens
 Provence-Alpes-Côte-d'Azur: PH Brunet, JC Delarozière,
 AC Durand, R Sambuc
 Réunion: B Bourgeon, J Guiserix
 Rhône-Alpes: M Labeeuw, AM Schott, T Hajri, N Amamra,
 A Merono

Appendix 2. REIN common core of data for dialysis patients

Common core of data at dialysis initiation	Annual update on the day of 1st RRT onset
Personal identification number	–
Demographic items	
City code	+
Place of birth city code or country	–
Date of birth, sex	–
Employment status	–
Clinical items	
Weight, height	+
Primary renal disease	–
EPO administration (before 1st RRT)	+
Co-morbid conditions and disabilities: diabetes, history of hypertension, congestive heart failure, ischaemic heart diseases, dysrhythmia, cerebrovascular disease, peripheral vascular disease, hepatic diseases, chronic obstructive pulmonary diseases, HIV infection, tobacco use, neoplasm, vision problem, amputations, deficit, inability to ambulate	+
Biology	
Serum creatinine	–
Serum albumin, haemoglobin	+
Treatment	
Date at first dialysis	–
Registration on transplant waiting list	+
Dialysis setting	+
Type of dialysis	+
Date of first fistula	–
1st emergency dialysis	–
Number of dialyses per week	+
Duration of each dialysis	+
Kt/V	+
Hospitalizations (number, duration)	+
Children (under 16)	
School status and living situation (family, institution)	+
Cranial circumference	+ (up to 3 years old)
Growth hormone therapy (date at start)	date at end (if any)
Enteral Nutrition (date at start)	date at end (if any)
Disabilities and psychomotor retardation	+