International Society of Nephrology Global Kidney Health Atlas: structures, organization, and services for the management of kidney failure in Western Europe

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ISN-GKHA: Structures, organization, and services for the management of kidney failure in Western Europe

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Manuscript word count: 4954

Running Title: ISN-GKHA - Western Europe

Funding Source

This work was supported by the International Society of Nephrology (Grant RES0033080 to the University of Alberta).

Abstract

Populations in the high-income countries of Western Europe are aging due to increased life expectancy. As the prevalence of diabetes and obesity has increased, so has the burden of kidney failure. To determine the global capacity for kidney replacement therapy and conservative kidney management, the International Society of Nephrology (ISN) conducted multinational, cross-sectional surveys and published the findings in the ISN-Global Kidney Health Atlas (ISN-GKHA). In the second iteration of the ISN-GKHA, we aimed to describe the availability, accessibility, quality, and affordability of kidney failure care in Western Europe. Among the 29 countries in Western Europe, 21 (72.4%) responded, representing 99% of the region's population. The burden of kidney failure prevalence varied widely, ranging from 760 per million population (pmp) in Iceland to 1,612 pmp in Portugal. Coverage of kidney replacement therapy from public funding was nearly universal, with the exceptions of Germany and Liechtenstein where part of the costs was covered by mandatory

insurance. Fourteen (67%) of 21 countries charged no fees at the point of care delivery but in 5 countries (24%), patients do pay some out-of-pocket costs. Chronic dialysis services (both hemodialysis and peritoneal dialysis) were available in all countries in the region, and kidney transplantation services were available in 19 (90%) countries. The incidence of kidney transplantation varied widely between countries from 12 pmp in Luxembourg to 70.45 pmp in Spain. Conservative kidney care was available in 18 (90%) of 21 countries. The median number of nephrologists was 22.9 pmp (range: 9.47-55.75 pmp). These data highlight the uniform capacity of Western Europe to provide kidney failure care, but also the scope for improvement in disease prevention and management, as exemplified by the variability in disease burden and transplantation rates.

Abstract word count: 284

Keywords (max 6): Kidney failure; end-stage kidney disease; Chronic kidney disease; Dialysis; Kidney transplantation; Kidney registries

Introduction

Compared to other world regions, Western Europe benefits from functional health care systems, established non-communicable disease guidelines, higher health professional density, high availability of essential medicines, and more widespread universal health coverage.[1,2] In line with this infrastructure, there has been a decline in premature mortality from the four major types of non-communicable diseases (cardiovascular diseases, cancer, diabetes, and chronic respiratory diseases).[3] However, large variability in mortality rates remain, both between sexes and between countries. One out of every 10 Europeans has chronic kidney disease (CKD); among contributing factors are the rising prevalence of

diabetes and obesity, and dynamics associated with an aging population.[4] In parallel with these changes, the prevalence of kidney replacement therapy (KRT; dialysis and kidney transplantation) is steadily growing and has led to an equally aging dialysis population.[5] Since 1964, the European Renal Association-European Dialysis and Transplant Association (ERA-EDTA) has collected data on KRT modalities such as dialysis and transplantation via national and regional kidney registries from 36 countries in Europe and has charted the evolution of kidney failure (KF) epidemiology through the publication of annual reports[6-10] and epidemiological trends.[11] As one of the world's largest international registries of kidney care, it contributes substantially to enabling international comparisons.

In 2020, nephrology in Europe faces a number of new challenges in addition to the well-known changes in population demographics with aging population and workforce challenges. First and foremost, the global pandemic resulting from severe acute respiratory syndrome (SARS)–coronavirus (CoV)-2 virus (referred to as COVID-19) has a number of far-reaching complications including high rates of acute kidney injury (AKI),[12] risk of transmission of infection among vulnerable in-center dialysis patients, and the suspension of transplant services to avoid additional immunosuppression at this time.[13] Secondly, the ongoing war and consequent population movement in Syria and elsewhere in the Middle East, Africa, and South America, have led to a rise in the number of refugees receiving KRT in European countries.[14] In addition to ethical, financial, and legal implications, forced migration in this context may increase the diversity of kidney pathologies, physical and psychological co-morbidities, and cultural nuances. Secondly, climate change may pose new problems, with an increasing number of heatwaves in Europe[15] and heat-related AKI as an important contributor to mortality in this setting.[16] There is also a climate-driven risk of increased 'tropical' infections, for example, poleward shifts of Aedes-borne virus distributions (particularly

dengue, chikungunya, and Zika), with their associated AKI morbidity.[17] Unexpected extreme weather conditions can also disrupt critical infrastructure (e.g., power and water supplies, transportation, and telecommunication services) required to deliver dialysis services.[18] Lastly, Brexit may have ramifications for patients with kidney disease in terms of reciprocal healthcare, the supply of medical consumables, organ sharing across the European Union (EU) countries participating in the Eurotransplant and healthcare in Northern Ireland,[19] as well as for European research and recruitment more broadly.[19] Though it is likely that in the short-to-medium term, Brexit as a geopolitical issue will pale in comparison to the COVID-19 threat to globalization. With this landscape in mind, we use data from the second International Society of Nephrology Global Kidney Health Atlas (ISN-GKHA) survey to report on the availability, accessibility, affordability, and quality of KF care in Western Europe. However, we should emphasize that this is only a snapshot of disease burden in the region. The methodology for this research is described in detail elsewhere.[20]

Results

Results of this study are presented in Tables and Figures and broadly summarized into two categories: desk research (Tables 1 – 2 and Supplementary Table S1) and survey administration (Figures 2 – 5 and Supplementary Figures S1-S7).

Setting

Western Europe has had various historical (non-communist versus formerly communist countries), geographic, and economic (high- rather than middle/low-income countries) definitions in the past. However, for the purpose of this analysis, we used the ISN regional definition, which includes continental Europe (Austria, Belgium, France, Germany, Ireland, Liechtenstein, Luxembourg, the Netherlands, Switzerland, and the United Kingdom),

Scandinavia (Denmark, Finland, Iceland, Norway, and Sweden), and Mediterranean Europe (Andorra, Greece, Israel, Italy, Malta, Monaco, Portugal, San Marino, Spain, and the Vatican).[21] This equated to a population of 433.7 million inhabitants living in predominantly industrialized, high-income countries. Germany (80.5 million), the United Kingdom (65.1 million), and France (67.4 million) are the most populous countries within Western Europe.[22]

Western Europe is one of the wealthiest regions of the world and continues to experience economic growth, as evidenced by an increase in the gross national income (GNI) per capita from US$ 19,752 in 2000 to US$ 35,420 in 2018 and a total regional gross domestic product (GDP) of US$ 18.8 trillion, representing 22% of the global economy.[22] Accordingly, the average life expectancy at birth has increased progressively to 80.9 years. However, despite faring better than many other regions in the world, income inequality still exists in Western Europe. For example, the Gini index, a statistical measure of income equality whereby 0 represents perfect equality and 100 represents perfect inequality, is 36 in the United Kingdom, 34 in Spain, and 33 in Greece.[23] The EU Regional Human Development Index report also shows a clear northwest/southeast divide across EU regions for the overall index, which is a parameter composite of a country's life expectancy, education index, and GNI per capita.[24] Within countries, differences exist among country regions as to performance in human development. This is especially the case for the United Kingdom, Spain, France, Italy, Germany, and Belgium. Capital city regions generally outperform non-capital city regions within countries.

Brief summary of the current state of kidney care in the region

The incidence of KF varies widely across Western European countries. According to the ERA-EDTA 2017 registry report based on data collected via national and regional kidney

registries, the incidence of KRT for such patients in Europe was 127 per million population (pmp).[10] Within Western European countries, this ranged from 97 pmp in Switzerland to 252 pmp in Greece. Nearly two-thirds of patients were male with a mean age of 65.3 years, and diabetic nephropathy was the underlying etiology in 23% of cases. Hemodialysis (HD) was the most frequent modality at the start of KRT, followed by peritoneal dialysis (PD) and then pre-emptive kidney transplant. In the Western Europe region, the prevalence of KRT was 854 pmp, ranging from 760 pmp in Iceland to 1,965 pmp in Portugal. It has been proposed that varying socioeconomic factors, prevention programs, and real differences in CKD incidence may account for these differences.[25]

Characteristics of participating countries

Forty-six respondents representing 21 of the 29 (72.4 %) countries in the ISN's Western Europe region completed the online questionnaire (Figure 1). The majority of respondents were nephrologists (n = 38, 85%), followed by policymakers (n = 4, 9%), other stakeholders (n = 2, 4%), non-nephrologist physicians (n = 1, 2%) and other health professionals (n = 1, 2%) with an overall response rate of 68.7%. Participating countries jointly represented a population of 433.1 million (99.9% of the total population in Western Europe). All participating countries were in the high-income category (n = 21, 100%), as were the eight territories that did not participate in the survey (Andorra, the Channel Islands, the Faroe Islands, Gibraltar, Greenland, the Isle of Man, Monaco, and San Marino). As a proportion of GDP, health expenditures in participating countries ranged from 12.1% in Switzerland to 6% in Luxembourg (Table 1).[26,27,28]

Burden of CKD and kidney failure in Western Europe

The average prevalence of CKD in Western Europe was 10.1% (95% CI: 9.6, 10.6), ranging from 7.84% in Israel to 11.84% in Sweden. The highest proportions of deaths and disability-adjusted life years (DALYs) attributed to CKD were found in Israel, Austria, and Greece (Supplementary Table S1).

Data on the prevalence of KF in Western Europe were available for all participating countries, with the exception of Liechtenstein and Malta. The median prevalence of treated KF in Western Europe was 1,038 pmp (interquartile range [IQR]: 948–1261), which is higher than the global median of 759 pmp. The countries with the highest prevalence were Portugal (1,612 pmp), Greece (1,319 pmp), and France (1,310 pmp) (Table 2).[29] The median number of new cases of treated KF in the region (131 pmp; IQR: 113-177.5) was lower than the global median (142 pmp). Greece, Portugal, and Israel had the highest incidences of KF in Western Europe (252 pmp, 230 pmp, and 193 pmp respectively). In all Western European countries, HD was the most common dialysis modality (Table 2).[29,30,31] However, PD accounted for a significant proportion of dialysis treatment in Iceland, Sweden, and Denmark (23%, 22%, and 21%, respectively). Patients living with a functioning kidney transplant comprised approximately two-thirds of all treated KF patients in Norway, Iceland, and Netherlands (70.6%, 66.7%, and 63.8% respectively). The country with the lowest prevalence of KF patients living with kidney transplants was Greece (242.1 pmp; 18.4% of all KF patients) (Table 2).[29]

Health finance and service delivery

In the vast majority of countries, costs of non-dialysis CKD and KRT care were covered by public funding (Figure 2). Services were free at the point of delivery with no out-of-pocket costs for the patient in 67% of countries in Western Europe, compared to just 43%

of countries around the world. Coverage of KRT costs by public funding (in whole or in part) was nearly universal in the region, with the exceptions of Germany and Liechtenstein, where part of the costs was covered by mandatory insurance.

Among the 21 participating countries, 18 (86%) had data available about the annual cost of dialysis. In the region, median annual costs (in USD) per person for maintenance HD ($60,037; IQR: $50,558–$77,040) and maintenance PD ($47,963; IQR: $30,248–$60,816) were well above global averages ($22,617 and $20,524, respectively) (Table 1).[32] Data on the annual cost of kidney transplantation in the first year were available for 13 countries; costs per patient range from $27,971 in the United Kingdom to $114,220 in France. Patients in 14 countries (67%) paid no out-of-pocket costs for KRT, and patients in five countries (France, Iceland, Netherlands, Sweden, and Switzerland) covered 1–25% of these costs (Table 1).[32] Fees were covered exclusively by private health insurance providers in Liechtenstein. A statutory health insurance model was used in Germany.

The organization and delivery of KF care was structured differently (no national framework) by regions in four countries (19%) and between adults and children in three countries (14%). In almost half of all countries, responsibility for KF care oversight rests with individual hospitals, trusts, or organizations (n = 10, 48%), followed by a national body (n = 7, 33%) and provincial or state level organizations (n = 7, 33%). Two countries (Germany and Liechtenstein) reported the organization and delivery of KF care as other.

Health workforce for nephrology care

Nephrologists are primarily responsible for KF care in Western Europe (n = 21, 100%), with some support from primary care physicians (n = 2, 10%) and nurse practitioners

(n = 2, 10%) in some countries. The median number of nephrologists (22.9 pmp, IQR: 16.0–29.9) and the median number of nephrology trainees (5.9 pmp, IQR: 3.1–9.3) in Western Europe were much higher than the median numbers worldwide (9.95 and 1.4 pmp, respectively) (Table 2).[33] There was, however, great variability within the region, with countries such as Greece, Italy, and Liechtenstein reporting more than 40 nephrologists pmp whereas the United Kingdom and Ireland both reported less than 10 nephrologists pmp. The most commonly reported workforce shortages were for both nephrologists (43%, n = 9) and dialysis nurses (43%, n = 9), followed by surgeons for HD access (38%, n = 8) and vascular access coordinators (29%, n = 6) (Supplementary Figure S1). Germany, Ireland, and Malta reported shortages of seven or more types of care providers, whereas Finland, France, Liechtenstein, Spain, and the United Kingdom did not report any workforce deficits.

Essential medications and health product access for kidney replacement therapy modalities

All countries in Western Europe had the capacity to provide chronic HD (Figure 3). The median number of HD centers was 6.9 pmp (n = 21, IQR: 4.5–10.1), with the highest densities in Liechtenstein and Greece (25.94 and 15.80 pmp, respectively) and the lowest in the United Kingdom and Denmark (0.95 and 2.32 pmp, respectively) (Table 2).[29] Home HD was available in 65% (n = 13) of countries in the region. In only one-third of countries (n = 7), more than 50% of HD patients began treatment with functioning vascular access (fistula or graft) (Supplementary Figure S2). In half of all countries (n = 10), 11–50% of patients started dialysis with a temporary dialysis catheter. PD was also widely available in all Western European countries (Figure 3). The median number of PD centers in the region was 2.3 pmp (n = 21, IQR: 1.8–3.6), which is above the global average. Liechtenstein and Switzerland had the highest PD capacity (centers pmp), whereas the United Kingdom and France had the lowest (Table 2).[29,30] All countries in Western Europe were able to offer

adequate frequency of PD exchanges (3–4 manual exchanges per day or equivalent cycles on automated PD), had the capacity to measure PD adequacy (via measurement of urea reduction ratio [URR] or Kt/V), and had efficient patient transport services available (Figure 3).

Kidney transplantation was available across most of the region (n = 19, 90%), with a regional median of 0.52 transplant centers pmp (n = 19, IQR: 0.4–0.8), just above the global median of 0.42 pmp (IQR: 0.20–0.72) (Table 2).[29] Iceland and Malta had the highest capacity for transplantation (5.82 and 2.23 transplant centers pmp, respectively), whereas Finland had the lowest (0.18 transplant centers pmp). All countries with transplant capacity performed a combination of deceased and living donor kidney transplants, with the exception of Iceland, which performs living donor kidney transplants only. The vast majority of countries with kidney transplantation available had national transplant waitlists (89%, n = 17), whereas the rest had regional lists only. Most countries were able to provide early and culturally appropriate information about transplantation to patients (95%, n = 19) (Figure 3). All countries in Western Europe were able to provide effective preventive therapy to control infections, timely access to operating space, appropriate immunosuppression treatment, and appropriate facilities to monitor immunosuppression drugs consistently. A standard organ procurement framework was available in all countries that have the capacity for transplantation.

In all surveyed countries in Western Europe, at least half of all patients with KF were able to access dialysis, a proportion that does not vary due to regional capacity or individual patient characteristics (Figure 4). Among those able to access dialysis, only a small minority (1–10%) began with PD in 50% of countries (n = 10); this proportion was affected by

regional capacity and patient characteristics in 35% and 25% of countries, respectively. In four countries (Finland, Malta, Norway, and Sweden), 26–50% of patients began with PD. In 60% of countries (n = 12), more than 50% of eligible patients were able to access transplantation services.

Conservative care (non-dialytic management of KF) was available in the majority of countries (n = 18, 90%) in Western Europe when medically advised or chosen by the patient (Figure 3). Among those countries able to offer this service, 65% (n = 13) took a multidisciplinary approach to care via shared decision-making and had decision-making tools readily available for patients and providers. Most countries (85%, n = 17) had the capacity to systematically and actively recognize and manage symptoms. Twelve countries (60%) were able to provide psychological, cultural, and spiritual support, but only nine countries (45%) had the resources to systematically train healthcare providers in conservative care. However, regional data for countries were not available and conservative care accessibility may vary within countries.

Reporting of kidney replacement therapy quality indicators

Twenty countries were able to provide information about the adequacy of PD; 19 and 18 countries were able to provide the same information about HD and transplantation, respectively. The least-reported indicator of dialysis adequacy was patient-reported outcome measures, with almost one-third of countries reporting that this information was collected by fewer than 10% of centers (Supplementary Figure S3). Technique survival in HD patients was also less commonly measured by centers, as were delayed graft function and rejection rates in transplant recipients. Small solute clearance (e.g. Kt/V or creatinine clearance) was measured in >75% of centers in 95% of countries.

Health information systems, statistics, and national health policy

Most countries in Western Europe had official dialysis and transplantation registries (n = 18 and 19, respectively), few had CKD registries (n = 3, 14.3%), and only Malta and the United Kingdom had AKI registries (Figure 5). Iceland and Luxembourg had no registries at all, whereas only Malta and the United Kingdom had registries for every aspect of kidney care. Participation in registries was mandatory in 74% of countries (14/19) for kidney transplantation and 67% of countries for dialysis (12/18), but only 33% of countries (1/3) for CKD. Nearly all registries had national coverage and collect general information on the etiology of kidney disease, dialysis modality, or transplant source (Supplementary Figure S4). Patient outcome measures were not as consistently collected, with only 33% and 42% of hospitalizations recorded for dialysis and kidney transplant patients, respectively. Quality-of-life measures were very infrequently collected; however, mortality rates were recorded for almost all dialysis and transplant patients.

Routine testing for kidney disease is available to almost all patients with diabetes and hypertension in the region, but only in 50% of countries to chronic users of nephrotoxic medications and in 10% of countries to high-risk ethnic groups (despite 35% of countries identifying ethnic groups as being at high risk for CKD). Testing was available in 70% of countries for those with a family history of kidney disease (Figure 5). Only one and two countries had AKI and CKD detection programs, respectively. Services to treat and diagnose complications of KF were mostly available in the region (Supplementary Figure S5).

Only 55% of countries (n = 11) in Western Europe had national strategies to improve care for CKD patients, including either CKD-specific strategies or those that had been

incorporated into non-communicable disease strategies, the former being more inclusive of all patients with kidney disease than the latter (Supplementary Figures S6 and S7). National CKD-specific policies were available in only five countries (25%). Recognition of kidney disease as a health priority at the government level was more common for KF, followed by CKD and AKI (65%, 50%, and 5% of countries, respectively). Advocacy groups for KF, CKD, and AKI existed in 35%, 20%, and 25% of countries, respectively. The most commonly cited barriers to optimal KF care were geography (15%), the individual patient (15%), and lack of political will (15%), followed by nephrologists (10%) and economic factors (10%) (Figure 5).

Discussion

Our study highlights several important aspects of KF care in Western Europe. The median prevalence of treated KF was higher than the global median, and there was variation between countries even in Western Europe. HD remains the main dialysis modality, and PD remains under-utilized. There was also striking variation in the incidence of kidney transplantation between countries. In the majority of countries, public funding covered costs associated with non-dialysis CKD and KRT care. Although the median number of nephrologists and nephrology trainees in Western Europe was higher than the global average, workforce shortages of nephrologists and other essential healthcare staff were still reported across the region. Most countries had dialysis and transplant centers, and official registries to capture dialysis and transplant activities, but very few had AKI or CKD detection programs. Only half of all countries in Western Europe had national strategies in place to improve CKD care.

All Western Europe is classified as a high-income region by the World Bank, however, there is substantial variation in treated KF incidence and prevalence rates. It has been proposed that varying prophylaxis programs, both in terms of primary prevention of CKD and how CKD progression is managed, as well as real differences in underlying CKD incidence may account for this variation,[25] which persists even with stratification by diabetes, hypertension, and obesity.[34] However, a decrease in KF incidence since 2001 has been noted among those between the ages of 60 and 69 in Denmark, from 400 ppm to 218 ppm, associated with a concurrent large increase in antihypertensive drug use, particularly drugs blocking the renin-angiotensin system (RAS).[35] There is substantial heterogeneity internationally in the control of hypertension with poorer than expected blood pressure control in some European cohorts.[36]

The EVEREST study,[37] an ERA-EDTA Registry initiative, identified GDP per capita and percentage of GDP spent on health care to be important in determining KRT incidence (i.e. there appears to be an 11% increase in KRT incidence associated with each 1% increase in GDP spent on health care), but some of the countries with the highest KF incidence such as Portugal, Greece, and Israel, have some of the lowest health expenditures. In Europe, the experience has been that dialysis has a disproportionately high impact on public health expenditure in countries with a lower GDP which carries the risk that this money is deviated from other urgent needs such as CKD primary and secondary prevention.[38] The risk of CKD progression can vary across countries even after accounting for the distributions of age, sex, comorbidities, and laboratory markers[39] and this variability has been demonstrated between Western European countries[40] Other factors that have been proposed to explain the wide variation in incidence, include differences in genetic predisposition,[41] birth weight,[42] lifestyle

factors such as exercise[43] or dietary habits,[44] and public health strategies to control hypertension,[45] obesity[46] and tobacco consumption.[47]

Although PD was widely available in Western European countries, HD remained the most frequent dialysis modality used; only a small minority of patients began dialysis with PD. For certain candidates, PD has a number of advantages over HD, including preservation of residual kidney function,[48] greater independence,[49] and better initial survival.[50] The availability of home HD varied among countries, even though in highly selected patients, it is associated with lower costs,[51] less need for specialized personnel, better control of blood pressure, anemia, and phosphate levels,[52] improved quality of life, and greater flexibility for patients compared to in-center dialysis.[53]

There was striking variation in the incidence of kidney transplantation amongst Western European countries, ranging from 12 pmp in Luxembourg to 70.45 pmp in Spain. With the exception of Iceland, Israel, and the Netherlands, the incidence of deceased donor kidney transplantation was much greater than that of living donor transplantation. Kidney transplantation is by far the most cost-effective KRT option due to a combination of prolonged survival, improved quality of life, and reduced medical costs after the first year.[54] Funded by the EU, the Effect of Differing Kidney Disease Treatment Modalities and Organ Donation and Transplantation Practices on Health Expenditure and Patient Outcomes (EDITH) project was established in 2017 to examine the epidemiology and costs of different treatment modalities for KF, including the reasons behind the substantial variability in access to kidney transplantation.[55] Some of the barriers appear to be fear of kidney rejection or graft failure, fear of surgery or medication, negative experiences with grafts (self or others), distrust of health care professionals, doing well on dialysis, religious opposition to

transplantation, and costs, all of which underscore the need for improved patient education and communication.[56] Better national health policies are clearly needed to improve the numbers. Different strategies may be required, depending on whether a country has a low level of deceased donor or living donor donation, or both. Countries with opt-out policies (or a practically defunct presumed consent system) such as Spain and Austria appear to have higher transplantation rates,[57] suggesting that Western Europe may benefit from a global opt-out strategy. In an opt-out strategy, organ donation is the default option at the time of death, and so people must explicitly "opt-out" of organ donation if they do not wish it, as opposed to an opt-in policy which necessitates explicit consent. However, in a more recent analysis of organ donation and transplantation rates in 35 countries, no significant difference was observed in rates of kidney (35.2 versus 42.3 respectively), non-kidney (28.7 versus 20.9, respectively), or total solid organ transplantation (63.6 versus 61.7, respectively).[58] This suggests that there are other barriers to organ donation that need to be addressed including education and infrastructure, and that opt-out policies alone are unlikely to be successful.[59] Collaboration in broader programs such as Eurotransplant, Scandiatransplant and the South Transplant Alliance may also improve transplant activity.[60] Another option may be to widen the donor pool to include expanded criteria donors and non-heartbeat donors, which are both under-utilized in Europe.

In 2019, upon request of the European Commission, the European Kidney Health Alliance (EKHA) formulated a joint statement of recommendations on how to improve organ donation and transplantation within the EU.[61] Their key recommendations were to mobilize political will to make organ donation and transplantation a priority, to improve legal and institutional framework, to streamline organization and invest in leadership at all levels, to allocate appropriate funds for organ donation and transplantation programs, to promote

education and training across all stakeholders, to eradicate inequities in organ donation, to boost benchmarking, and to leverage research.

In the vast majority of countries, non-dialysis CKD and KRT care were publicly funded, but out-of-pocket co-payments varied. However, the annual costs of dialysis and kidney transplantation were more than twice as high in Western Europe as the global median. Overall, 2% of health expenditures are allocated to KRT, which is required for just 0.1% of the population.[62] Promotion of more cost-effective forms of KRT (PD, home HD) or kidney transplantation may decrease financial pressure. Primary prevention of CKD by preventing underlying conditions such as diabetes mellitus and hypertension is also paramount.

Despite having more nephrologists and nephrology trainees in Western Europe compared to the rest of the world, there was much variation across the region, with countries such as Ireland and the United Kingdom both reporting less than 10 nephrologists pmp. Crucially, Ireland and the United Kingdom did not have particularly low numbers of nephrology trainees, suggesting that a lack of judicious workforce planning was central to these disparities. Other proposed contributing factors include declining interest in nephrology among trainees,[63] over-reliance on foreign medical graduates,[64] and erosion of nephrology practice scope by other specialists.[65]

Patient-reported outcome measures were very infrequently collected in Western European kidney units and registries compared to other parts of the world. Their importance in healthcare is increasingly recognized, as they can quantify a wide variety of health concepts that are relevant to the patient, such as quality of life, functional status, and symptom burden.[66] Patients with advanced CKD often experience poor health-related quality

of life and numerous physical and emotional disease related symptoms.[67] Routine collection of patient-reported outcome measures, as occurs in Australia and New Zealand,[68] could improve symptom management, promote shared decision making, and better address patients' needs.

Very few countries had AKI or CKD registries, or corresponding detection programs. AKI registries not only enable better tracking of the epidemiology of AKI, its burden, associated mortality, and longer-term adverse kidney outcomes (i.e. subsequent development of CKD), but also facilitate temporal and regional comparisons.[69] Similarly, CKD registries permit longitudinal study and analysis of outcomes, and can generate prediction factors influencing the prognosis, care patterns, and disparities in the delivery of care.[70] They create opportunities for quality improvement and KRT planning. However, the corollary is that registries are very time-consuming and costly when potentially affected individuals cannot be easily identified, and thus their contribution must be weighed against their cost. Population-based screening for CKD is also controversial. Early detection of proteinuria in an unselected population has not been shown to be cost-effective.[71] However, the See Kidney Disease (SeeKD) targeted screening project in Canada that screened adults with risk factors for CKD (i.e., diabetes, hypertension, vascular disease, family history of kidney problems, etc.) identified a high proportion of individuals with risk factors for CKD and a high prevalence of unrecognized CKD.[72] Kidney Disease: Improving Global Outcomes (KDIGO) recommends that all countries should have a targeted CKD screening program;[73] countries in Western Europe generally comply with this recommendation by routinely testing all patients with hypertension, diabetes, and vascular disease. More uniform testing of high-risk ethnic groups or those with a family history of CKD is needed, however. Only about half of all countries recognize CKD as a health priority and have national strategies to improve care, with few

specific policies. National CKD strategies can help develop a consistent approach to address key risk factors in the prevention, detection, and management of kidney diseases to minimize their progression and complications.

The most commonly cited barriers to kidney failure care were geography, the individual patient, and lack of political will (Figure 5). It has been shown rural patients have less access to dialysis units and home dialysis therapies when compared to urban patients,[74] and that that geographic location was associated with less frequent patient visits by dialysis providers.[75] Patient-specific factors may include absence of symptoms, dialysis fears, work-related concerns, socio-economic circumstances, and cultural differences.[76,77] Lastly, it is well-recognized that improving global access to safe, sustainable, and equitable integrated kidney failure care will require key stakeholders at governmental and policymaker level.[78]

In summary, the region is performing better in all aspects of kidney care overall compared to other regions, but improvements can be made through expansion of CKD prevention efforts, and realignment of priorities (less emphasis on KRT provision and more on prevention efforts). There is also a need for better workforce planning, multidisciplinary teams, and telemedicine. Collection and reporting of quality indicators, particularly patient-reported outcomes, should be routinely incorporated into KF care. Health information systems should be expanded to prevent and manage KF. KF prevention and treatment should also be more broadly promoted by implementing policies, strategies, and advocacy programs, and mitigating barriers.

Role of the Funder/Sponsor

The ISN provided administrative support for the design and implementation of the study and data collection activities. The authors were responsible for data management, analysis,

and interpretation, as well as manuscript preparation, review, and approval, and the decision to submit the manuscript for publication.

Acknowledgement

We thank Kara Stephenson Gehman in ISN-GKHA for carefully editing the English text of a draft of this manuscript. We thank Jo-Ann Donner, Coordinator at the ISN, for her prominent role and leadership in the manuscript management, editorial reviews, and submission process to Kidney International Supplements, Sandrine Damster, Senior Research Project Manager at the ISN, and Alberta Kidney Disease Network staff (Ghenette Houston, Sue Szigety, and Sophanny Tiv) for helping to organize and conduct the survey and for providing project management support. We also thank the ISN headquarters staff including the Executive Director, Charu Malik, and the Advocacy team. We also appreciate the support from the ISN's Executive Committee, regional leadership, and Affiliated Society leaders at the regional and country levels for their help with the ISN-GKA survey.

Disclosure

KE reports grants from Astra Zeneca, Bayer, Fresenius, and Vifor, during the conduct of the study; personal fees from Akebia, Bayer, Fresenius and Vifor and grants from Amgen, Genzyme, and Shire, outside the submitted work. DWJ reports grants and personal fees from Baxter Healthcare and Fresenius Medical Care, travel sponsorship from Amgen, personal fees from Astra Zeneca, AWAK, and Ono, and grants from National Health and Medical Research Council of Australia, outside the submitted work. VJ reports grants from GlaxoSmithKline and Baxter Healthcare, provides scientific leadership to George Clinical, and consultancy fees for Biocon, Zudis Cadilla, and NephroPlus, all paid to his institution,

outside the submitted work. ER reports personal fees and non-financial support from Alexion Pharmaceuticals, outside the submitted work. All other authors have nothing to declare.

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Table 1. Health finance, service delivery, and workforce prevalence in the 21 countries in Western Europe that participated in the ISN-GKHA survey.[26,27,28,32]

Country	Area (km^2)	Total population (2018)	GDP (PPP) ($ billions)†	Total health expenditures (% of GDP)†	Annual cost KRT§ (US$) & Out-of-pocket cost (% paid by patient from total cost)*		
					HD	PD	KT (first year)
Global** Median [IQR]	-	-	-	6.5 [4.9-8.8]	22,617 [14,882-49,690]	20,524 [14,305-33,905]	25,356 [6,138-17,522]
Western Europe** Median [IQR]	-	-	441.0 [266.0-2,048.0]	9.8 [8.7-10.6]	60,037 [50,558-77,040]	47,963 [30,248-60,816]	54,342 [34,090-71,777]
Austria	83,871	8,793,370	441.0	10.4	56,252[0%]	30,248[0%]	67,059[0%]
Belgium	30,528	11,570,762	529.2	10.0	67,512[0%]	61,643[0%]	38,451[0%]
Denmark	43,094	5,809,502	287.8	10.4	59,576[0%]	28,102[0%]	25,836[0%]
Finland	357,022	5,537,364	244.9	9.4	78,233[0%]	66,816[0%]	36,117[0%]
France	643,801	67,364,357	2856.0	11.1	85,436[1-25%]	69,516[1-25%]	114,220[1-25%]
Germany	357,022	80,457,737	4199.0	11.2	76,642	51,196	101,915
Greece	131,957	10,761,523	299.3	8.4	45,435[0%]	56,354[0%]	63,196[0%]
Iceland	572	343,518	18.2	8.6	73,320[1-25%]	17,155[1-25%]	-[1-25%]
Ireland	70,723	5,068,050	353.3	7.8	60,498[0%]	36,926[0%]	-[0%]
Israel	20,770	8,424,904	317.1	7.4	56,174[0%]	65,716[0%]	-[0%]
Italy	2,586	62,246,674	2317.0	9.0	46,912[0%]	26,254[0%]	71,461[0%]
Liechtenstein	160	38,547	5.0	-	-	-	-
Luxembourg	2,586	605,764	62.1	6.0	-[0%]	-[0%]	-[0%]
Malta	316	449,043	19.3	9.6	-[0%]	-[0%]	-[0%]
Netherlands	41,543	17,151,228	924.4	10.7	103,187[1-25%]	67,974[1-25%]	71,882[1-25%]
Norway	323,802	5,372,191	381.2	10.0	50,847[0%]	19,061[0%]	33,414[0%]
Portugal	450,295	10,335,493	314.1	9.0	32,846[0%]	32,109[0%]	105,183[0%]
Spain	505,370	49,331,076	1778.0	9.2	56,602[0%]	39,414[0%]	45,487[0%]
Sweden	450,295	10,040,995	518.0	11.0	92,285[1-25%]	83,193[1-25%]	-[1-25%]
Switzerland	41,277	8,292,809	523.1	12.1	67,800[1-25%]	47,963[1-25%]	-[1-25%]
United Kingdom	243,610	65,105,246	2925.0	9.9	49,690[0%]	31,505[0%]	27,971[0%]

Abbreviations: ISN: International Society of Nephrology; GKHA: Global Kidney Health Atlas; GDP: gross domestic product; PPP: purchasing power parity; KRT: kidney replacement therapy; HD: hemodialysis, PD: peritoneal dialysis; KT: Kidney transplant; IQR: interquartile range

† Estimates are in US$ 2017
§ Detailed reference list on annual cost of KRT is available in the Supplementary Appendix
*Costs are in US$ 2016
** Median and interquartile ranges are calculated for the selected countries in the ISN-GKHA survey only

"–": Data not reported/unavailable

Table 2. Kidney replacement therapy and nephrology workforce statistics for the 21 countries in Western Europe that participated in ISN-GKHA survey.[29,33,30,31]

Country	Treated KF (pmp)		Prevalence of chronic dialysis (pmp)			Chronic dialysis centers (pmp)		Kidney transplantation (pmp)			Nephrology workforce (pmp)	
	Incidence	Prevalence	HD	PD	Total (HD + PD)	HD	PD	Incidence	Prevalence	Centers	Nephrologists	Nephrology trainees
Global* Median [IQR]	142 [106-193]	787 [522-1047]	310.0 [99.0-597.0]	25.0 [2.0-56.0]	359.0 [112.0-636.0]	4.5 [1.0-10.0]	1.3 [0.4-2.5]	14.0 [5.0-36.0]	269.0 [66.0-468.0]	0.4 [0.2-0.7]	10.0 [1.2-22.9]	1.4 [0.3-3.7]
Western Europe* Median [IQR]	131 [113-178]	1038 [948-1261]	477.5 [319.4-670.1]	52.8 [43.5-67.4]	518.4 [376.0-717.6]	6.9 [4.5-10.1]	2.3 [1.8-3.6]	45.1 [32.2-51.9]	547.9 [486.1-619.6]	0.5 [0.4-0.8]	22.9 [16.0-29.9]	5.9 [3.1-9.3]
Austria	129	1087	477.5	40.9	518.4	9.1	1.0	49.2	569.0	0.5	34.1	5.7
Belgium	182	1287	663.3	54.3	717.6	4.6	2.3	48.1	569.2	0.6	-	-
Denmark	131	958	364.5	94.7	459.2	2.3	2.3	45.1	499.2	0.5	25.8	4.5
Finland	100	909	291.6	69.7	361.3	5.4	3.6	43.6	547.9	0.2	14.5	1.8
France	173	1310	670.1	46.2	716.3	4.2	1.2	58.2	593.4	0.5	20.0	5.1
Germany	-	-	768.1	38.8	806.9	9.9	2.5	23.4	-	0.4	18.6	3.7
Greece	252	1319	1010.0	66.7	1076.7	15.8	2.8	15.7	242.1	0.4	55.8	7.4
Iceland	143	760	195.1	58.2	253.3	11.6	2.9	26.7	506.7	5.8	29.1	-
Ireland	88	827	310.1	44.3	354.4	4.5	2.0	40.0	473.0	0.2	9.5	5.9
Israel	193	1138	662.8	43.5	706.3	9.3	2.5	44.2	432.0	0.7	29.7	2.4
Italy	140	1236	738.8	78.3	817.1	9.9	3.6	37.8	419.0	0.7	48.2	8.0
Liechtenstein	-	-	-	-	-	25.9	25.9	-	-	-	51.9	0.0
Luxembourg	-	-	596.7	4.7	601.4	8.3	1.7	12.0	-	-	21.5	-
Malta	-	-	-	-	-	4.5	2.2	52.5	-	2.2	13.4	22.3
Netherlands	115	1038	323.2	52.8	376.0	4.4	2.3	57.6	661.8	0.5	17.5	2.3
Norway	111	962	232.5	49.9	282.4	4.7	4.3	51.7	679.6	0.2	27.9	18.6
Portugal	230	1612	871.3	48.1	919.4	10.2	1.7	51.4	693.0	0.7	27.5	9.7
Spain	141	1213	499.8	67.4	567.2	6.9	2.2	70.5	645.7	0.9	20.3	7.3
Sweden	116	987	319.4	88.6	408.0	6.8	4.2	47.9	579.0	0.4	22.9	9.0
Switzerland	97	937	395.1	40.2	435.3	12.1	7.2	42.4	501.9	0.7	30.4	5.1
United Kingdom	118	971	383.8	53.3	437.1	1.0	0.8	52.1	533.8	0.3	9.8	6.1

Abbreviations: ISN: International Society of Nephrology; GKHA: Global Kidney Health Atlas; KF: kidney failure; pmp: per million population; HD: hemodialysis; PD: peritoneal dialysis; IQR: interquartile range

* Median values and interquartile ranges are calculated for the selected countries in the ISN-GKHA survey only
"–": Data not reported/unavailable

Figure Legends

Figure 1: Countries in the ISN Western Europe region that participated in the ISN-GKHA survey.

ISN: International Society of Nephrology; GKHA: Global Kidney Health Atlas

Figure 2: Funding structures for non-dialysis chronic kidney disease and kidney replacement therapy care.

CKD: chronic kidney disease; KRT: kidney replacement therapy; HD: hemodialysis; PD: peritoneal dialysis; gov't: government; NGOs: non-governmental organizations; N/A: not provided

(* Absolute number of countries in each category expressed as a percentage of total number of countries).

Figure 3: Availability of choice in kidney replacement therapy or conservative care for patients with kidney failure.

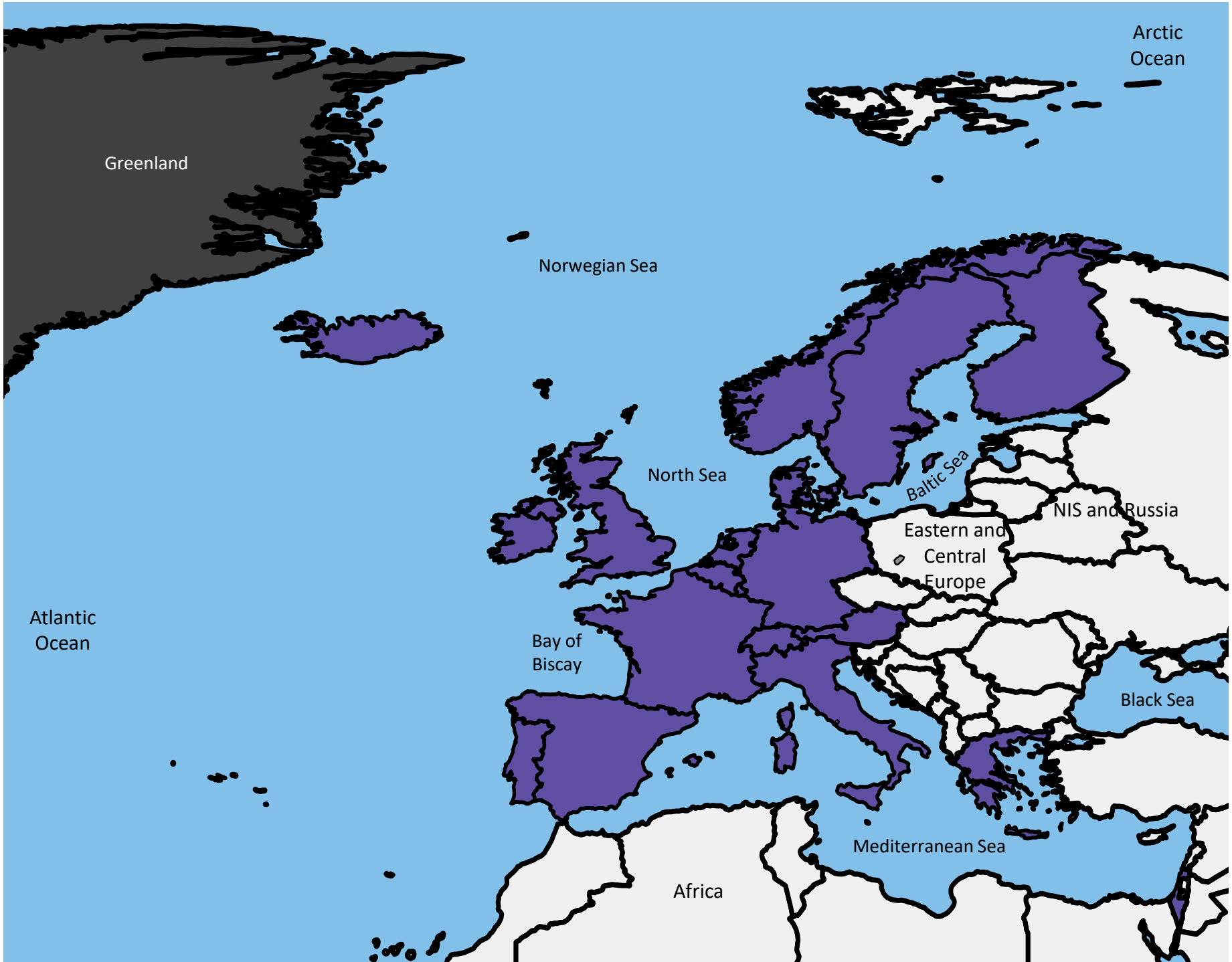
HD: hemodialysis; PD: peritoneal dialysis; URR: urea reduction ratio

Figure 4: Accessibility of kidney replacement therapy for patients with kidney failure.

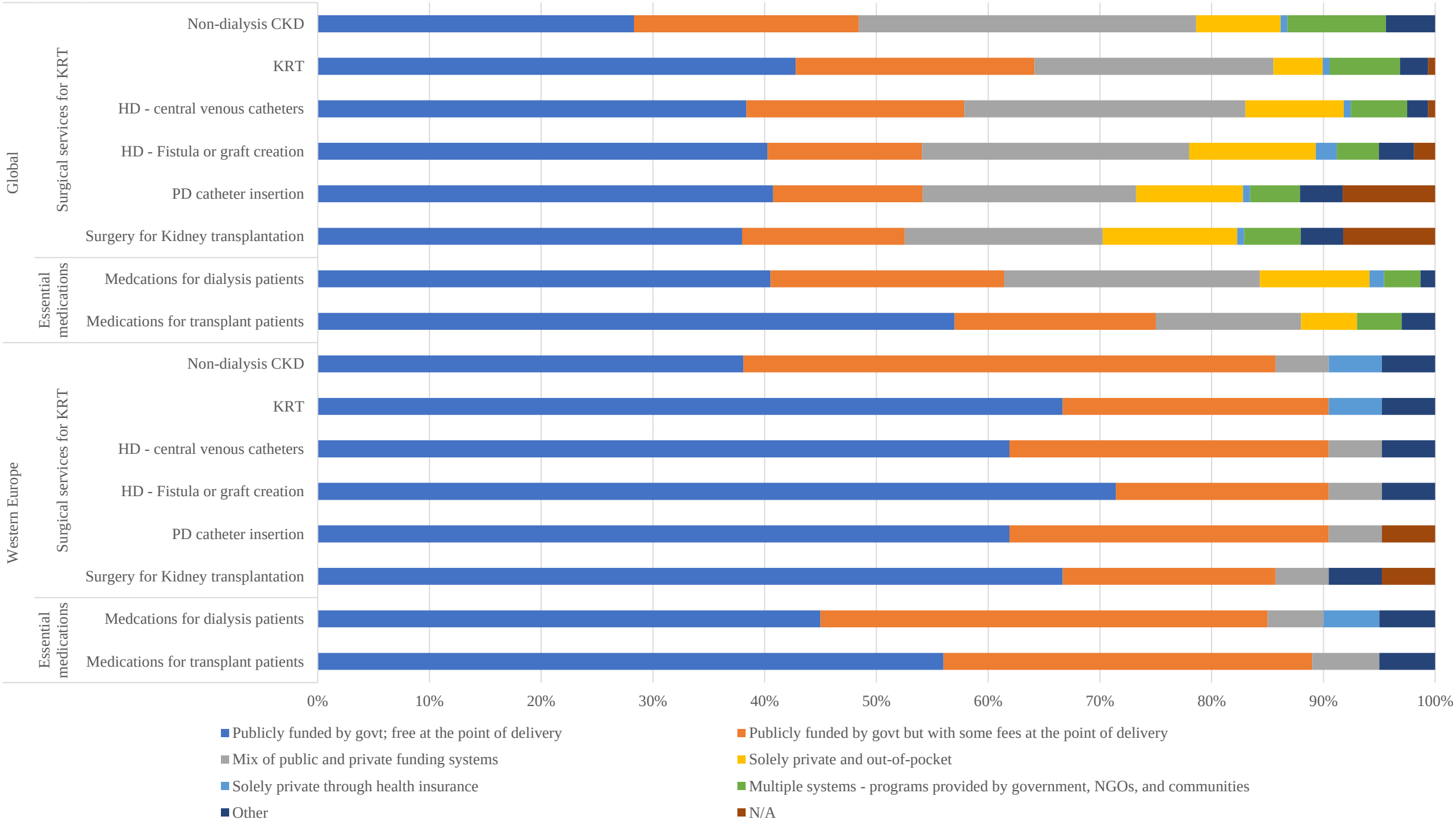
KF: kidney failure; PD: peritoneal dialysis; N/A: not provided

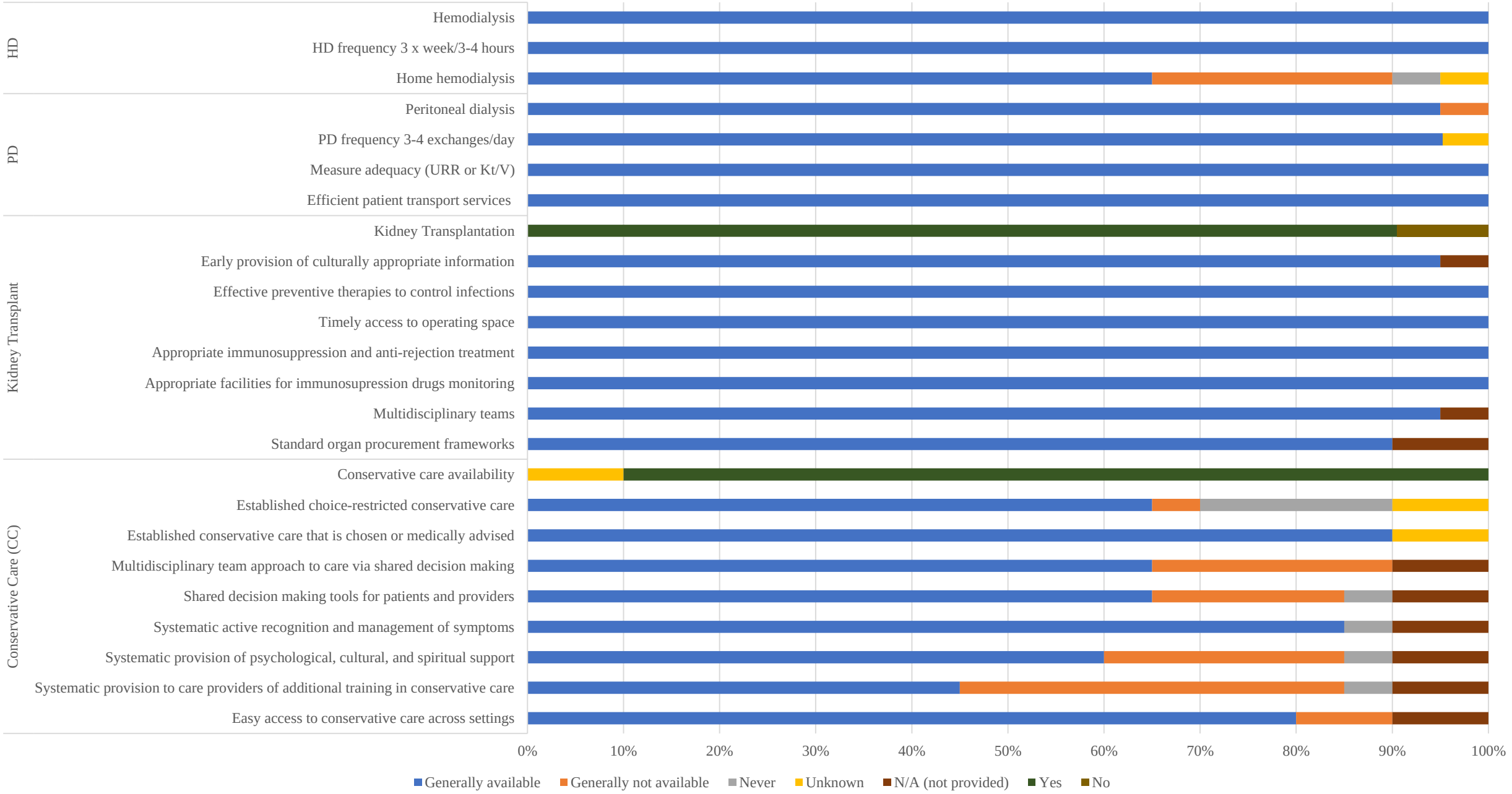
Figure 5. Country level scorecard for registries, national policies, advocacy, and barriers to optimal kidney failure care in Western Europe.

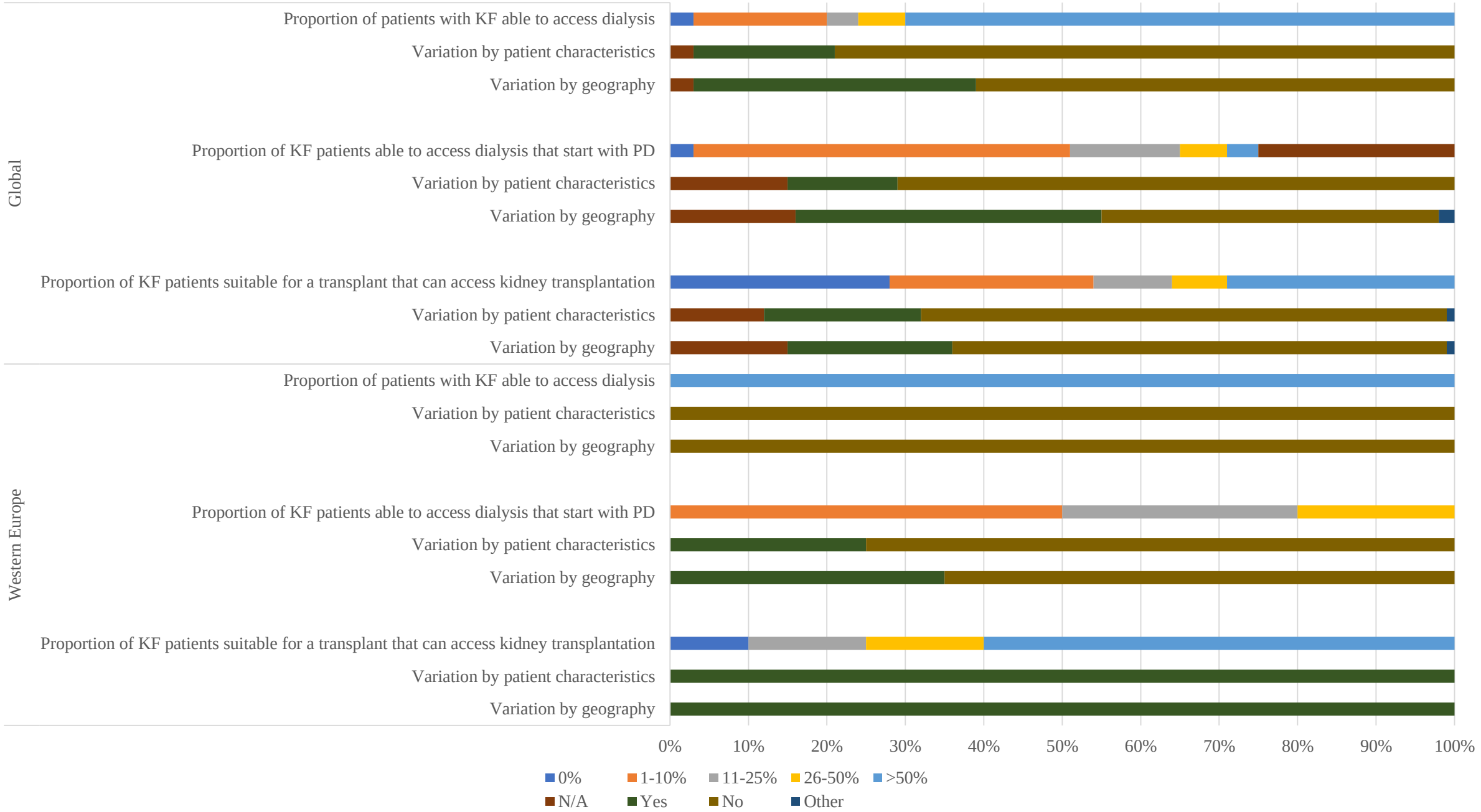
CKD: chronic kidney disease; AKI: acute kidney injury; KF: kidney failure; KRT: kidney replacement therapy; HTN: hypertension; DM: diabetes mellitus; CVD: cardiovascular disease; FHx: Family history

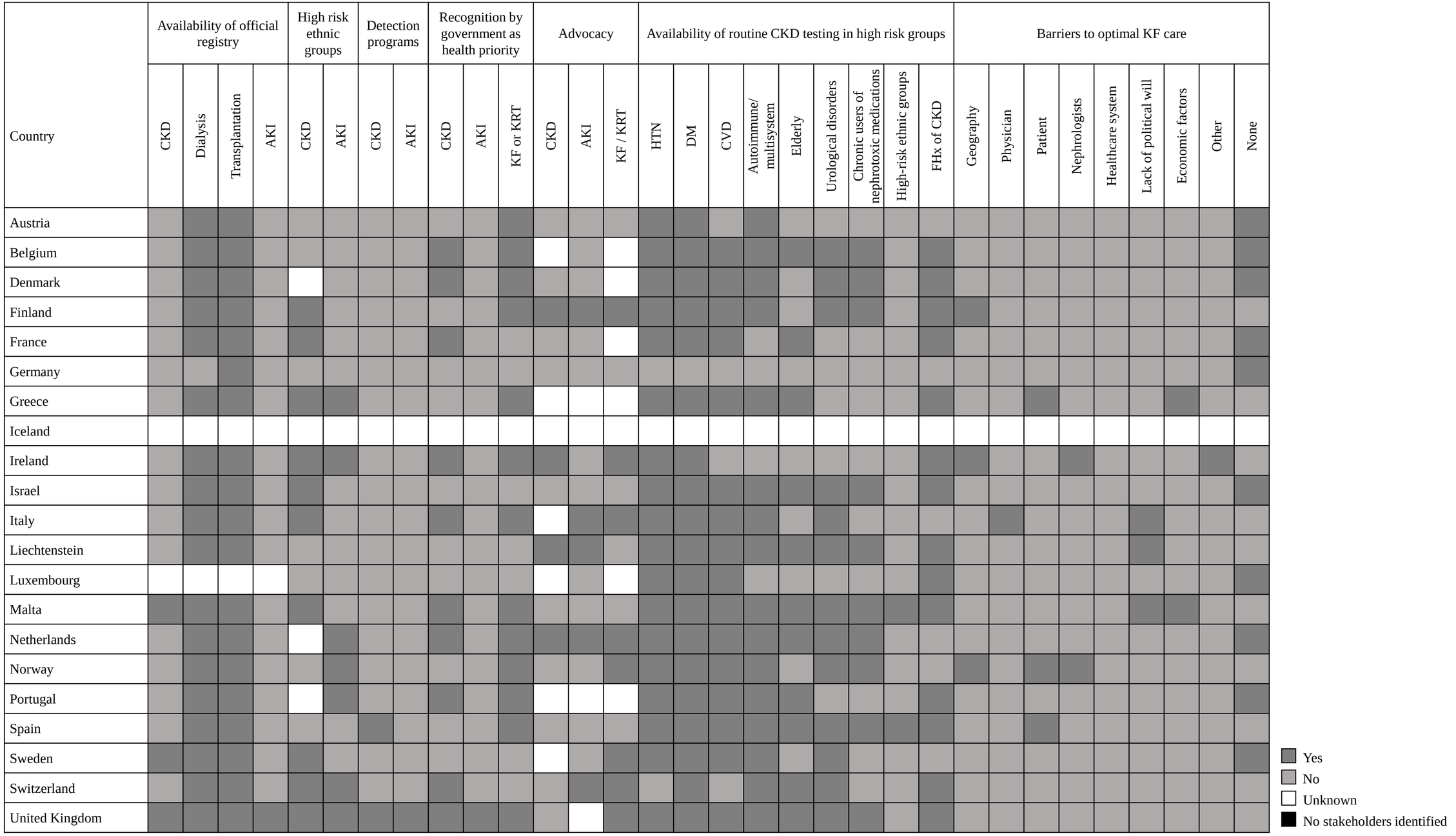


Western Europe


Global
Surgical services for KRT
Non-dialysis CKD
KRT
HD - central venous catheters
HD - Fistula or graft creation
PD catheter insertion
Surgery for Kidney transplantation
Essential medications
Medcations for dialysis patients
Medications for transplant patients
Western Europe
Surgical services for KRT
Non-dialysis CKD
KRT
HD - central venous catheters
HD - Fistula or graft creation
PD catheter insertion
Surgery for Kidney transplantation
Essential medications
Medcations for dialysis patients
Medications for transplant patients
0%
10%
20%
30%
40%
50%
60%
70%
80%
90%
100%
Publicly funded by govt; free at the point of delivery
Publicly funded by govt but with some fees at the point of delivery
Mix of public and private funding systems
Solely private and out-of-pocket
Solely private through health insurance
Multiple systems - programs provided by government, NGOs, and communities
Other
N/A


HD
Hemodialysis
HD frequency 3 x week/3-4 hours
Home hemodialysis
PD
Peritoneal dialysis
PD frequency 3-4 exchanges/day
Measure adequacy (URR or Kt/V)
Efficient patient transport services
Kidney Transplant
Kidney Transplantation
Early provision of culturally appropriate information
Effective preventive therapies to control infections
Timely access to operating space
Appropriate immunosuppression and anti-rejection treatment
Appropriate facilities for immunosupression drugs monitoring
Multidisciplinary teams
Standard organ procurement frameworks
Conservative Care (CC)
Conservative care availability
Established choice-restricted conservative care
Established conservative care that is chosen or medically advised
Multidisciplinary team approach to care via shared decision making
Shared decision making tools for patients and providers
Systematic active recognition and management of symptoms
Systematic provision of psychological, cultural, and spiritual support
Systematic provision to care providers of additional training in conservative care
Easy access to conservative care across settings
0%
10%
20%
30%
40%
50%
60%
70%
80%
90%
100%
Generally available
Generally not available
Never
Unknown
N/A (not provided)
Yes
No


Global
Proportion of patients with KF able to access dialysis
Variation by patient characteristics
Variation by geography
Proportion of KF patients able to access dialysis that start with PD
Variation by patient characteristics
Variation by geography
Proportion of KF patients suitable for a transplant that can access kidney transplantation
Variation by patient characteristics
Variation by geography
Western Europe
Proportion of patients with KF able to access dialysis
Variation by patient characteristics
Variation by geography
Proportion of KF patients able to access dialysis that start with PD
Variation by patient characteristics
Variation by geography
Proportion of KF patients suitable for a transplant that can access kidney transplantation
Variation by patient characteristics
Variation by geography
0%
10%
20%
30%
40%
50%
60%
70%
80%
90%
100%
0%
1-10%
11-25%
26-50%
>50%
N/A
Yes
No
Other


Country
Availability of official registry
CKD
Dialysis
Transplantation
AKI
High risk ethnic groups
CKD
AKI
Detection programs
CKD
AKI
Recognition by government as health priority
CKD
AKI
KF or KRT
Advocacy
CKD
AKI
KF / KRT
Availability of routine CKD testing in high risk groups
HTN
DM
CVD
Autoimmune/ multisystem
Elderly
Urological disorders
Chronic users of nephrotoxic medications
High-risk ethnic groups
FHx of CKD
Barriers to optimal KF care
Geography
Physician
Patient
Nephrologists
Healthcare system
Lack of political will
Economic factors
Other
None
Austria
Belgium
Denmark
Finland
France
Germany
Greece
Iceland
Ireland
Israel
Italy
Liechtenstein
Luxembourg
Malta
Netherlands
Norway
Portugal
Spain
Sweden
Switzerland
United Kingdom
Yes
No
Unknown
No stakeholders identified