

ORIGINAL ARTICLE

Twenty years of the French Renal Epidemiology and Information Network

Isabelle Kazes¹, Justine Solignac², Mathilde Lassalle³, Lucile Mercadal⁴ and Cécile Couchoud³; on behalf of the REIN registry

¹Service de Néphrologie, Centre Hospitalo-Universitaire de Reims, Reims, France, ²Service de Néphrologie, Assistance Publique Hôpitaux de Marseille, Marseille, France, ³Registre REIN, Agence de la biomédecine, Saint Denis La Plaine, France and ⁴Service de Néphrologie, Hôpital de la Pitié Salpêtrière, APHP, Paris, France

Correspondence to: Cécile Couchoud; E-mail: Cecile.couchoud@biomedecine.fr

ABSTRACT

Background. The French Renal Epidemiology and Information Network (REIN) is 20 years old. It is not just a national data registry, but rather an epidemiological and informational network serving patients with chronic kidney disease, nephrology teams and health services.

Methods. The past 10-year trends of the incidence and prevalence of renal replacement therapy by dialysis or kidney transplantation and waitlist activity are presented. To detect potential significant changes in trends from 2012 and 2021, a Joinpoint regression model was used.

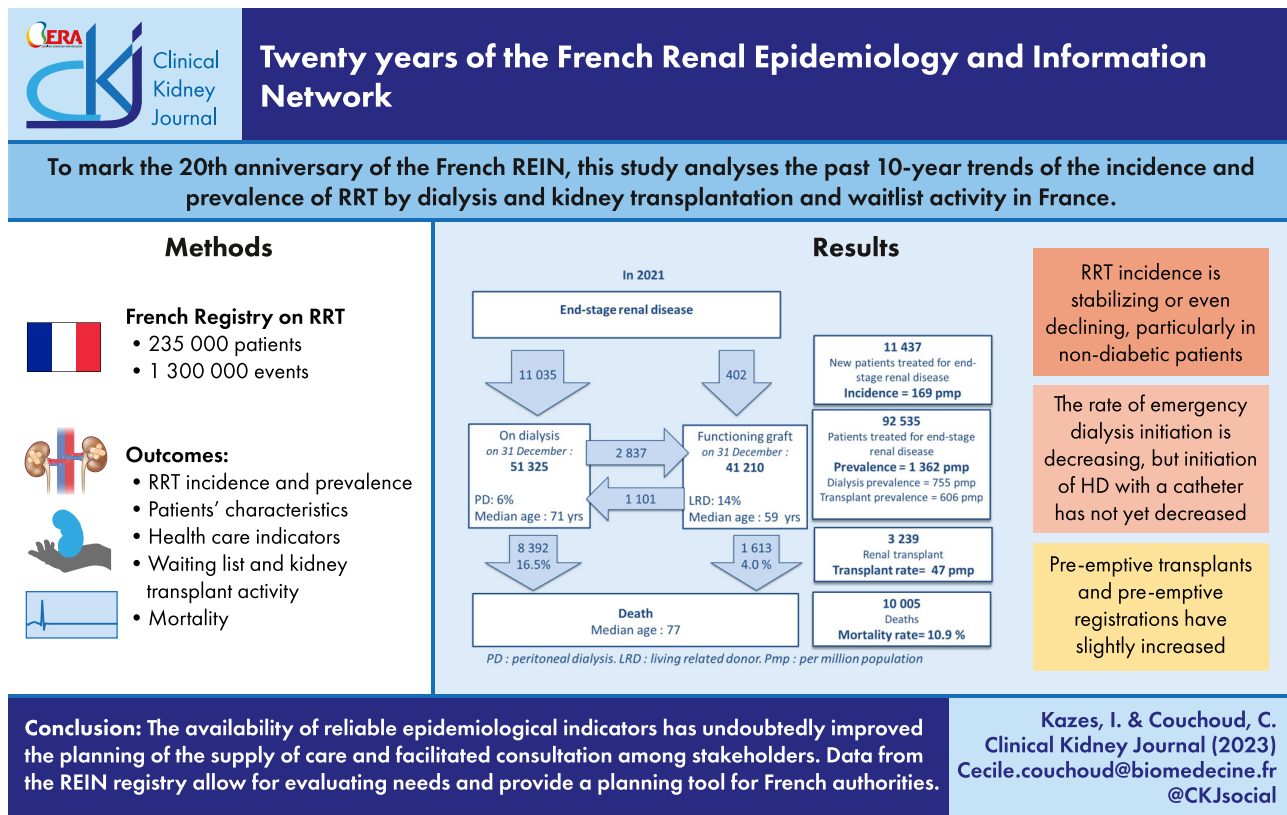
Results. The overall incidence of treated end-stage kidney disease (ESKD) was 169 per million population (pmp) in 2021. It was stable despite an increase in the incidence of diabetes. We found a decreasing trend in the proportion of patients starting dialysis in an emergency but an increase in those starting haemodialysis (HD) with a temporary catheter. Peritoneal dialysis decreased by 1.7% each year, whereas home HD, although involving only 1% of dialysis patients, increased by 10% each year. For patients not treated at home, the median time to drive from the patient's home to the dialysis unit was 17 min. The proportion of patients on the transplantation waitlist at the start of dialysis increased from 7% to 12%. Among the 111 263 new ESKD patients from 2012 to 2021, 8% received a first transplant at 1 year and 20% at 5 years. Among kidney transplant recipients, the mean time on the waitlist increased from 13.8 to 22.6 months. Living donor transplants increased in frequency, representing 15% of kidney transplants.

Conclusions. Data from the REIN registry allow for the evaluation of needs and provide a planning tool for French authorities. The progressive implementation of automatic data retrieval from dialysis informatics charts might alleviate the burden of data collection. Furthermore, the research activity the REIN engenders, resulting in renewed confidence by health authorities in the dynamism of French nephrology, allows for an optimistic outlook for the REIN.

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GRAPHICAL ABSTRACT



Conclusion: The availability of reliable epidemiological indicators has undoubtedly improved the planning of the supply of care and facilitated consultation among stakeholders. Data from the REIN registry allow for evaluating needs and provide a planning tool for French authorities.

Kazes, I. & Couchoud, C.
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Cecile.couchoud@biomedecine.fr
@CKJsocial

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KEY LEARNING POINTS

What was known:

- The epidemiology of renal replacement therapy (RRT) has evolved considerably in recent years in Europe as a result of changes in practices and in the clinical characteristics of patients.
- In France, these developments have been closely monitored by the French Renal Epidemiology and Information Network (REIN).

This study adds:

- As in other countries, the incidence of RRT in France is stabilizing or even declining, particularly in non-diabetic patients.
- The rate of emergency dialysis initiation is decreasing, but initiation of haemodialysis (HD) with a catheter has not yet decreased.
- HD in a facility remained the main modality of treatment, while the number of home dialysis patients remains low.
- The proportion of pre-emptive transplants and pre-emptive registrations has slightly increased, but because of the shortage of organs, the median waiting time before a kidney transplant has been increasing steadily since 2012.

Potential impact:

- The availability of reliable epidemiological indicators of RRT has undoubtedly improved the planning of the supply of care in this field and facilitated consultation among stakeholders.
- There is great potential for REIN data to improve evaluation, health economics and research in patients with severe CKD.

INTRODUCTION

The epidemiology of renal replacement therapy (RRT) has evolved considerably in recent years in Europe as a result of changes in practices and in the clinical characteristics of

patients. In France, these developments have been closely monitored by the French Renal Epidemiology and Information Network (REIN). The REIN, at 20 years old, is not just a data registry, but rather it is an epidemiological network in nephrology serving individuals with chronic kidney disease (CKD),

nephrology teams and health services in France [1]. It provides epidemiological information on the population's renal health, enabling the steering of health policy and the evaluation of quality to improve access to care and practices. The REIN data inform people with kidney disease in an era in which health democracy, the right to information for all and shared decision making are inseparable from the practice of medicine.

In the mid-1990s, when the demand for RRT and its cost to the healthcare system was exploding in Europe, France had no reliable data to estimate the incidence and prevalence of the treatment. Four arguments were put forward in favour of setting up a national registry rather than repeated cross-sectional surveys. The first was the need for accurate knowledge of trends in the incidence and prevalence of kidney disease with replacement therapy to plan the provision of care according to the specific needs of the population in each region. The second was the importance of monitoring access to dialysis and kidney transplantation and the survival of patients after initiation of these treatments. The third was the feasibility of setting up a national registry, with easy identification of patients spread over a limited number of structures, the support of nephrologists and patients and the experience of the *Etablissement français des greffes* (now *Agence de la biomédecine*) with information systems in this field. The final argument was the favourable cost:benefit ratio and the usefulness of such a registry for the health administration and the potential for evaluation and research.

Since 2002, the REIN registry has progressively spread throughout the country. Nationwide coverage (i.e. all 13 metropolitan regions and 5 overseas districts) was reached by the end of 2012. Since then, four overseas territories (Polynésie Française, Nouvelle Calédonie, Wallis et Futuna and Saint-Pierre-et-Miquelon) have joined the REIN.

The goal of the present study was to analyse the past 10-year trends of the incidence and prevalence of RRT by dialysis and kidney transplantation and waitlist activity in France. It also presents what we have learned and what we can expect from the REIN.

MATERIALS AND METHODS

The French renal healthcare organization

The French healthcare system is based on a statutory health insurance system consisting of several subsystems depending on the professional status of insured persons [2]. Patients with end-stage kidney disease (ESKD), in particular those starting RRT, are eligible for 100% reimbursement of necessary healthcare [3]. ESKD patients undergoing dialysis are cared for in four types of structures [4]: a haemodialysis (HD) centre (hospital-based), where medical permanence is guaranteed; a medicalized HD unit, created in 2002, where medical on-call service is provided with a minimum of one onsite visit per week; self-care units, in which medical on-call duty is ensured with a minimum onsite visit once a month; and home dialysis, including HD and peritoneal dialysis (PD), for which medical permanence is ensured with a visit at least once a month. For each modality of treatment, minimum staffing standards have been defined. This graduated organization allows for the best possible adaptation to the health needs of the dialysis patient. Another objective of health authorities is to preserve a local care offer.

REIN organization

The REIN registry relies on a network of nephrologists, epidemiologists, patients and public health representatives coordinated regionally and nationally [1]. The REIN data warehouse is fed from two main sources of information: information that comes directly from the dialysis centre via a specific application (DIADEM) and information that comes directly from the transplant centre via a specific application (CRISTAL) that is coordinated by the *Agence de la biomédecine* [5]. Both databases share a unique identifier for the patient that allows for analysing the overall RRT trajectory of the patient. Thus far, the warehouse does not include patients with stage 5 chronic kidney disease (CKD) on conservative treatment. Data quality is controlled by research assistants based in each region and a data manager at the national level [6].

Population

In this study of 10-year trends, we included patients undergoing dialysis or kidney transplantation from 2012 to 2021 in the 13 regions of mainland France plus 4 of the 5 overseas districts but not the 5 overseas territories.

Information

The following patient baseline characteristics at the time of starting dialysis or kidney transplantation were used in the present article: age; sex; primary renal disease; presence of diabetes, heart failure (stage 1–4, New York Heart Association classification), peripheral vascular disease (stage 1–4 Leriche classification), cerebrovascular disease (stroke or transitory ischaemic event), pulmonary disease (in stable state, partial pressure of oxygen <60 mmHg or cough with permanent or recurrent expectoration 3 months/year for 2 consecutive years) and obesity (body mass index ≥ 30 kg/m²); emergency start of dialysis (first dialysis session performed within 24 hours because of vital risk); first dialysis technique (HD/PD); estimated glomerular filtration rate (eGFR) at initiation; and the use of a temporary HD catheter at initiation and type of vascular access. The complete list of available data in the registry can be found in a previous article [5].

Data on the modality of dialysis, ownership of the nephrology facility (public university, public non-university, private not-for-profit, private for-profit) were collected on 31 December each year.

Statistics

Data for new (incident) patients were collected from the first day of RRT (dialysis or pre-emptive kidney transplantation). Patients with a diagnosis of acute renal failure were not included in the analysis. The incidence rate per million population (pmp) represents the number of new patients starting RRT for ESKD in a given year divided by the general population on 30 June of that same year. The prevalence rate pmp represents the number of patients alive who were receiving renal RRT for ESKD on 31 December in a given year divided by the general population on that same date. The age and sex distribution of the general population was provided by the National Institute of Statistics and Economic Studies (<https://insee.fr>). Adjusted rates (direct standardization) were derived by applying the observed variable-specific rates to the population. Access to the kidney

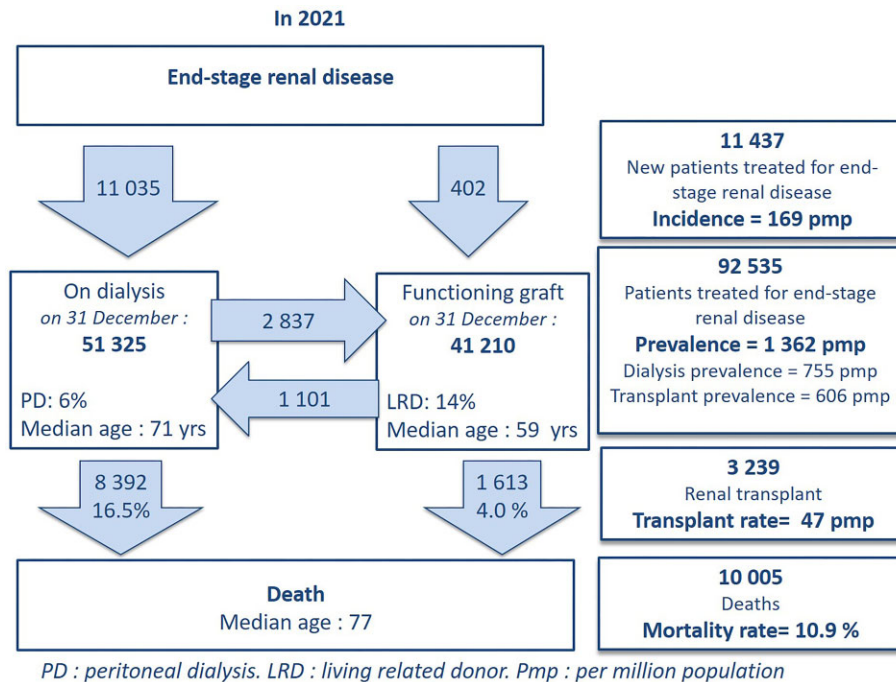


Figure 1: Main epidemiological indicators for 2021.

transplantation waitlist and to kidney transplantation was estimated by taking into account the competing risk of death. In the first case, the event of interest was the time from dialysis start and registration on the waitlist up to 31 December 2021. In case of pre-emptive registration (registration before dialysis start), the time before registration on the waitlist was set to zero. Considering the access to kidney transplantation, the outcome was the time from dialysis start and renal transplant up to 31 December 2021. Pre-emptive transplantations were excluded from this analysis. These analyses included all incident patients who started RRT from 2012 to 2021. Cumulative incidences were calculated by the method described by Fine and Gray.

To detect potential significant changes in trends over the years, we used a Joinpoint regression model and expressed changes as annual percentage change. Analyses were performed with SAS Enterprise Guide 7.1 (SAS Institute, Cary, NC, USA) and the Joinpoint Trend Analysis Software from the National Cancer Institute, Command-Line version (<https://surveillance.cancer.gov/joinpoint/>).

RESULTS

The main epidemiological indicators for 2021 are presented in Fig. 1. The overall incidence of treated ESKD was 169 pmp in 2021. The age- and sex-adjusted incidence was 1.8 times higher in the overseas districts than in mainland France. Within mainland France, there were also large regional variations not explained by age and sex variations in the general population of these regions (Fig. 2).

In France, the adjusted incidence of ESKD was stable from 2012 to 2021 despite an increase in the incidence of patients with associated diabetes (+3.5% per year from 2012 to 2017) (Fig. 3). The incidence has decreased by 1.5% per year since 2012 among diabetes-free ESKD patients and since 2016 among patients >75 years of age (-3% per year). In absolute numbers, patients 65–74 years of age represented the age group with the

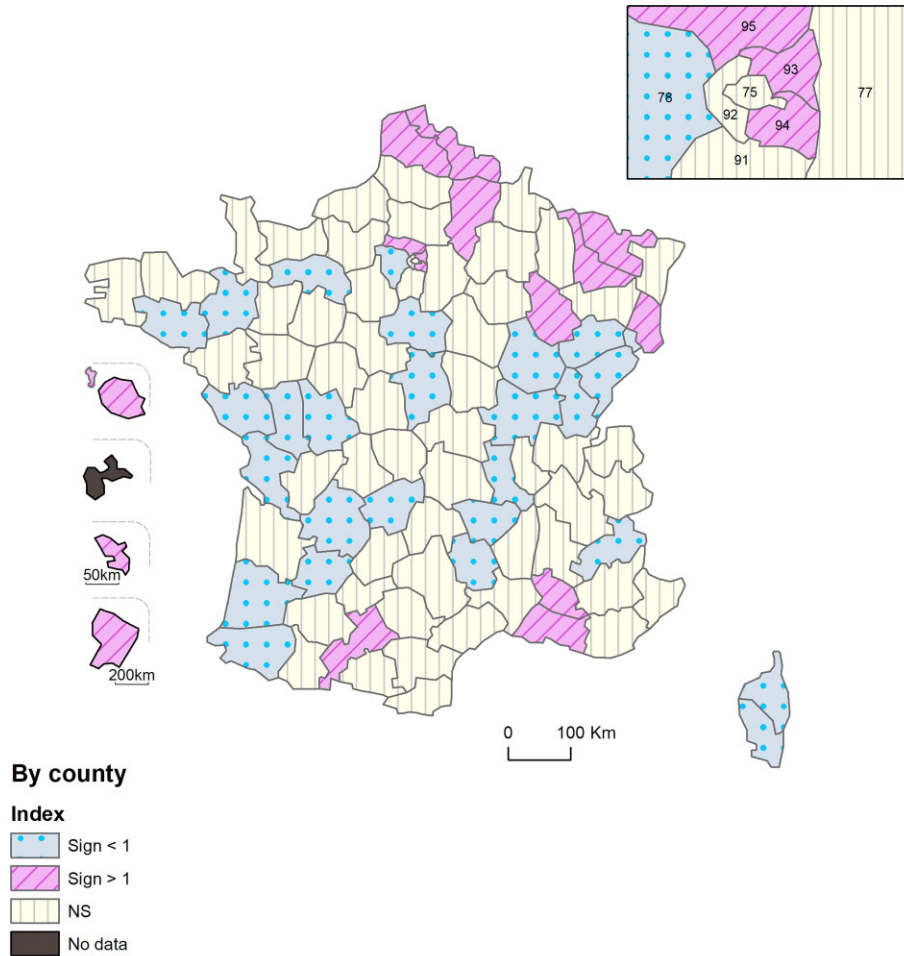
largest volume increase, 6% per year up to 2017. After an increase of 4% per year from 2012 to 2017, numbers for those ≥85 years of age seemed stable.

In 2021, the median age of incident patients starting RRT was 71.0 years; however, there was a decreasing trend in the proportion of people >75 years of age starting dialysis (-1% per year from 2012 to 2021) (Fig. 4). The number of patients with cardiovascular risk factors such as diabetes (+2.6% annually from 2012 to 2017, now stable) or obesity (+1.7% annually) at dialysis initiation reflects the impact of these factors on the epidemiology of kidney disease. The proportion of patients with heart failure or peripheral vascular disease was stable, but that of patients with cerebrovascular disease (stroke or transitory ischaemic event) or pulmonary disease increased by 1% per year. Hypertensive and vascular nephropathy (25%) and diabetic nephropathy (23%) account for almost half of all cases and primary glomerulonephritis for 10%. However, the nature of the primary renal disease is unknown for 18% of patients at the time of initiation of replacement therapy, which tends to underestimate the actual proportion and incidence of these four types of nephropathy.

The proportion of patients starting treatment in an emergency has decreased annually since 2012 (2.2% per year), whereas that of patients starting HD with a temporary catheter increased (0.6% per year) (Fig. 5). The median eGFR at dialysis initiation stabilized at 9 ml/min/1.73 m² since 2015.

At the national level, in 2020, for patients not treated at home, the median time to drive from the patient's home to the dialysis unit was 17 minutes (Fig. 6). Public establishments took care of 25% of HD patients, private for-profit establishments 38% and private non-profit establishments 37%. In contrast, 21% of PD patients were cared for by public facilities, 7% by private for-profit facilities and 72% by private not-for-profit facilities. HD in a facility remained the main modality of treatment, with a major increase in the use of medicalized dialysis units. PD decreased by 1.7% each year and home HD increased by 10% each year

Comparative incidence index of chronic kidney disease treated by replacement therapy in 2021



Source: Agence de la biomédecine

Figure 2: Comparative incidence index of CKD treated by replacement therapy in 2021.

(Fig. 7). The arteriovenous fistula is the vascular approach used by 74% of HD patients, while a bypass and a tunneled catheter are used in 2% and 23% of cases, respectively. The proportion of patients with a catheter increases with age, reaching 29% in those >85 years of age.

The proportion of patients on the kidney transplant waitlist at the start of dialysis increased from 7% to 12% between 2012 and 2021 (Fig. 8). For patients <60 years of age, the registration rate was 18% at the start of dialysis and 50% at 1 year after dialysis start in 2012 as compared with 25% at the start of dialysis and 52% at 1 year after dialysis start in 2021. Among the 111 263 new ESKD patients between 2012 and 2021, 8% received a first transplant at 1 year and 20% at 5 years. Access to kidney transplantation varied across age groups (Fig. 9). For half of the patients <60 years of age, the time required to access transplantation was 52 months. Among kidney transplantation recipients, the mean time on the waitlist increased from 13.8 to 22.6 months. The duration of dialysis before transplantation followed a less marked increase, from 20.6 to 26.3 months, reflecting earlier waitlist registration.

Although the annual number of transplantations increased from 3044 to 3252 between 2012 and 2021, the year 2020 was

marked by a temporary suspension of activity and a decline of 29% as compared with 2019. Living donor transplants increased, representing 15% of the kidney transplantations. The Maastricht III program (organ donation after circulatory death category III after the withdrawal of life-sustaining treatment), developed in 2015, showed excellent results, with immediate recovery of function in >85% of transplantations and good kidney function at 1 year [7]. In all, 15% of patients who underwent transplantation in 2021 received a pre-emptive transplant.

DISCUSSION

We wondered whether 20 years after its creation, the REIN registry has met the expectations of the health administration, clinicians, patient associations and researchers. The availability of reliable epidemiological indicators of RRT has undoubtedly improved the planning of the supply of care in this field and facilitated consultation among stakeholders. The data allow for comparisons with data from other countries, although caution should be exercised because of different case mix and medical practices. The REIN is also a research tool that provides nephrologists and researchers with high-quality data regarding both

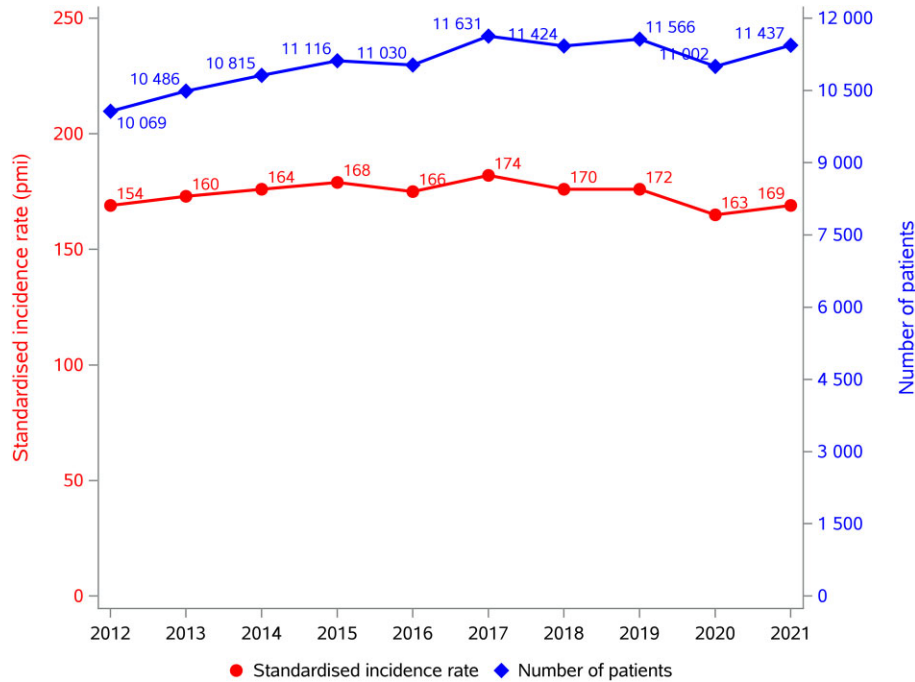


Figure 3: Evolution of the standardized incidence rate and number of patients from 2012 to 2021.

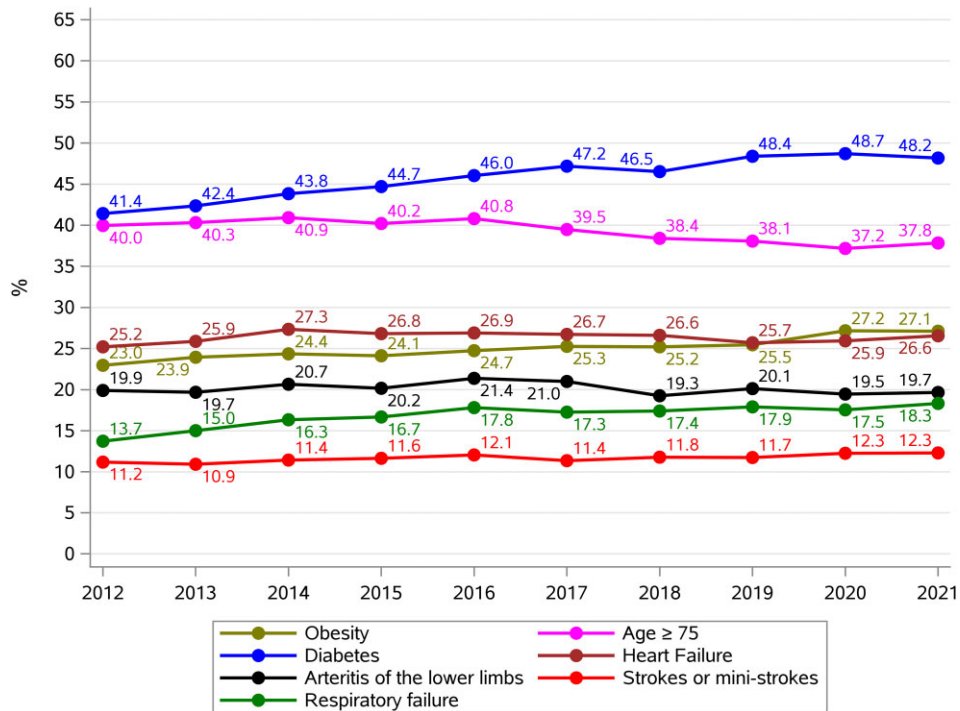


Figure 4: Evolution of the clinical characteristics of new dialysis patients from 2012 to 2021.

dialysis and kidney transplantation. In addition, the Agence de la biomédecine offers methodological support and some funding for research projects via an annual call for tenders.

The French healthcare system differs from that of many other countries in several respects: expenses are covered by a national health insurance fund; dialysis treatment activities

are planned and authorized at a regional level, with a very precise distinction between the different dialysis structures; and various providers include not-for-profit and public establishments. By providing precise epidemiological data, the REIN registry allows for supporting the planning of the care offer. However, the departmental level is sometimes too broad to describe

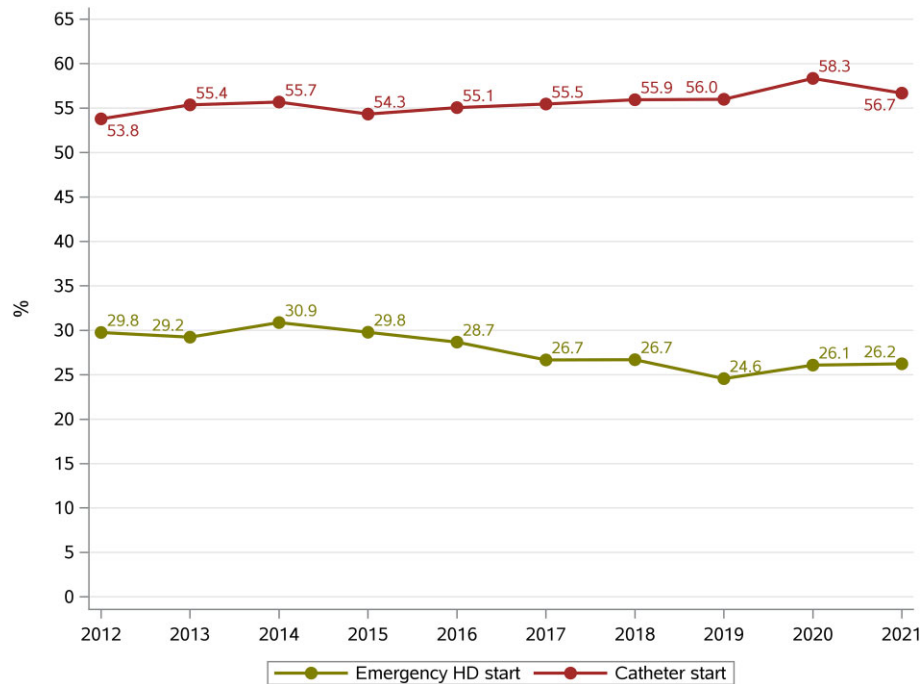


Figure 5: Evolution of the management conditions of new dialysis patients from 2012 to 2021.

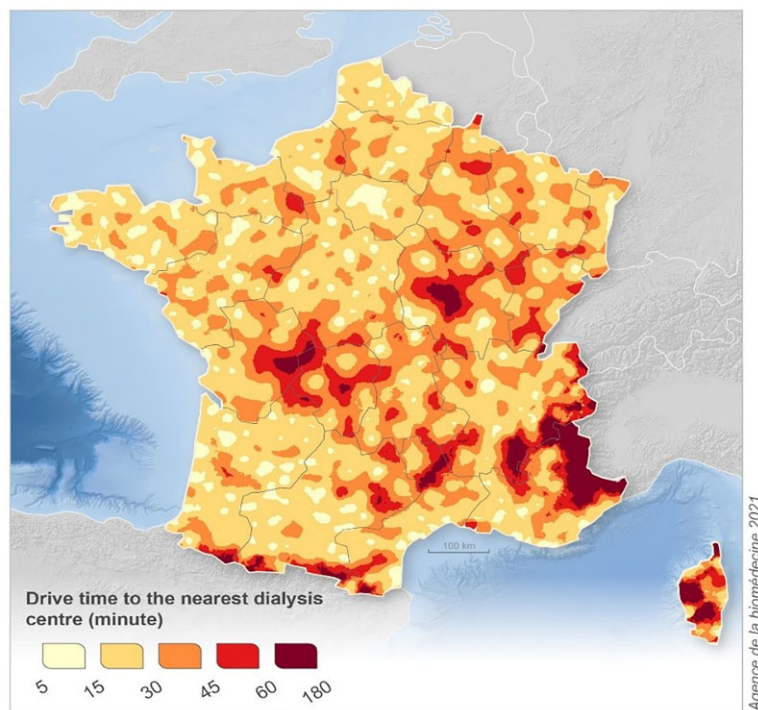


Figure 6: Driving time to the nearest dialysis centre in 2020.

certain practice indicators [8, 9]. For this reason, care networks, identified as groups of care units caring for comparable patients, have been identified and seem to be better suited to describe and analyse dialysis activity across the territory [10].

There are important variations in the incidence of RRT among countries, mainly explained by access to renal care [11,

12]. However, spatial variations also exist at the subnational level [13, 14]. In France, spatial variations in the incidence of RRT have been repeatedly explored using the REIN data, showing that social disadvantage and health status of the general population explain the substantial variations [15]. These studies also highlight the variability in practices, in particular decisions

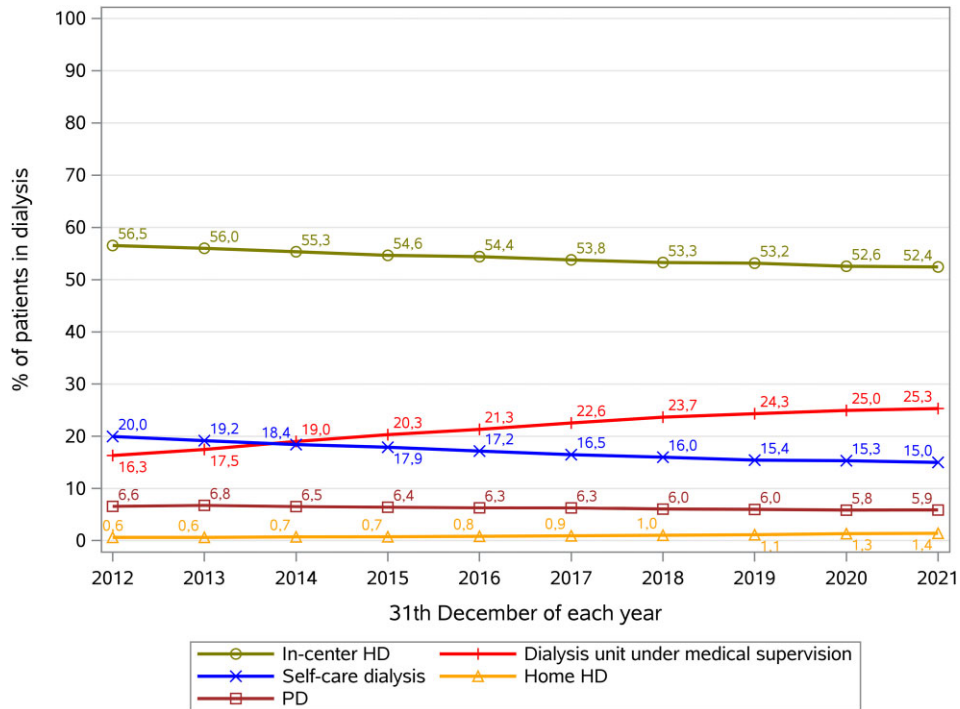


Figure 7: Evolution of the distribution of the modalities of dialysis treatment on 31 December each year from 2012 to 2021.

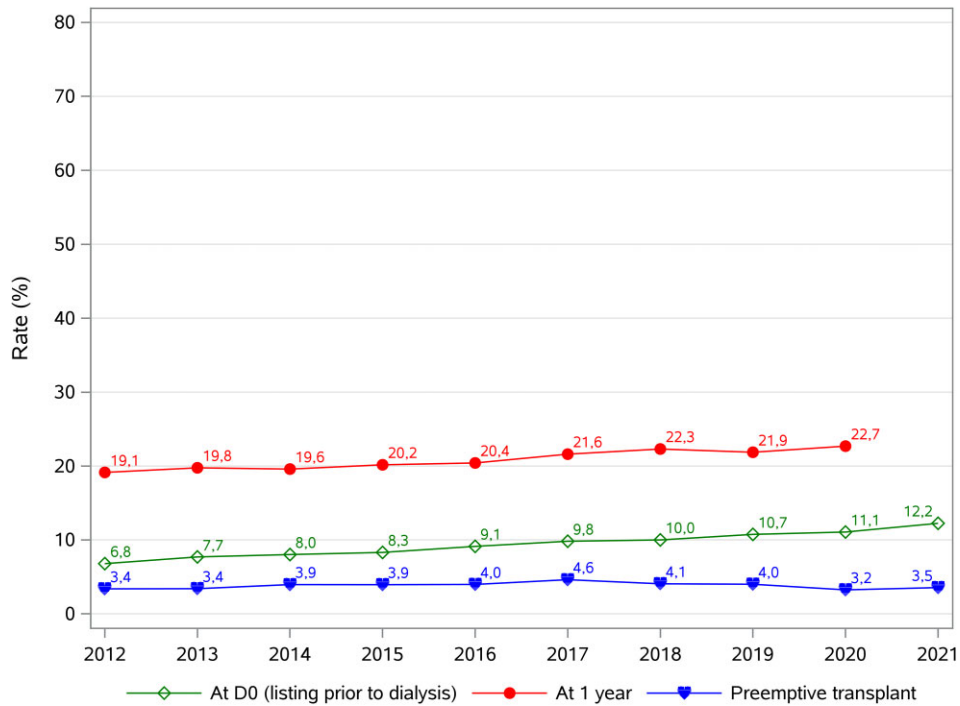


Figure 8: Evolution of access to the waitlist and pre-emptive transplantations from 2012 to 2021.

concerning the initiation of RRT and the modality of the first treatment. These results have been confirmed and refined in other regions on a smaller scale [16–18]. Social disadvantage is also associated with the choice of the modality of dialysis [19]. As in other countries, in France, the incidence of RRT is stabilizing or even decreasing, especially in diabetes-free patients with

CKD. In Europe, the incidence of RRT increased by 1.1% per year from 2001 to 2008, with a decline of 2.2% per year from 2008 to 2011 [20]. This decline was mainly observed in patients 45–74 years of age. There were variations among countries, with some countries (Austria, Scotland, Finland) showing an earlier decline. While the incidence of diabetic nephropathy in France

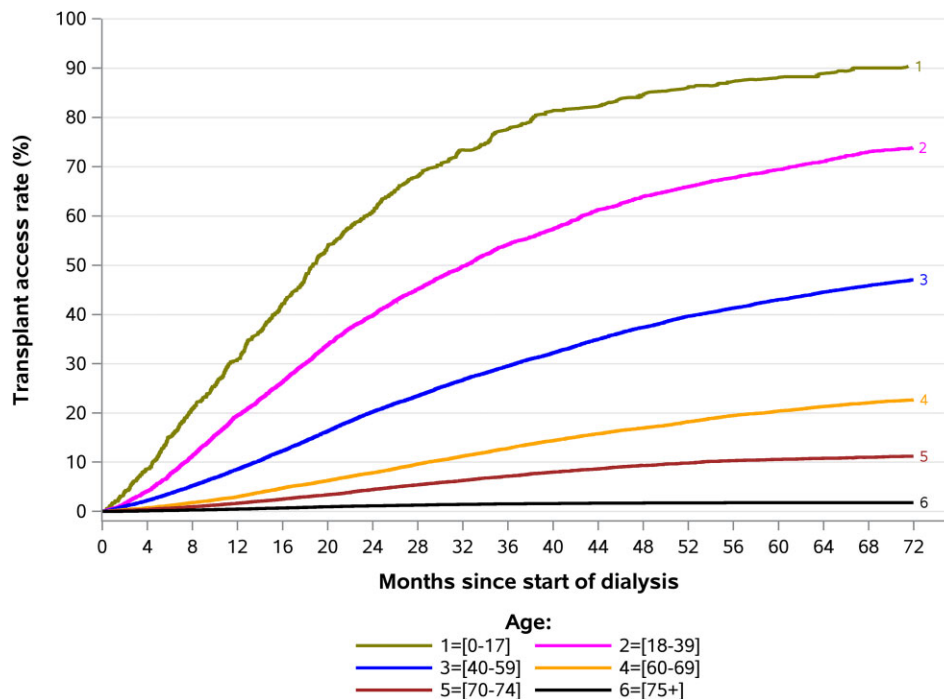


Figure 9: Transplantation access rate for patients starting dialysis, by age.

only began to decrease in 2018, other causes such as glomerulonephritis and hypertensive nephropathy began to decrease as early as 2015.

Arrival at the RRT stage is a reflection of upstream care management. In April 2015, at the instigation of the REIN scientific committee, a working group was set up to consider the opportunity and feasibility of registering in the REIN patients with stage 5 CKD not treated by dialysis [21]. Indeed, a keener understanding of the population of stage 5 CKD patients is crucial to better understand the practices of access to replacement therapy or conservative treatment and to anticipate future needs [22]. Extending the scope of data will allow for better understanding the temporal and spatial variations in incidence. Unfortunately, this extension of the REIN registry has been slow in getting started. The study conducted in a few volunteer regions highlighted the difficulties in identifying patients and the resulting heavy workload. However, efforts could be considered to identify and register in REIN those patients who have reached ESRD and opting for conservative treatment.

We observed a decrease in the rate of initiation of dialysis in an emergency (i.e. initiated less than 24 hours after a nephrological evaluation considering a vital risk for the patient). This item has been declared a priority. The proportion of emergency starts in each region is an indicator of interest, regularly transmitted to the regional health agencies. Its improvement is the result of an effort to understand and better anticipate the initiation of RRT. Unfortunately, the initiation of HD with a catheter, another indicator of a lack of optimal care and, especially, access to a nephrology pathway and HD preparation, has not decreased for the time being. Several studies based on REIN data have been conducted to understand the determinants of the conditions for starting dialysis [23, 24]. Because clinical characteristics of patients do not explain everything, there is room for improvement in management. However, the stagnation of the proportion of patients starting HD with a catheter must be interpreted

by taking into account the availability of vascular surgeons as well as the vascular state of the patients, which itself depends on cardiovascular comorbidities. In fact, for some individuals, the choice of a catheter considers their low life expectancy and the difficulties in performing fistula or bypass surgery. Approximately 15% of patients did not have a nephrological consultation before the initiation of dialysis. For some, their renal disease was unknown. For others, it was probably known to their general practitioner. The follow-up of these patients and the criteria for referring them to nephrologists must be improved by closer collaboration. Various tools have been put in place to highlight the eGFR via the biological data provided for each patient and the general practitioner to refer patients with renal failure to a nephrologist before stage 5. As in other countries, PD decreased despite a number of unsuccessful initiatives by the health authorities and nephrology societies. But home HD seems to be gaining in popularity. Much hope is pinned on the new funding scheme for stage 4 and 5 CKD patients. In fact, since 2019 the French government has implemented a bundled payment system for stage 4 and 5 CKD patients to slow the progression of renal disease, better prepare for the initiation of dialysis or the decision of conservative treatment, develop home dialysis and prepare for pre-emptive transplantation. A fixed-price organization with different healthcare actors (a secretary, nurse, dietitian, 'super nurse', social worker and nephrologist) are proposed to follow stage 4 and 5 CKD patients. This new organization should improve the health status of patients initiating dialysis. With the dynamics launched by the new financing methods, we can envisage having data concerning the management of patients with stage 4 CKD, opening new perspectives for studies, in particular on the determinants of the progression of renal disease. Evaluation of the impact of this change is under way but was made difficult by the coronavirus disease 2019 pandemic.

The REIN registry has been an essential tool in the medico-economic evaluation of RRT modalities [25, 26] and has

encouraged the development of preventive measures in the French Health 2022 plan. In recent years, linking of the REIN registry to the French national health database has paved the way to evaluating patients' care pathways before and after the start of RRT [27, 28]. These data have great potential for evaluation, health economics and research, and their exploitation should become more widespread. Data analysis showed a high degree of heterogeneity in trajectories and a direct link with the conditions for starting dialysis [29, 30]. Such approaches must be expanded for developing recommendations to improve management and slow the progression of renal disease.

The global vision of access to kidney transplantation is possible with the REIN registry, which brings together data on dialysis and transplantation. National recommendations published in 2015 aimed to reduce delays in registration on the waitlist for kidney transplantation. The rate of pre-emptive registration on the waitlist (i.e. before the start of dialysis) has increased over the past 10 years. Similarly, pre-emptive transplantation has increased in frequency, showing a trend toward earlier registration of patients in the history of their disease. However, at dialysis start, the registration rate in 2019 was 19.8% in the UK versus 7.5% in France. This difference may be explained in part by a younger and less comorbid dialysis population in the UK, with a median age of 64.2 years at initiation of dialysis versus 70.6 years in France [31]. The proportion of pre-emptive transplantation in France (3% of incident patients) remains lower than in neighbouring countries: 5.5% in Spain from 2006 to 2019 [32] and ~8% in the UK from 2014 to 2019 [31]. Many studies based on REIN data have shown variations in practice and inequities in access to the waitlist or renal graft and transplant outcomes [9, 17, 33–37]. Age, the presence of diabetes and body mass index >35 kg/m² are associated with less access to the waitlist. The REIN registry showed that variations in registration among dialysis networks are slight after taking into account the clinical characteristics of patients. The assessment of benefits and risks to access kidney transplantation is shared by French dialysis and transplantation networks, and patients' age at registration on the waitlist is the factor associated with greater variability [9]. The mean time on the waitlist before kidney transplantation has been gradually increasing since 2012 in the context of graft shortage. The likelihood for a patient to receive a kidney in the entire incident ESKD cohort is low. The issue of access to transplantation must include the delicate process of evaluating indications and contraindications, registration on the active waitlist and the graft allocation system.

The REIN contributes to various research projects. In elderly patients, the REIN allowed identifying heterogeneous trajectories specific to this growing older population, raising ethical, organizational and economic issues [38]. As well, the REIN allows comprehensive assessment of paediatric patient's trajectories and identification of areas of improvement [39–43].

Despite many qualities, the limitation of the REIN registry is that it is based on specific manual data collection. Therefore, it relies on the motivation of nephrologists and health-care professionals and would be impossible without the presence of research assistants. The progressive implementation of automatic data retrieval from dialysis informatics charts might alleviate the burden of data collection. Then efforts can be directed toward other aspects not currently covered, such as patient-reported outcome measurements and intervention research. Broadening the REIN's scope to include earlier stages of the disease would provide a better understanding of future needs and developments and enable evaluation of prevention efforts. The aim is to move towards a renal health information

network serving a global renal health policy focused on prevention, quality of care and innovation.

CONCLUSION

Over the past 20 years, the REIN registry has made it possible to monitor developments in RRT. As in other countries, the incidence of RRT is stabilizing or even declining, particularly in non-diabetic patients. The rate of emergency dialysis initiation is decreasing, but initiation of HD with a catheter has not yet decreased. HD in a facility remained the main modality of treatment, while the number of home dialysis patients remains low. The proportion of pre-emptive transplants and pre-emptive registrations has slightly increased. But because of the shortage of organs, the median waiting time before a kidney transplant has been increasing steadily since 2012.

Beyond its undeniable contribution as a planning and evaluation tool, the REIN registry is also successful because of its growing role in training and raising the awareness of kidney health professionals, particularly young nephrologists, in the epidemiology and public health aspects of kidney failure. The continuity of funding, the renewed confidence of the health authorities in the REIN and the dynamism of French nephrology in the broadest sense of the term allow us to look to the future of the REIN with confidence and optimism.

SUPPLEMENTARY DATA

Supplementary data are available at [ckj](#) online.

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None.

DATA AVAILABILITY STATEMENT

All data used for this research were extracted from the REIN registry, coordinated and supported by the French Biomedecine Agency. The access to national data is regulated by a scientific committee of French Biomedecine Agency which analyzes each request. Data cannot be made publicly available due to legal restrictions. However, data are available upon request. If readers need information about the data from the REIN registry, they can contact Dr. Cecile Couchoud who coordinates the REIN at the national level (email adress: cecile.couchoud@biomedecine.fr).

CONFLICT OF INTEREST STATEMENT

None declared.

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