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Assessment of the Completeness and Representativeness of the RDPLF Registry Using the French National REIN Registry as a Reference

(Exhaustivité et concordance des données du RDPLF par rapport au registre national REIN)

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Summary

For more than 40 years, the French Language Peritoneal Dialysis (and Home Hemodialysis) Registry (RDPLF) has been a major source of data on home dialysis treatment modalities. Since centers participate on a voluntary basis, the question of its completeness and national representativeness remains essential. This study evaluates these parameters by comparing RDPLF data with those from the 2026 report of the French national REIN registry, which is considered comprehensive for France.

The comparison is based on data as of December 31, 2024; several common indicators were analyzed: number of prevalent and incident patients on peritoneal dialysis, regional distribution of patients, treatment modalities by age, level of autonomy, use of assistance, and parameters related to anemia. The results show that the RDPLF captures between 90% and 97% of prevalent patients recorded in REIN. The number of incident patients is slightly higher in the RDPLF, likely due to differences in the timing of data updates. Despite these discrepancies, the trends observed in the two registries are remarkably consistent.

A comparison of patient characteristics and treatment practices reveals a very high degree of consistency. The distributions of peritoneal dialysis techniques by age, levels of autonomy, and dialysis modalities are virtually identical.

These results confirm the RDPLF's national representativeness for peritoneal dialysis in France and highlight the complementary nature of the two registries. While REIN provides comprehensive surveillance of chronic kidney disease, the RDPLF offers detailed, specialized clinical data on home-based treatments. This complementarity is a significant asset for evaluating practices and developing home dialysis strategies.

Résumé

Le Registre de Dialyse Péritonéale de Langue Française (RDPLF) constitue depuis plus de quarante ans une source majeure de données sur les modalités thérapeutiques de dialyse à domicile. Sa participation reposant sur le volontariat des centres, la question de son exhaustivité et de sa représentativité nationale reste essentielle. Cette étude évalue ces para-mètres en comparant les données du RDPLF à celles du rapport 2026 du Registre national français REIN, réputé exhaustif pour la France.

La comparaison porte sur les données du 31 décembre 2024 ; plusieurs indicateurs communs ont été analysés : nombre de patients prévalents et incidents en dialyse péritonéale, répartition régionale des patients, modalités de traitement selon l'âge, niveau d'autonomie, recours à l'assistance et paramètres liés à l'anémie. Les résultats montrent que le RDPLF recense entre 90 % et 97 % des patients prévalents enregistrés dans REIN. Les effectifs de patients incidents sont légèrement supérieurs dans le RDPLF, probablement en raison de différences dans la temporalité de mise à jour des données. Malgré ces écarts, les tendances observées dans les deux registres sont remarquablement concordantes.

La comparaison des caractéristiques des patients et des pratiques de prise en charge révèle une très forte cohérence. Les distributions des techniques de dialyse péritonéale selon l'âge, les niveaux d'autonomie et les modalités d'assistance sont quasiment identiques.

Ces résultats confirment la représentativité nationale du RDPLF pour la dialyse péritonéale en France et soulignent la complémentarité des deux registres. Alors que REIN fournit une surveillance exhaustive de l'insuffisance rénale chronique, le RDPLF apporte des données cliniques continues détaillées et spécialisées sur les traitements à domicile. Cette complémentarité constitue un atout important pour l'évaluation des pratiques et le développement des stratégies de dialyse à domicile.

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Keywords: registry, RDPLF, REIN, peritoneal dialysis, hemodialysis,completeness.

Mots-clés : registre, RDPLF, REIN, dialyse péritonéale, hémodialysie, exhaustivité.

Introduction

The French Language Peritoneal Dialysis (and Home Hemodialysis) Registry (RDPLF) is a nonprofit organization that maintains a database of patients receiving home dialysis. Patients undergoing peritoneal dialysis have been included in the registry since 1979 in France and since 1986 in Belgium and French-speaking Switzerland. Centers in Algeria, Morocco, and Tunisia also participate. While it is difficult to assess the completeness of data from the various French-speaking countries, France has had the advantage of a mandatory national registry since 2002—the REIN registry (Network for Epidemiology and Information in Nephrology), managed by the French Biomedicine Agency—which has been considered comprehensive since 2012 [1]. The REIN registry covers all conditions and treatments for chronic kidney disease; the RDPLF specializes solely in the follow-up of patients treated with a home dialysis method (peritoneal dialysis and home hemodialysis). Participation in the RDPLF registry is voluntary, whereas participation in the REIN registry is institutional and mandatory in France; the latter is therefore comprehensive for France. Because participation in the RDPLF is not mandatory, the aim of this article is to evaluate the completeness of the number of French patients treated with peritoneal dialysis (PD) included in the RDPLF compared to the REIN registry.

Method

The REIN registry publishes an annual report based on records verified two years prior. The latest report, published in March 2026, covers all French centers for which data had been entered through December 31, 2024 [2]. This report covers all renal replacement therapies, including transplantation. Peritoneal dialysis and home hemodialysis are included in this report.

The RDPLF database consists of a mandatory, comprehensive main module covering all patients treated in participating centers; other optional modules supplement the main module and focus on specific aspects of treatment, such as nutritional management and dialysis dose, catheter placement techniques and complications, anemia management, nursing training, and heart failure. All optional modules are linked to one another and to the main module. *Figure 1* illustrates the general structure of the RDPLF database, including the total number of patients included.

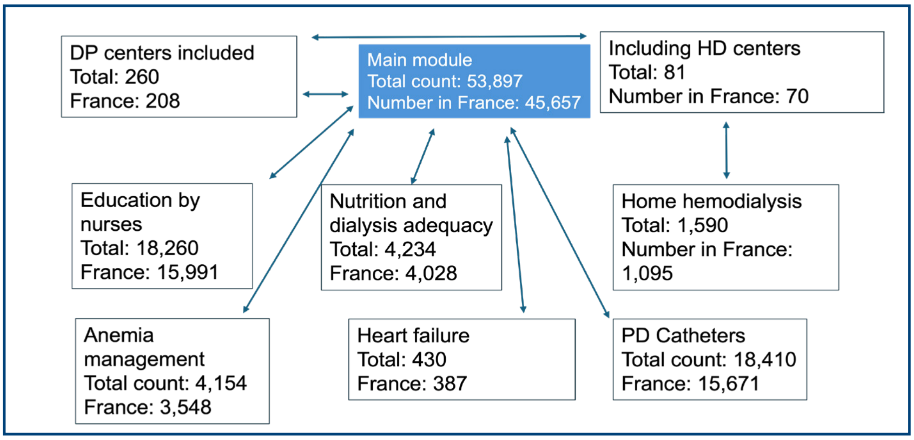

Figure 1. Structure of the RDPLF database.
The database consists of a main module that is mandatory for all participating centers and optional modules chosen by the centers based on their interests or capabilities. The term «Total», in the figures, correspond to the total number of centers and patients included since 1979, while the France" figures correspond to the total number of patients in France included since 1979. PD: peritoneal dialysis. HD: home hemodialysis.

PD data published in the REIN report are often included in the general data for dialysis patients of all methods, such as those relating to BMI, albumin, or other laboratory data. Home hemodialysis is often included in home hemodialysis, whether self-administered or not. Therefore, we selected only the variables that were identical in the REIN report and the RDPLF. In the tables of the REIN report, when numbers were presented as a percentage of a total, we performed the calculation to compare the numbers with those from the RDPLF. For each number studied, we indicate the figure or table number in the report from which it was derived.

The number of prevalent and incident patients with PD and HDD in the REIN report was calculated based on the percentages of the total number of patients listed in the report. We calculated the same figures for the same dates using the RDPLF database. The annual trends in PD incidence and prevalence from the REIN report are available at https://www.agence-biomedecine.fr/fr/search?tags=228 [accessed on 05/15/2026] in the form of Excel tables, which we used as a reference to compare the prevalence and incidence figures in the RDPLF registry.

We compared only the information concerning metropolitan France; in fact, outside of metropolitan France, the overseas administrative regions monitored by REIN include patients from Guadeloupe, French Guiana, Martinique, Mayotte, and Réunion, whereas only patients from Réunion are included in the RDPLF; conversely, the RDPLF monitors patients from New Caledonia and Tahiti. It would therefore not be possible to compare the comprehensiveness of the data outside of mainland France.

Results

Number of prevalent and incident patients.

The REIN figures were extracted from the Excel table

For comparable dates, the RDPLF contains between 90% and 97% of the patients recorded in the REIN database (*Figure 2*); the number of incident patients during the same years is slightly higher in the RDPLF, ranging from 114% to 123% (Figure 3). Despite these differences, the trends are similar.

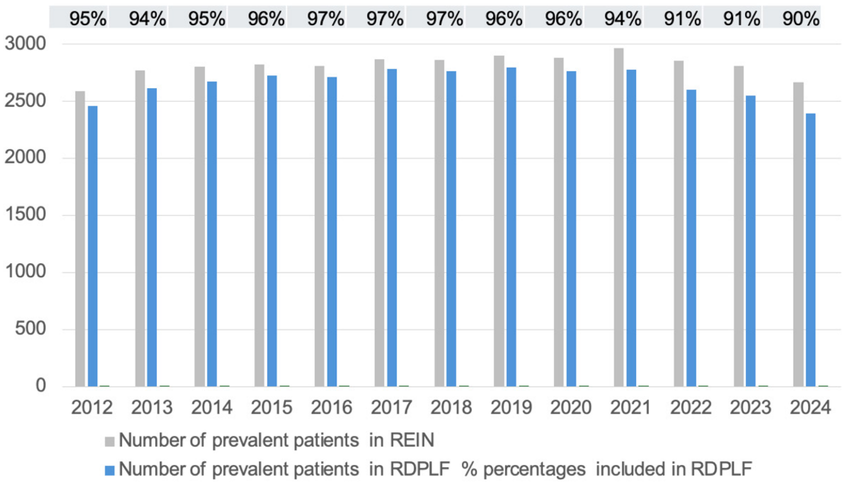

Figure 2. Trend in the number of prevalent patients as of December 31, 2024, recorded in the REIN registry and the RDPLF.

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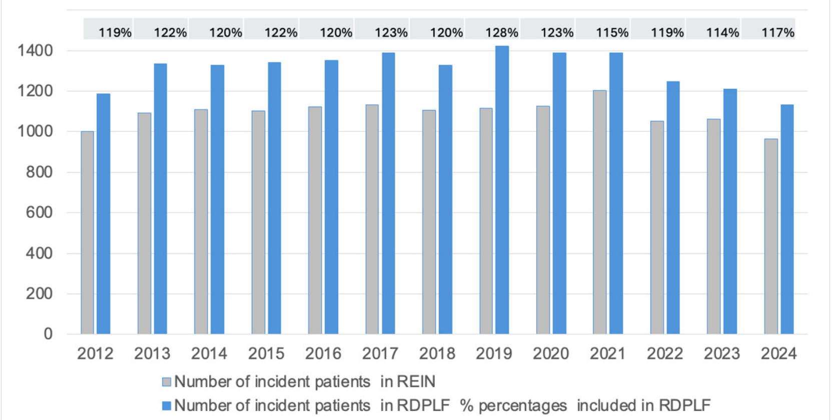

Figure 3. Trend in number of incident patients since 2012 recorded in the REIN registry and the RDPLF.

Distribution of the number of patients whose first treatment for renal failure was PD

The REIN data are extracted from Table 3-15 of the report; the RDPLF figures represent patients who had not undergone any other renal replacement therapy prior to starting PD. The number of patients is 963 in the RDPLF and 965 in REIN, representing 94% of REIN patients registered in the RDPLF; at the regional level, three regions have less than 90% of patients included in REIN, and two regions have more than 100% of REIN patients registered in the RDPLF (*Table I*).

Distribution of PD techniques as of December 31, 2024, by age

Table I. Regional distribution of the number of patients whose first treatment in 2014 was peritoneal dialysis.

Regions	RDPLF	RDPLF/REIN	REIN
Auvergne-Rhône-Alpes	121	83%	146
Grand Est	103	95%	108
Ile-de-France	101	94%	108
Nouvelle-Aquitaine	97	123%	79
Occitanie	91	85%	107
Provence-Alpes-Côte d’Azur	85	108%	79
Hauts-de-France	79	77%	103
Pays de la Loire	68	100%	68
Normandy	65	97%	67
Burgundy-Franche-Comté	45	96%	47
Brittany	34	92%	37
Centre-Val de Loire	13	93%	14
Corsica	2	100%	2
Total	904	94%	965

RDPLF: number of patients registered in the RDPLF; REIN: number of patients registered in the REIN registry; RDPLF/REIN: percentage of REIN patients registered in the RDPLF.

The peritoneal dialysis techniques used by patients as of December 31, 2024, by age were reproduced from Figure 4-6 of the REIN report. The figures obtained from the RDPLF database for the same period are very close to, or even identical to, those of the REIN registry (*Figure 4*).

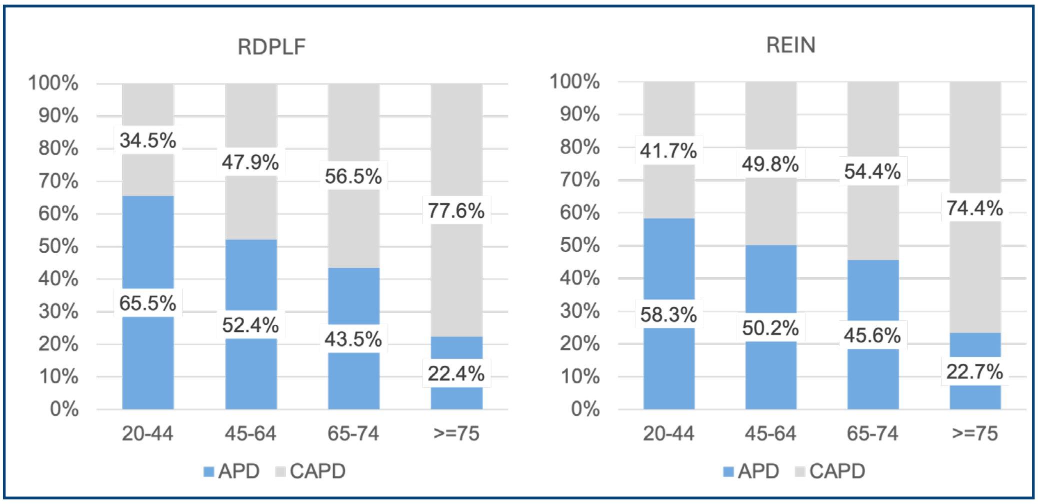

Figure 4. Peritoneal dialysis techniques used by age, according to the RDPLF and REIN registries, as of December 31, 2024.

APD: Automated Peritoneal Dialysis; CAPD: Continuous Ambulatory Peritoneal Dialysis.

Autonomy and peritoneal dialysis in the REIN and RDPLF registries

Data from the REIN registry are obtained from Table 4-16 of the REIN report. The number of patients reported in the RDPLF is higher than in the REIN registry for these items, but the percentages are virtually identical in both registries. The few differences can be explained by a higher percentage of unspecified assistance types in the REIN registry (*Table II*).

Table II. Percentages of patients treated with APD or CAPD and percentages by degree of autonomy and assistance, in the REIN registry and the RDPLF.

	APD Assistance Total APD (REIN): 40.9% Total APD (RDPLF): 41.0%				CAPD Assistance Total CAPD (REIN): 59.1% Total CAPD (RDPLF): 59%			
Sources	unassisted	nurse	family	unknown	unassisted	nurse	family	unknown
RDPLF n=2563	33.3%	5.4%	2.4%	0.0%	30.1%	25.4%	3.0%	0.4%
REIN n=2198	27.00%	5.00%	4.80%	4.10%	23.10%	24.20%	5.10%	6.70%

CAPD: Continuous Ambulatory Peritoneal Dialysis; APD: Automated Peritoneal Dialysis; n: number of patients included.

Assessment of Anemia

The RDPLF anemia module is optional; thus, in 2014, it covered only 23 of the 151 RDPLF centers, and 115 of the 1,206 patients—just under 10%—had data recorded at the start of treatment.

According to Figure 3-6 of the REIN report, at the start of PD treatment:
- 75% of patients had Hb ≥ 10 g/L.
- 16% of patients had Hb < 10 g/L while taking erythropoiesis-stimulating agents (ESAs).
- 10% of patients had Hb < 10 g/L without ESAs.

However, this data was actually obtained from the optional module of the RDPLF, so it cannot be compared with a comprehensive national survey.

Home Hemodialysis

According to Table 4-6 of the REIN report, hemodialysis modality was reported for 38,673 patients: 1.7% of them, or 657, were treated with home hemodialysis (HHD). As of the same date, 313 patients were receiving HD at home in the RDPLF database, representing 47% of patients included in the REIN registry.

The data presented in the REIN report regarding HHD differ from those in the RDPLF or are grouped with other forms of self-administered dialysis. It is not possible to use this method to compare the two databases on other items. The number of sessions per week, for example, is available in the RDPLF but is not included in the report.

Discussion

In 2006, we collaborated with the REIN registry to assess the quality of the information and the concordance of shared data.

Good overall concordance between REIN and the RDPLF for common data was demonstrated in a previous article published in 2006 [3]. That study highlighted the reliability and representativeness of both registries and the synergy of their activities in monitoring PD treatments. Twenty years later, we felt it was useful to verify the concordance of the main common information recorded in both registries. The operating procedures and objectives of the two registries remain very different (*Table III*).

Table III. Main differences between the RDPLF and REIN registries.

Characteristics	RDPLF	REIN
Type of registry	Specialized	General
Field	Home dialysis	All CKD
Scale	French-speaking	National (France)
Objective	Clinical improvement	Epidemiology / public health
Data	Highly detailed (PD/HHD)	Standardized, comprehensive
Operation	Voluntary	Mandatory, institutional
Update	Continuous, real time	Continuous + annual validation
Objective	Clinical monitoring	National surveillance
Quality control	Local / pragmatic	Structured / institutional
Funding	Nonprofit organizations, companies, and donations	Public, Biomedicine Agency

CKD: Chronique Kidey Desease; PD: Peritoneal Dialysis; HHD: home hemodialysis

Cross-referencing complementary registries such as the RDPLF and REIN is recommended to enrich the analyses and improve their robustness, provided that regulatory and methodological requirements related to data matching are met; this would require a common patient identifier, which raises ethical issues that are difficult to resolve as of today. The 2006 article [3] demonstrated excellent concordance in biological and anthropometric data values for patients common to both databases. The present study is not based on a cross-referencing of the two databases; no physical or software link exists between the two registries. The publication of the REIN report thus allows for, completely independently of the two systems, a comparison of the completeness of patient coverage. As of a fixed date, the completeness of prevalent patients is always greater than 90% of the number of patients included in REIN; on an annual basis, the completeness is always higher than that of REIN. These apparent differences are easily explained by the updating procedures: In REIN, each patient is updated annually, whereas in the RDPLF, centers update all their patients in real time or nearly so as changes occur. The number of patients at a given time or period is therefore not up to date at the same time in both registries. Nevertheless, these differences are negligible, as shown by the analysis of the results that are consistent with the report: The distribution of techniques and modes of assistance are similar, for example.
The fact that the RDPLF's optional modules are not exhaustive could reduce their representativeness but can supplement certain missing data in the REIN report: for example, information on haemoglobin levels and the use of ASE was obtained from the anaemia module of the RDPLF. For the centres that use them, the optional modules are primarily a means of monitoring their clinical practice; however, they can also provide a national overview of data not included in the REIN report. It may be possible to compare other biological, clinical or anthropometric values by using information not included in the report.

As with PD, HD is documented in greater detail in the RDPLF; thus, the duration of home sessions, complications related to vascular access, the percentage of return visits to the center, transfers between home dialysis techniques, etc., are recorded [4]. The REIN report we used as a reference did not include the same data as those available in the RDPLF, and only the number of patients included could be assessed: Only 47% of HDD patients recorded in REIN are in the RDPLF; it will be useful in the future to attempt to compare variables common to both registries. National participation by HDD units is more difficult to achieve than for PD, likely for various reasons: lack of time on the part of the teams and lack of motivation. This difference is indirectly confirmed by the number of publications in the Bulletin de la Dialyse à Domicile, in which the number of submissions on HDD is significantly lower than those on PD.

At a time when policymakers and doctors are seeking to promote home dialysis, the RDPLF is undoubtedly one of the strongest advocates for this approach: Not only does it maintain a reliable, specialized database on home care, but it also provides direct support to teams by offering them direct access to basic statistics generated from the database, mailing lists reserved for nurses and doctors alike, a protocol server, and a free, open-access bilingual journal for both authors and readers. This is made possible thanks to the work of the nurses and doctors who regularly update their data and the authors who share their knowledge and experience in the database (https://bdd.rdplf.org).

The weakness of this study lies in the small number of variables common to both registries that could be compared. A more in-depth study would be useful and could be achieved by obtaining REIN data that are not included in its report but are identical to those in the RDPLF.

Conclusion

The RDPLF database has a coverage rate, in terms of the number of patients included, compared to the REIN registry, that exceeds 90% for prevalent patients and 100% for incident patients. As in the study conducted 20 years earlier [3], the two registries appear to be complementary and synergistic in promoting and advancing home dialysis techniques. We encourage French-speaking RDPLF member countries that have a national registry to also verify the consistency of data between their respective registries and the RDPLF.

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Authors' Contributions

Emmanuel Fabre: Developed the database, contributed to the extraction of RDPLF data, and reviewed the article; Walid Arkouche, Jacques Chanliau, Max Dratwa, Belkacem Issad, Marie-Christine Padernoz, Ghislaine Veniez: Participate in the operation of the RDPLF, reviewed the article, and provided constructive feedback; Christian Verger: Conceived and wrote the article.

Ethical considerations

This study was conducted in accordance with the ethical principles of the Declaration of Helsinki.

Patient Consent

Centers participating in the RDPLF provide patients included in the study with an informed consent form for inclusion in the database. All data are processed after complete anonymization.

Artificial intelligence

The authors declare that this manuscript is the result of their own original work. No artificial intelligence tools or applications were used for data analysis, generation of results, or the creation and drafting of the text.

Conflicts of Interest

The authors declare that they have no conflicts of interest related to the writing of this text.

Data availability

The datasets generated and analyzed in this study are available from the author upon reasonable request.

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