Kidney Health for Life (KH4L)

Chronic Kidney Disease Multinational Inventory

March 31, 2014

Kidney Health for Life

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Kidney Health for Life (KH4L) initiative

Kidney Health for Life (KH4L) is an international multistakeholder initiative with administrative support from the International Society of Nephrology (ISN). KH4L engages at the international level through an International Steering Group and at country level through a network of KH4L national steering groups. The overarching goal of the KH4L initiative is to work collaboratively with existing organizations and programs to promote early detection and effective treatment of chronic kidney disease (CKD). Through gaining an understanding of current health policies, practices and infrastructure relevant to CKD, KH4L aims to inform revisions of current policies and practices to facilitate delivery of high-quality care for patients with CKD.

The KH4L multistakeholder group brings together representatives of the international kidney community and associations. Having agreed on an action plan for implementation in liaison with national steering groups and an international multidisciplinary advisory group, the International Steering Group sets the main KH4L priorities. The national steering groups are drawn from 19 participating countries and consist of patients, healthcare professionals, policymakers, and other key stakeholders. The National Steering Groups set country priorities and objectives according to the international KH4L road map, and also drive local implementation.

The KH4L strategic objectives are:

1. To develop a systematic international inventory to evaluate present status, gaps and inequalities in care for CKD patients – with an emphasis on early detection and management – and to recommend ways to address gaps and inequalities in care.
2. To comprehensively describe models for effective CKD care, based on the results of the inventory.
3. To disseminate best practices to promote and facilitate improvement in national healthcare systems with regard to CKD care.
4. To guide national strategic initiatives for optimal care of CKD patients.

In the initial phase, as stipulated by the International Steering Group, the KH4L initiative focused on Canada, Israel and a list of countries in Europe, namely, Austria, Belgium, Denmark, Finland, France, Germany, Greece, Ireland, Italy, Netherlands, Norway, Portugal, Spain, Sweden, Switzerland, Turkey and the United Kingdom (UK).

The International Steering Group engaged the Alberta Kidney Disease Network (AKDN) to develop the systematic international inventory described above. The AKDN is a Canadian not-for-profit organization and a joint initiative of researchers from the Universities of Alberta and Calgary. This research project was supported by the International Society of Nephrology through an unrestricted grant from AbbVie.

Executive summary

Considerable efforts have been made within individual countries to improve the care of CKD patients, though anecdotal experience suggests that these efforts, the approaches taken and the progress attained vary substantially between and within countries. Since no concerted attempt has been made until now to summarize current care practices, little is known about the best way to structure health systems to facilitate CKD prevention and control, or how to integrate these objectives into emerging national and international strategies for NCDs. This inventory includes a synopsis of the various models of CKD care in the participating countries (mainly in Western Europe, Canada and Israel), including the perceptions of key stakeholders about the current quality of CKD care.

Key objectives

Primary objectives:

- Facilitate understanding of the structure, organization and delivery of CKD care at a multinational level.
- Facilitate between-country and within-country comparisons and analyses, identifying key strengths of certain systems, and explore opportunities for international collaborations for optimal CKD care.

Secondary objectives:

- Engage major stakeholders (World Health Organization, United Nations, European Union, World Bank) to increase the profile of CKD among the NCDs as a leading public health issue.
- Define the information structures that a global CKD care surveillance network would need in order to optimize health and outcomes for patients anywhere in the world who have or are at risk of developing CKD.

The inventory

First, the inventory provides an overview of existing CKD care policy and context in the healthcare system, with a description and evaluation of relevant policies, financing, structures, guidelines and care initiatives across the countries studied. Second, it provides an overview of how CKD care is organized in individual countries and a description of CKD burden between selected countries, focusing on elements that are most relevant to service delivery and policy Third, it provides a synthesis and comparative analysis of the information from the individual countries. Fourth, it makes recommendations to policymakers, practitioners, and researchers about the optimal organization and delivery of CKD care.

Data were obtained from multiple sources, including renal registries, government reports and published literature for quantitative data, and a detailed survey of key stakeholders from each country for additional qualitative information.

Based on the recommendation of the KH4L Steering Committee, 19 countries were selected for inclusion, namely, Austria, Belgium, Canada, Denmark, Finland, France, Germany, Greece, Ireland, Israel, Italy, Netherlands, Norway, Portugal, Spain, Sweden, Switzerland, Turkey, and the United Kingdom. All of the countries except Canada and Israel are located in Europe, and they all share similar political and healthcare policy systems. Canada and Israel were chosen because the administrative structures of their health systems resemble those of the European nations.

All included countries have a universal healthcare system that strives for equitable access to health care, and/or that facilitates access based on need rather than ability to pay. Despite this, access to care is at least partly contingent upon financial factors, such as the degree of copayment for medications or services. In all included countries, basic health care services are free at the point of delivery, and mechanisms exist to reduce the financial burden associated with copayments. Access to facilities, services, or medications was not identified as a major barrier to optimal CKD care for any country overall. However, this overall judgment does not consider individual-level factors that likely do influence access to care (such as race, social status, educational attainment, mobility status), or regional differences in specialist availability, travel time, etc, that may influence access to care within particular countries.

There were significant variations in CKD care organization and delivery across countries. There was a general absence of CKD coordinated care pathways, policies and frameworks. Only three of the 19 countries (Ireland, Norway, UK) have a national service framework for CKD. In only 11 of the countries are CKD care guidelines available, with a variable degree of implementation. None of the countries with guidelines have established schemes to monitor adherence – except the UK Quality Outcomes Framework (QoF), which rewards performance for achieving certain thresholds in quality of care parameters. Few countries used QI strategies (continuous monitoring of structures, process of care and outcomes to ensure optimal healthcare delivery). For most countries, ESRD care is the sole focus of kidney-related QI activities, which are often administered in conjunction with a national registry.

Overall, CKD is not perceived to be a health care priority for decision makers (political leaders) and is not included in the national NCD agenda in most countries. In only three countries (Ireland, Norway, UK) did the majority of respondents (>75%) believe that CKD was recognized as a health priority by the national (federal) government. There is limited awareness about the clinical significance of CKD among providers and the general population. In most countries, regional/provincial authorities and individual hospitals were responsible for the oversight of CKD care.

The distribution of the nephrology workforce across countries was variable, with Italy having the highest number of nephrologists (94 per 1000 ESRD patients), and Turkey the lowest (7 per 1000 ESRD patients). All countries except Portugal, Canada, UK, Turkey and Ireland had at least one nephrologist per 50 ESRD patients. Multidisciplinary teams (groups of healthcare professionals representing the different disciplines needed for comprehensive CKD care) were lacking as only eight countries had organized multidisciplinary teams for CKD care. The exact mix of disciplines needed also varied across settings within individual countries.

The medicines, equipment and technologies needed to diagnose and manage CKD are generally available in all countries, including treatment with long-term dialysis and kidney transplantation. Data on kidney failure treated with renal replacement (dialysis and transplantation) were consistently available for the 16 countries that have a renal registry. Only Sweden had a registry for less severe forms of CKD. Data on the burden and costs of early CKD care are very limited, as only the UK had nationally representative data on processes of CKD care and outcomes through the government-led QoF.

The key barriers limiting effective CKD care delivery were broadly identified as political (lack of government commitment), economic (absent/limited funding with competing priorities), organizational (lack of structures and poor coordination) and low awareness about CKD and its consequences among the general population, primary care providers and political leaders.

In summary, the inventory identified some consistent findings across countries: substantial limitations of available CKD data (disease burden, process of care and outcomes), a general absence of national strategies for CKD care, workforce limitations (especially for allied health professionals), low awareness of CKD, and generic barriers to quality healthcare. These barriers include political (lack of government commitment), economic (limitations in resource availability) and organizational (issues with care organization and delivery) factors.

To overcome these barriers and limitations, many of the countries included in the inventory have implemented strategies towards improving the overall quality of CKD care, but many have not. Since not all countries will be able to support a coordinated national approach to CKD management (eg, those where regional authorities have primary responsibility for care delivery), other strategies will be needed in these settings. There is therefore a need for more commitment and effective leadership by the global nephrology community, the relevant key global bodies including the ISN and its sister societies, and other partners in global chronic disease advocacy (International Diabetes Federation [IDF], World Heart Federation [WHF], World Hypertension League, UN, EU, OECD, WHO and the World Bank) to build a strong advocacy platform in order to garner a political will on the part of national governments for more tightly organised CKD care structures and delivery systems. Progress will require concerted efforts in each country at the national level and would be facilitated by leadership by credible, respected and impartial international and national organizations (ISN, ERA/EDTA, and national nephrology associations) that can use lessons learned in one country for the benefit of others.

Structure

The inventory is structured with the first section (introduction) providing a synopsis of the background, context and objectives for the inventory. A brief description of the methods used for this initiative is presented in this section. The second section outlines the specific country reports in 19 separate chapters. Each chapter contains a country-specific profile, governance structure, organization of healthcare systems and the specifics of CKD (structure, access, workforce and capacity, disease burden and stakeholder perceptions of CKD care delivery). The third section summarizes the key findings for specific countries. The fourth section presents a synthesis, comparison and analysis of individual country data, to facilitate understanding of performance variations over time and across the included countries. The final section summarizes the findings, highlighting gaps, challenges and opportunities for improvement, and makes recommendations for the future.

Policy Brief

This policy brief summarizes the Chronic Kidney Disease Multinational Inventory, a report produced by the Alberta Kidney Disease Network (AKDN) for the Kidney Health for Life (KH4L) initiative with support from the International Society of Nephrology (ISN).

Context

Chronic kidney disease (CKD) is a global public health problem because of its serious health consequences and high healthcare costs. CKD is common, associated with low quality of life, treatable, and linked to other major non-communicable chronic diseases (NCDs) such as diabetes, hypertension and cardiovascular diseases (CVD). Because of increasing attention to the costs and consequences of CKD, considerable effort has been made by individual countries to improve the care of people with or at risk for CKD. Anecdotal experience suggests that the approaches taken and progress attained have varied substantially between and within countries. Since no concerted attempt has previously been made to summarize work and progress to date, little is known about the best way to structure health systems to facilitate CKD prevention and control, or how to integrate these objectives into emerging national and international strategies to manage NCDs.

The purpose of this inventory is to summarize the structure and format of selected national efforts to deliver high-quality CKD care; to assess whether these characteristics are associated with health system performance; and to facilitate understanding of performance variations over time and between countries.

The inventory has 5 key objectives:

1. Provide an overview of existing CKD care policy and context in the healthcare system, including a description and evaluation of relevant policies, financing, structures, guidelines and care initiatives.
2. Provide an overview of how CKD care is structured and delivered (and the various roles of the key stakeholders) within the included countries. Where possible, important within-country regional variation is described.
3. Describe and compare relevant epidemiological aspects of CKD (burden of disease, costs and consequences) between selected countries, focusing on elements that are most relevant to service delivery and development of health policy.
4. Summarize the epidemiological status of end stage renal disease (ESRD) and its treatment by renal replacement therapy (RRT), focusing on elements that are most relevant to prevention and control of CKD.
5. Synthesize individual country data and identify specific best practices/quality measures that could be considered for uptake internationally.

Methodology

KH4L is an international multi-stakeholder initiative whose goal is to work collaboratively with existing organizations and initiatives at international and national levels to promote early detection and effective treatment of CKD. Through understanding relevant health policies, practices and infrastructure, KH4L aims to facilitate high standards of care for CKD patients.

In the development of this report, we synthesized the various approaches to CKD management and control across 19 wealthy countries (Austria, Belgium, Canada, Denmark, Finland, France, Germany, Greece, Ireland, Israel, Italy, Netherlands, Norway, Portugal, Spain, Sweden, Switzerland, Turkey and the United Kingdom). The report was developed through an extensive literature research and surveys.

Data for the inventory were collected by searching published and unpublished documents from international organizations/bodies (OECD, WHO, UN, Commonwealth Fund). In addition, we considered other data sources such as reports published by national governments (and occasionally regional governments within countries) on the organization and delivery of CKD care. Additional reports were identified based on guidance from key stakeholders (opinion leaders and national nephrology society/ISN leaders). This was supplemented with a review of data from renal registries (ERA-EDTA Registry, UK Renal Registry, Canadian Organ Replacement Register [CORR]), and for the European countries that do not provide data to the ERA-EDTA Registry (Germany, Ireland and Switzerland), local national registry data was used where possible. We also consulted national nephrology societies, who directly provided data as well as suggestions for alternative data sources pertaining to their own country.

We identified country-specific project leaders through the International Society of Nephrology (ISN), KH4L National Steering Groups, ISN leadership, and CKD opinion leaders in the identified countries. The project leaders served as a resource for data sources, contacts for interviews, and reviewers for their individual country-specific chapters of the inventory.

The survey was delivered to the various stakeholders electronically or on paper according to their preferences. The stakeholders (patients, care providers and policymakers) were identified by the country project leaders and were supplemented by an email list provided by the ISN. Three categories of respondents were involved:

- Care providers such as specialist physicians (nephrologists, cardiologists and endocrinologists) and family physicians or general practitioners.
- Policymakers including those involved directly with the organization of CKD care (renal policymakers) and those with a general remit (non-renal health policymakers).
- CKD patients and their relatives, and leaders or representatives.

This survey was followed up by interviews of the national experts and opinion leaders on CKD care policy by telephone and videoconferences to clarify discrepancies or gaps in the data obtained from the survey.

Findings

The countries studied share common attributes of health systems organization but exhibit significant variation in the specifics of how CKD care is delivered. All the countries have well-organized, publicly funded healthcare systems that provide at least basic coverage for medical services, and all are signatories to a WHO action plan for the prevention and control of NCDs over the next decade. No major financial barriers to accessing CKD care as it is currently delivered were identified for any of the countries. Most countries require copayments to access care (consultations and medications), although these payments are reduced or eliminated on the basis of medical or financial need. Chronic kidney disease is not recognized as a health care priority for decision makers (political leaders) and is not included in the national NCD agenda in most countries. Perhaps as a result, only three countries (Ireland, Norway, UK) have a national service framework for CKD. In 17 countries, regional/provincial authorities and individual hospitals share responsibility for the oversight of CKD care. Coordinated care pathways for CKD are generally absent, and CKD care guidelines are available in only 11 of the countries, with a variable degree of implementation. Some countries identified an inadequate supply of nephrologists as a potential barrier to effective CKD care, but the supply of primary care physicians and nurses is generally not considered a major barrier to the delivery of optimal CKD care.

Data on kidney failure treated with dialysis or transplantation are available in all countries. Sixteen of the countries had a registry to monitor trends in the treatment of kidney failure, and only Sweden had a registry for less severe forms of CKD. Nationally representative data on the burden of early CKD and costs of care are very limited. National data on processes of CKD care and outcomes are available only for the UK through its government-led quality and outcomes framework. Stakeholders identified the key barriers to effective CKD care delivery as political (lack of government commitment), economic (absent/limited funding with competing priorities), organizational (lack of structures and poor coordination) and low awareness about CKD and its consequences among the general population, primary care providers and political leaders.

Policy implications

Different nations with varying health system structures and organization

Issue: The difficulties in comparing health policy across countries are widely acknowledged; these stem from the inherent cultural, political, geographical and economic differences between countries, as well as differences in disease burden and reporting practices across nations.

Recommendation: Variation in structures and organization makes it difficult to identify and apply a universal approach for development of an effective and sustainable CKD care policy for the various countries. The ISN in collaboration with other stakeholder organizations (WHO, UN, World Bank, European Union and related organizations) should develop a global framework for an effective and sustainable CKD care delivery model.

Countries sharing common barriers and challenges

Issue: A number of barriers to the optimal care of people with non-dialysis dependent CKD are common across the 19 countries studied: limited workforce capacity; the nearly complete absence of mechanisms for disease surveillance or the coordinated management of people with CKD; poor integration of CKD care with other NCD control initiatives; and low awareness of the significance of CKD.

Recommendation: These common challenges reflect the need for international cooperation to strengthen health systems and policies for CKD care: some countries are further ahead than others, but all have considerable work to do.

Global health, building partnerships and supporting the poor nations

Issue: Although all the countries studied were relatively wealthy, the findings have implications for CKD care in other settings. Many of the opportunities and obstacles identified may be equally applicable to less developed nations in Sub-Saharan Africa and South Asia where renal replacement therapy (dialysis and transplant) is completely unavailable or unaffordable.

Recommendation: Relevant international stakeholders (ISN, WHO, UN, World Bank) should consider how these findings and recommendations could be applied to health systems in these low- or middle-income countries.

Research and development

Issue: The findings also have important implications for the CKD research agenda. In the last few decades, kidney research has concentrated mainly on basic aspects of disease (pathogenesis and pathophysiology), epidemiology (defining disease measures, burden, population trends and outcomes) and therapeutics (clinical trials to prove effective interventions). This emphasis has yielded high-quality information on pathophysiology and development of evidence-based guidelines for CKD care.

Recommendation: Given the observed variability in how care is organized and delivered across countries in the report, what is most needed now is high-quality research on optimal care structures, care pathways, behaviour change (for providers and patients) and a better understanding of how to ensure uptake of best practices across nations.

Acronyms and abbreviations

AKDN	Alberta Kidney Disease Network
AKI	Acute kidney injury
CEAPIR	European Kidney Patients' Federation
CKD	Chronic kidney disease
CKD-EPI	Chronic Kidney Disease Epidemiology Collaboration
COPD	Chronic obstructive pulmonary disease
CSN	Canadian Society of Nephrology
CVD	Cardiovascular diseases
ERA-EDTA	European Renal Association – European Dialysis and Transplant Association
ESRD	End stage renal disease
FFS	Fee-for-service
FTEs	Full time equivalents
GDP	Gross domestic product
GHIS	General Health Insurance Scheme
GP(s)	General physicians
HD	Hemodialysis
HMOs	Health maintenance organizations
ISN	International Society of Nephrology
KDIGO	Kidney Disease Improving Global Outcomes
KH4L	Kidney Health for Life
MDT	Multidisciplinary teams
MOH	Ministry of Health
NCDs	Non-communicable chronic diseases
NEOERICA	New Opportunities for Early Renal Intervention by Computerised Assessment
NHI	National Health Insurance
NHS	National Health Service
NICE	National Institute for Health and Care Excellence
NKF/KDOQI	National Kidney Foundation / Kidney Disease Outcomes Quality Initiative
NSFs	National Service Frameworks
OECD	Organisation for Economic Co-operation and Development
PCPs	Primary care physicians
PD	Peritoneal dialysis
Pmp	Per million population
PREVEND	Prevention of Renal and Vascular End stage Disease study
QI	Quality Improvement
QICKD	Quality Improvement in CKD study
QoF	Quality and Outcomes Framework
RRT	Renal replacement therapy
SHI	Statutory Health Insurance Scheme
WHO	World Health Organization

Acknowledgments

I wish to express our appreciation to the KH4L International Steering Committee for the opportunity granted us to lead this project (Appendix). We owe a great debt of gratitude to all the people and organizations that have, in various ways, contributed to the development and completion of this Inventory including the external advisory committee (Appendix) for an extensive peer-review from conception to completion of this report. The Steering Committee's guidance and direction kept us in focus during the conduct of this work, in-addition to the valuable reviews of the draft from proposal to completion. The national KH4L network members have also contributed greatly by serving as our resource for additional data sources and contacts for interviews within their individual countries, and many of them have read the draft of their individual country chapters offering useful suggestions and/or amendments that vastly improved the content of the report.

A similar degree of gratitude also goes to the various individuals who though not part of the KH4L network, but have contributed greatly in the success of this work in a similar role (listed in Appendix). In particular, we acknowledged the support of Dr Giovanni Strippoli (support with the provider survey in Italy), and Mr Mark Murphy (Executive Director, Irish Kidney Association) for his monumental contribution with the patients' survey in Ireland, and the rest of Europe. The Kidney Foundation of Canada contribution in mobilising patients for participation is also greatly acknowledged. We are also grateful to Louise Fox (Green Fox Consulting Ltd) for her efficient coordination and handling of logistics during the various phases of the project.

I also wish to thank my staff and innumerable colleagues at the AKDN, who have provided enormous support during the conduct of this work, providing invaluable assistance in reviewing, editing and revising several versions of the draft from the beginning to completion.

Finally, I thank all the survey participants (care providers and policymakers) and patients who supported this initiative by their involvement in the surveys.

The unrestricted funding support from Abbvie to ISN for the conduct of this work is greatly acknowledged.

Marcello Tonelli MD, SM, FRCPC
Professor of Medicine
Canada Research Chair in Optimal Care of Chronic Kidney Disease
Alberta Kidney Disease Network
University of Alberta

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Summary of findings

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Section 1

Introduction

A: Background

Chronic kidney disease (CKD) is a global public health problem because of its associated adverse health outcomes, and high healthcare costs. CKD is common, associated with low quality of life, treatable and linked to other major non-communicable chronic diseases (NCDs) such as diabetes, hypertension and cardiovascular diseases (CVD).[1-10] Because of increasing attention to the costs and consequences of CKD, considerable effort has been made by individual countries to improve the care of people with or at risk for CKD. Anecdotal experience suggests that the approaches taken and progress attained have varied substantially between and within countries. Since no concerted attempt has previously been made to summarize work and progress to date, little is known about the best way to structure health systems to facilitate CKD prevention and control, or how to integrate these objectives into emerging national and international strategies to manage NCDs.

The purpose of this inventory is to summarize the structure and format of selected national efforts to deliver high-quality CKD care; to assess whether these characteristics are associated with health system performance; and to facilitate understanding of performance variations over time and between countries. The inventory has the following key objectives:

A1: Objectives

1. Provide an overview of existing CKD care policy and context in the healthcare system, including a description and evaluation of relevant policies, financing, structures, guidelines and care initiatives. The focus is on key supporting elements of each country's healthcare system (eg, availability of subsidized drug plans, supply of healthcare workers, overall NCD strategy).
2. Provide an overview of how CKD care is structured and delivered (and the various roles of the key stakeholders) within the included countries. Where possible, important within-country regional variation is described.
3. Describe and compare relevant CKD epidemiology between selected countries, focusing on elements that are most relevant to service delivery and development of health policy (burden of disease, quality of care delivery, rate of complications and the roles and perceptions of key stakeholders). Where possible, projections of future burden and secular changes within and between countries are presented and discussed.
4. Summarize the epidemiology of end stage renal disease (ESRD) and its treatment by renal replacement therapy (RRT), focusing on elements that are most relevant to prevention and control of CKD (eg, availability of transplant services, out-of-pocket costs associated with chronic dialysis, overall expenditures on RRT as compared with CKD prevention).
5. Synthesize individual country data and identify specific best practices/quality measures that could be considered for uptake internationally.

B: Methodology

Kidney Health for Life (KH4L) is an international multistakeholder initiative whose goal is to work collaboratively with existing organizations and initiatives – at international and national levels – to promote early detection and effective treatment of CKD. Through understanding and potentially helping to shape relevant health policies, practices and infrastructure, KH4L aims to facilitate the implementation of high standards of care for CKD patients.

B1: Approach

In line with the key objectives of the inventory and the specific guidance provided by the KH4L steering committee, we applied the following approach.

B1.1: Country-specific project leaders

Country-specific project leaders were identified through the International Society of Nephrology (ISN), KH4L National Steering Groups, ISN leadership, and CKD opinion leaders in the identified countries (Appendix).

The roles of these project leaders were:

1. To organize and follow up responses with the people to be interviewed in a country.
2. To serve as a link between the Steering Committee, AKDN[11] and country stakeholders.
   - To serve as a resource for additional data sources and contacts for interviews.
   - To serve as country-specific opinion leaders (and identify others).
   - To vet and review country-specific chapters of the inventory.

B2: Data collection

Data for the inventory were collected using a scoping review and a de novo survey. The scoping review summarized findings from published scientific literature, government reports and other relevant data sources. In addition to the published literature, extensive use of the grey literature, including websites, reports and white papers, was made. Grey literature sources were identified mostly through contact with the project leaders and other country-specific opinion leaders.

The survey was delivered electronically using a customized email list delivered through the SurveyMonkey portal[12]; findings from the survey were analysed using standard statistical packages. Survey respondents included the various stakeholders (care providers and policymakers) identified by the country project leaders and were supplemented by an email list provided by the ISN. We also surveyed patients living with CKD who were identified through national patients' associations and/or KH4L National Steering Committee members. There were three categories of respondent:

- Care providers such as specialist physicians (nephrologists, cardiologists and endocrinologists) and family physicians or general practitioners.
- Policymakers, both those involved directly with the organization of CKD care (renal policymakers) and general (non-renal) health policymakers.
- CKD patients and their relatives and leaders or representatives.

A minimum of 13 stakeholders were involved in each country comprising:

- 1 (or more) general practitioner/family doctor.
- 1 (or more) endocrinologist/diabetologist.
- 1 (or more) cardiologist.
- 6–7 nephrologists.
- 2 government/health authority officials.
- 1 (or more) patient or patient representative.

Each of these groups of study population was sent an invitation letter (eAppendices 1 A–D) to participate with a link to complete the survey via the SurveyMonkey portal. There were four sets of questionnaires on the various domains of CKD epidemiology and organization of care, with questions worded differently as appropriate for each group (eAppendices 2 A–D); the content and format of the questions was guided by preliminary results of the scoping review and by a pilot phase in which the survey was administered to a limited group of respondents. There was a follow-up to the electronic survey (by telephone, videoconference, or face-to-face as appropriate) to clarify discrepancies or gaps in the data obtained from the survey.

B3: Data sources

The following data sources were utilized for this project:

B3.1: Renal registries

All the listed countries for the inventory (except Canada) report data on RRT to the ERA-EDTA Registry where data are already available covering a period of ten years: 2000–2010.[13] This source was supplemented for the four countries of the UK with the reports published from the UK Renal Registry (UKRR).[14] For Canada, Canadian Organ Replacement Register (CORR) reports on the level of activity and outcomes of vital organ transplantation and renal dialysis activities in Canada from 2000 to 2010 were used.[15] For the countries that do not provide data to the ERA-EDTA Registry, local national registry data were used where possible (Germany [data until 2006 only], Ireland and Switzerland).

B3.2: Statistics/published reports from government where available

In addition to reports from renal registries, we considered other data sources such as reports published by national governments (and occasionally regional governments within countries) on the organization and delivery of CKD care.[16-25] Several of these reports were identified through the grey literature search and guidance from key stakeholders.

B3.3: National nephrology societies and KH4L National Steering Committees

National nephrology societies and KH4L national steering committees were an important resource utilized for data gathering on some aspects of the inventory by providing data directly and/or linking to data sources and grey literature available for their individual countries.

B3.4: Opinion leaders/focus groups and survey questionnaires

Standardized and pilot-tested survey questionnaires designed to gather primary data particularly on the aspects of policy and organization of care (eAppendices 2A–D) were administered to the various stakeholders. Respondents were specifically asked about important within-country heterogeneity in these characteristics – which were flagged for further study and addressed during interviews. Survey respondents were asked to identify other potential key respondents, increasing the likelihood that all relevant information was appropriately captured.

B4: Limitations and pitfalls of data sources

First, while data from renal registries may be of high quality, incomplete data and inconsistent definitions between countries are potential limitations. Similarly, some registries collect data from only part of a country, and judgment needs to be made on how representative these data are for the remainder. Second, the survey that we administered to country contacts relied on questionnaires, which by definition depend on the knowledge and perceptions of respondents who agreed to be surveyed, and are subject to response bias. To minimize these effects, potential survey participants were carefully selected, and every attempt was made to increase the response rate among those invited to participate. We also chose a range of respondents with different expertise (primary care providers and specialists, policymakers and patients across the broad spectrum of CKD). The interviews focused on areas of uncertainty or ambiguity and probed respondents for additional sources of relevant data.

B5: Steps in data collation

- Evaluation of the Renal Registry Data Reports from 1998 to date, with additional data requested as required from the registry directors.
- A grey literature search for data on CKD care delivery. Results from the grey literature search were supplemented by the survey – especially questions inquiring about patient education or self-management, multidisciplinary team involvement, and processes for care evaluation and quality improvement.
- Electronic survey using the SurveyMonkey portal. Findings from the self-completed survey were supplemented by direct interview using video- and teleconferences.

B6: Scoping review methodology

To conducting the scoping review we used a standard approach including framing the research question, and developing a protocol for the identification and selection of relevant studies, as well as analysis, synthesis and interpretation. It is important to recognize that standard methods for scoping reviews differ from those for full systematic reviews. First, in a scoping review the relevance of a study to the research theme is more important than its quality, and thus studies are not generally excluded on the basis of quality alone. Second and more importantly, the scoping review methodology encompasses consultation and follow-up with key stakeholders to resolve inconsistencies, close gaps, confirm or refute hypotheses formed during the earlier phases, and put the findings into context.

B7: Data quality and consistency

First, the survey content and format were based on a background review of published and grey literature. Second, country-specific draft reports were reviewed by key stakeholders (Appendix) to ensure consistency and reliability. Third, any ambiguity or inconsistency identified during earlier phases was addressed by brief follow-up inquiries; areas where ambiguity remained were specifically mentioned in the relevant sections of this report. Finally, the draft report was peer-reviewed by the KH4L Steering Committee, specific country project leaders, interested key respondents, a selection of international experts drawn from the ISN, and additional experts as recommended by the Steering Committee.

B8: Development of the survey questionnaires

The development of the survey questionnaires followed the basic framework provided by the Steering Committee for the Inventory, as well as prior CKD management guidelines published by leading groups such as Kidney Disease Improving Global Outcomes (KDIGO), European Renal Association / European Dialysis and Transplant Association (ERA/EDTA) and the National Kidney Foundation Kidney Disease Outcomes Quality Initiative (NKF/KDOQI). The patient-specific questionnaire was based on the Picker Institute Model (www.pickerinstitute.org), which in turn is based on eight widely used dimensions of patient perspectives.[26] This model has been widely used in national patient satisfaction surveys across Australia, Europe and North America. Other elements of the patient-specific questionnaire were obtained from the European Kidney Federation Renal Survey Questionnaire (http://www.ceapir.org/wb/index.php).[27] The questionnaire that was administered to policymakers was based on the European Heart Charter Questionnaire.[28]

Based on the frameworks described above, six common themes relevant to optimal CKD care were identified for enquiry:

- Health systems, policies and structures.
- Organization and structure of CKD care.
- Access and quality of care.
- Quality assurance and improvement (capacity and workforce, barriers).
- Disease burden and risk factors.
- Network perceptions of care (providers, patients and policymakers).

The survey questionnaires were drafted based on these six domains (eAppendix 2A-D). The questionnaires were further developed in consultation with the Steering Committee, survey design experts, and epidemiologists in the AKDN and the School of Public Health of the University of Alberta and Department of Community Health Sciences at the University of Calgary. The initial versions of the questionnaires were piloted in a group of relevant stakeholders in Canada and further refined based on input from our international collaborators and the Steering Committee members. Based on the feedback obtained, the questionnaires were modified for reasonable face and construct validity. Comment boxes were added at the end of each questionnaire to collect open-ended suggestions for the inventory. Respondents were also asked to suggest additional data sources and/or other key respondents.

C: Partners

- KH4L steering committee (Appendix).
- Collaborative network of opinion leaders and national society and ISN leaders from each country/region identified based on the ISN/ERA-EDTA websites and in consultation with the KH4L National Steering Committee (Appendix).
- Leaders/directors of CKD programs and other relevant stakeholders identified in consultation with the National Society and ISN leaders in each country, and also with input from the Steering Committee (Appendix).
- International Society of Nephrology Policy Task Force

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Kidney Health for Life (KH4L)

Chronic Kidney Disease
Multinational Inventory

Section 2

Specific Country Reports

Definition of terms

CKD care plan

National plan/strategy for NCDs:

Refers to a country having at least one policy plan in place to address NCDs and associated risk factors, irrespective of whether the policy is operational.

National plan/strategy-CKD specific:

Refers to a specific official decision or set of decisions aimed at executing a government-endorsed course of action, including goals and priorities for CKD care.

Guideline/Service framework:

Guidelines refer to a recommended (ideally evidence-based) course of action to guide CKD management for providers. A Service framework refers to defined pathways for clinical care implementation.

CKD (non-RRT) Registry:

Refers to a national registry that would ideally include data on burden of disease, risk factors, progression, process of care and outcomes for patients with CKD before the onset of RRT.

Planned actions:

Refers to a deliberate attempt or a step taken at a government level to develop a policy, framework or guidelines (and associated dissemination strategies) for CKD care.

Renal units

These refer to centres with a comprehensive renal care program that includes dialysis and/or transplantation services, and ambulatory CKD care.

Dialysis units

These refer to ‘hub’ units in which kidney specialists are permanently based and which have inpatient kidney care services.

Satellite dialysis units

These refer to units that are often smaller, run by nursing staff and supervised by kidney specialists from the larger hub units.

Nephrologists supply per 1000 ESRD patients

This represents the number of FTE nephrologists available in a country for every 1000 prevalent ESRD patients on RRT (dialysis and transplantation), obtained as the ratio of prevalent RRT patients/total number of FTE nephrologists.

Nephrologists supply per 1000 CKD patients

This represents the number of FTE nephrologists available in a country for every 1000 prevalent CKD patients, obtained as the ratio of prevalent CKD patients/total number of FTE nephrologists. The prevalence of CKD was assumed at 10% for all countries for this purpose.

Austria

COUNTRY OVERVIEW

Facts

Area	83,871 sq km
Total population	8,219,743 (2012)

CKD care plan

National plan/strategy for NCDs	No
National plan/strategy: CKD specific	No
Guideline/Service framework	No
CKD (non-RRT) Registry	No
Planned actions	Yes (Austrian Federal Institute for Health; OEBIG)

Disease burden

ESRD data	
Incidence, pmp	138.5 (2010)
Prevalence, pmp	995.9 (2010)
CKD data	Not available
Costs data	
GDP (PPP)	$356.5 billion
Total health expenditures (% of GDP)	11.0
CKD costs data (as % total health expenditure)	Not available

Capacity and workforce

Hospital bed capacity	7.7 per 1000 population
Physicians supply	4.8 per 1000 population
Nurses supply	7.7 per 1000 population
Nephrologists supply	27 per 1000 ESRD population
Renal units, N	51
Dialysis centres, N	67
Transplant centres, N	4

PPP = purchasing power parity.

A. Health systems, policies and structure

A1: Governance structure

Austria is a federal republic of nine states (Länder). A Land is distinct self-governing entity with legislative and administrative competencies.[1-4] Länder are divided into districts, which are conglomerates of local communities or boroughs. All areas of the healthcare system are primarily the regulatory responsibility of the federal government. Healthcare is provided by 21 health insurance funds and the Federation of Austrian Social Insurance Institutions in liaison with the provider professional bodies.[1, 5] The Austrian healthcare system is defined by the interaction of public, private not-for-profit and private profit-making players.

A2: Healthcare system organization

A2.1: Coverage

Healthcare coverage is universal for all types of services including physician and diagnostic (imaging and laboratory) services and medications.

A2.2: Individual copayment

There are generally no copayments for healthcare expenses except for medications, for which copayments are usually €2 to €3 per medication to a maximum of €180 per year.

A2.3: Financing

Total health spending is about 11% of total GDP (above the 9.5% OECD average) through a mix of public, private not-for-profit and private profit-making players. Publicly funded healthcare by government, the social insurance system and private care funding represent 25%, 45% and 25% of total health expenditures respectively. The remaining portion represents out-of-pocket payments by households and other private not-for-profit organizations.[6]

A2.4: Organization of care delivery

A2.4.1: Primary care

Primary care is delivered by primary care physicians (PCPs), who are the patients' first points of contact with the healthcare system.

A2.4.2: Specialist care

Specialist care is accessed predominantly via hospitals. Referrals are required for access to specialists; PCPs serve as the gatekeepers.

A3: Physician compensation

PCP services are paid by fee-for-service (FFS) or capitation, and outpatient specialist services are paid by FFS.

A4: NCD policy and strategy

The Austrian NCD strategy is based on the WHO global action plan for the prevention and control of non-communicable diseases (NCDs) for 2013–2020. The federal- and Länder-level Policy Framework for the Management of Chronic Diseases includes preventive check-ups among the services the social health insurance system is required to provide.

A5: CKD-specific policies, guidelines and/or service frameworks

A5.1: Specific policies

There is no CKD-specific policy.

A5.2: Guidelines

Nephrologists mostly follow international guidelines. A national guideline is available for management of diabetic nephropathy only, and was developed jointly by the Austrian Society of Diabetology and the Austrian Society of Nephrology.

A5.3: Structures/systems for monitoring uptake of guidelines

No structures or systems are in place to monitor adherence to the international CKD guideline and/or the national guideline on the management of diabetic nephropathy.

A5.4: CKD as a healthcare priority

The majority of the survey respondents (80%) believed CKD was not recognized as a health priority in Austria at any level of government.

A5.5: CKD care advocacy

There is no advocacy group specifically for CKD; advocacy groups have focused mainly on patients with ESRD. The chief responsibility of nephrologists in Austria is perceived to be the care of dialysis and transplant patients.

B. Organization and structure of CKD care

There are no organized structures for early CKD care. Some hospital units offer nephrology outpatient clinics, which see patients with CKD if they are referred.[7-9]

B1: Role of care providers

B1.1: PCPs and other specialists

Care for people with early stages of CKD (1–4) is provided mainly by PCPs.

B1.2: Nephrologists

Nephrologists care mostly for late stages of CKD (stage 5 and RRT), usually in hospital-based facilities.

B2: CKD care structures

B2.1: RRT care

There are well-established programs for dialysis and transplantation care delivered in 67 dialysis units comprising 51 renal divisions and 16 private centres for dialysis. There are four transplant centres, located mainly in universities. ESRD treatment is covered by the Austrian Health Plan (OESG) through an institute (Austrian Federal Institute for Health; OEBIG) commissioned by the Austrian Ministry of Health.[5]

B2.2: CKD care (non-RRT)

No organized clinical care pathway or program is in place for CKD patients.

B2.3: Regional variation in structures and practice patterns for CKD care

There is little perceived variation in CKD care structures or patterns of CKD practice across the nine Länder. However there are reported differences in chronic disease management priorities (for instance, some Länder have a well-developed diabetes management program, while others have none).

C. Access and quality of care

C1: Availability and access to care

CKD care and delivery (including all forms of RRT) are wholly covered and accessible to all residents. This includes all aspects of ambulatory or hospital care inclusive of physician and diagnostics (laboratory and imaging) services. However, not all medication costs are publicly funded (see Section A2.2). Nephrologists are available only in hospital-based facilities. Patients need a referral to access specialist nephrology care.

C2: Referral criteria

There are currently no national criteria for referral to nephrologists. However, the Austrian Society of Nephrology is working to develop the criteria as part of the national CKD guideline currently being developed.

C3: Quality management programs

A national quality management program is available only for ESRD patients through OESG and the Austrian Dialysis and Transplant Registry.

C4: CKD registry

There is no registry for early CKD patients.

D. Capacity, workforce and access to multidisciplinary teams

D1: Physician workforce

Early CKD care is provided by PCPs. Advanced renal care (stage 5 CKD and RRT) is carried out by nephrologists. There are 225 registered nephrologists and 31 nephrology trainees (Table 2-1).

D2: Multidisciplinary teams and other professionals

For early CKD care there are no multidisciplinary teams of nurses, dieticians, psychologists, social workers, nephrologists, vascular access and transplant coordinators.

D3: Workforce limitations

Based on the opinion of the respondents there is a limited capacity for nephrologists, renal pharmacists and social workers (Table 2-1).

Table 2-1

Workforce	*Availability*
Physicians per 1000 population	4.8
Nephrologists per 1000 ESRD patients	27
Nephrologists per 1000 CKD patients	0.27
Nurses per 1000 population	7.7
Presence of multidisciplinary teams for CKD	No
Disciplines with most pronounced lack of capacity for CKD care, in the opinion of survey respondents	Nephrologists, Renal pharmacists, Renal social workers

E. Barriers to optimal CKD care

E1: Top five barriers to optimal CKD care (in descending importance)

1. Organizational factors
2. Policymakers’ low awareness of early detection and prevention of CKD
3. Care providers’ low awareness of early detection and prevention of CKD
4. Political factors
5. Attitudes of the care providers

Organizational factors

- Different priorities and administrative structures across the nine Länder.
- There is a perceived lack of coordination in primary and secondary care, because the specialists are mainly hospital-based, which interferes with their communication with PCPs.

Political factors

Policymakers are perceived to lack interest in funding early CKD care. The Austrian Society of Nephrology is lobbying policymakers to demonstrate the potential clinical and economic benefits of better CKD care.

CKD awareness

Overall, awareness of the importance of CKD is low among PCPs, policymakers, patients and the general population.

F. CKD burden and risk factors

F1: Epidemiology of CKD

In 2010, the number of adult patients starting RRT in Austria was 1162, equating to an incidence rate of 138.5 pmp. Diabetes and vascular diseases are the leading causes of ESRD.[7, 10]

As of December 31, 2010, there were 8355 adult patients receiving RRT in Austria. The Austrian prevalence of RRT was 995.9 pmp, an increase of 1.76% from 2009. The growth rate from 2009 to 2010 for prevalent patients was an increase of 0.96% for hemodialysis (HD), a rise of 0.88% for peritoneal dialysis (PD) and an increase of 2.6% in functioning transplant. Only 1 patient currently receives home HD in Austria.

Transplantation continued as the most common treatment modality (49.1%), HD was used in 46.3% of RRT patients and PD in 4.6%. Transplant prevalence at the end of 2010 was 488.6 pmp.

F2: Epidemiology of CKD

There is no published data on CKD epidemiology. In the KH4L survey, the prevalence of CKD in Austria was estimated at 5.1–10%.

F3: CKD cost data

There are no data on CKD care cost.

F4: CKD risk factors

A high burden of risk factors is associated with CKD at the population level including increasing age, diabetes, hypertension, smoking, alcohol use and obesity (Table 2-2).

Table 2-2

Risk factors	*Prevalence (year)*
Age >65 years	17.5% (2009)
Diabetes	9.1% (2011)
Hypertension	43.8% (2011)
Smoking	23.2% (2009)
Alcohol use	12.1 L* (2009)
Obesity	12.4% (2009)

*Mean annual consumption per capita.

G. Perceptions of care (providers, patients and policymakers)

G1: Efficiency in CKD care delivery

Efficiency was rated as average by 60% of the Austrian respondents and as excellent by 40%.

G2: Patient education

According to the CEAPIR European Kidney Patients' Federation 2011 survey results, about 70% patients say they have never received education to help them manage their CKD. Educational materials are generally available for RRT patients only.

G3: Patients' involvement in their care

Patients' involvement was rated as average in the KH4L survey. According to the CEAPIR European Kidney Patients' Federation 2011 survey results, about 50% of ESRD patients feel they are very involved in making decisions about their treatment.[11]

G4: Patients' perceptions of quality of care received

Perceived quality of care was rated as above average in the KH4L survey. According to the CEAPIR European Kidney Patients' Federation 2011 survey results, about 90% of patients are very satisfied with care for their kidney disease, and another 7% are somewhat satisfied.

H. Opportunities for and obstacles to improvement

H1: Opportunities

- Universal healthcare system and well-developed infrastructure.
- Presence of a strong patient organization for advocacy.
- Presence of a strong professional nephrology association for advocacy.
- Integration of education about CKD into existing CME activities for PCPs and other specialists.
- Extensive insurance and medication databases that can be leveraged for surveillance studies.

H2: Obstacles

- Lack of communication between nephrologists and PCPs, which affects referral of new patients and management of referred patients.
- Lack of disease management program for CKD.
- Reimbursement structure for nephrologists that favours the care of dialysis patients.
- Relative shortage of nephrologists.
- Low awareness among patients about the importance of CKD care.
- Inertia by policymakers to implement change.
- Multiple insurance systems making funding and coordination of care unduly complex.

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Belgium

COUNTRY OVERVIEW

Facts

Area	30,528 sq km
Total population	10,438,353 (2012)

CKD care plan

National plan/strategy for NCDs	Yes
National plan/strategy: CKD Specific	No
Guideline/Service framework	No
CKD (non-RRT) Registry	No
Planned actions	Yes

Disease burden

ESRD data	
Incidence/pmp	195.2 (Dutch) and 191.7 (French) (2010)
Prevalence/pmp	1166.1 (Dutch) and 1237.4 (French) (2010)
CKD data	
Prevalence	17.2% (elderly population)
Costs data	
GDP (PPP)	$418.6 billion (2011)
Total health expenditures (% of GDP)	11.8
CKD costs data (as % total health expenditure)	No data

Capacity and workforce

Hospital bed capacity	4.2 per 1000 population
Physicians supply	2.9 per 1000 population
Nurses supply	9.6 per 1000 population
Nephrologists supply population	23 per 1000 ESRD
Renal units, N	65
Dialysis centres, N	54
Transplant centres, N	7

PPP = purchasing power parity.

A. Health systems, policies and structures

A1: Governance structure

Belgium is a federation divided into Dutch-speaking Flanders in the north, French-speaking Wallonia in the south and a small German-speaking part around the borders with Germany.[1-4] There are three levels of government: the federal government, the federated entities (three regions and three communities) and the local governments (provinces and municipalities). The federated entities include the Flemish, Walloon and Brussels-Capital regions and the Flemish, French and German communities. Health care is a dual responsibility of the federal authorities and the federated entities (regions and communities). The federal authorities are responsible for the regulation and financing of the compulsory health insurance and for the regulatory functions of accreditation and medications control and pricing. The federated entities are responsible for health promotion and prevention, coordination of primary health care and the implementation of accreditation and regulation standards in the respective regions of the country.[5]

A2: Healthcare system organization

A2.1: Coverage

Healthcare coverage is universal for all types of services including physician and diagnostic (imaging and laboratory) services and medications.

A2.2: Individual copayment

Only about 20% of the total health care expenditures are paid by the patients. These payments take the form of official copayments, supplements and payments for non-reimbursed medical acts, medications and devices.

A2.3: Financing

The Belgian health system is based on the principle of social insurance, and the whole population is covered by compulsory health insurance based on a social security system. Financing is based on direct taxation, social security contributions related to income and alternative financing related to the consumption of goods and services.[5]

The total health spending was 10.5% of GDP (above the 9.5% OECD average), financed by an interaction between public, independent providers and private not-for-profit providers:

- Public (taxes + social security) = 75.6%
- Private/other sources = remainder

A2.4: Organization of care delivery

A2.4.1: Primary care

Primary care is delivered by PCPs and PCPs are the patients' first point of contact with the healthcare system. To access primary care, a patient must register with a PCP.

A2.4.2: Specialist care

Specialist care is accessed predominantly via hospitals (private non-profit or public). Most specialists work independently in hospitals or in private practices on an ambulatory basis.

A3: Physician compensation

PCPs and outpatient specialist services are paid by FFS.

A4: NCD policy and strategy

- The NCD strategy is based in part on the WHO action plan for the prevention and control of NCDs for 2013–2020.
- The regional governments' policy framework for the management of chronic diseases includes regional plans for diabetes, CVD, cancer and chronic respiratory illnesses.

A5: CKD-specific policies, guidelines and/or service frameworks

A5.1: Specific policies

There is no specific CKD policy. Recently, a voluntary system is being introduced to make an official contract between the PCP, the nephrologist and the patient with CKD, but this is yet to be implemented widely.

A5.2: Guidelines

There is no national or regional guideline for CKD management in Belgium. In some centres, nephrologists use the international KDIGO guideline. However, some nephrologists were of the opinion that European guidelines such as the ERA-EDTA guideline are better suited for local needs.

The Belgian centre for evidence-based medicine (Belgian Branch of the Dutch Cochrane Centre) have initiated guidelines recently, but yet to be widely adopted.

A5.3: Structures/systems for monitoring uptake of guidelines

This is not applicable as there is no national guideline.

A5.4: CKD as a healthcare priority

No level of government recognizes CKD as a healthcare priority.

A5.5: CKD care advocacy

There is no official advocacy group to raise the profile of CKD with any level of government. In the KH4L survey, 82% of the 22 respondents (care providers) thought there was no advocacy group at the higher levels of government to raise the profile of CKD and its prevention.

B. Organization and structure of CKD care

There are no organized structures for early CKD care. Oversight of CKD care is provided by individual hospitals through PCPs and other specialists until advanced stages (stage 5 and RRT), when nephrologists take over.[6]

B1: Role of care providers

B1.1: PCPs and other specialists

Early CKD care is provided mainly by PCPs and other specialists (cardiologists, endocrinologists, etc) until stage 4 CKD.

B1.2: Nephrologists

Nephrologists care mostly for patients with primary renal diseases and those with stage 5 CKD and RRT.

B2: CKD care structures

B2.1: CKD care (RRT)

There are about 65 renal units in the country, each with up to three attached satellite units. Social security covers the whole spectrum of RRT care (dialysis and transplantation).

B2.2: CKD care (non-RRT)

No organized clinical care pathway or program is in place for CKD patients. Certain policies such as the high relative reimbursement for RRT (dialysis) and low relative reimbursement for CKD care and prevention activities limit nephrologists' interest in early CKD.[3]

B2.3: Regional variation in structures and practice patterns for CKD care

There is no major variation in CKD care between the two major regions of North and South in Belgium. Cultural differences are noticeable in patients' attitude toward their care, but this was generally not perceived to translate into structural differences in delivery of chronic disease care.

C. Access and quality of care

C1: Availability and access to care

CKD care and delivery including all forms of RRT are wholly covered by social insurance and accessible to all residents. ESRD care and delivery are covered by the public insurance system and thus are accessible to all residents. However, a small copayment (see A2.2) applies to medications and transportation to access specialized care services.

C2: Referral criteria

There are no defined criteria for nephrology referrals.

C3: Quality management programs

A national quality management program only for ESRD patients on RRT is being organized through the renal registry.

C4: CKD registry

There is no registry for early CKD patients.

D. Capacity, workforce and access to multidisciplinary teams

D1: Physician workforce

Early CKD care is provided by PCPs. Nephrologists care for patients with advanced CKD (stage 5) or patients on RRT. There are about 300 nephrologists in the country (Table 2-3).

D2: Multidisciplinary teams and other professionals

Access varies across centres: some centres have multidisciplinary teams of dieticians, psychologists, nurses and social workers, while others do not.

D3: Workforce limitations

There are reported deficiencies in the number of vascular access coordinators, nurse practitioners and counselors/psychologists (Table 2-3).

Table 2-3

Workforce	*Availability*
Physicians per 1000 population	4.0
Nephrologists per 1000 ESRD patients	23
Nephrologists per 1000 CKD patients	0.30
Nurses per 1000 population	14.8
Presence of multidisciplinary teams for CKD	Yes
Disciplines with most pronounced lack of capacity for CKD care, in the opinion of survey respondents	Vascular access coordinators, Nurse practitioners, Counselors/ psychologists

E. Barriers to optimal CKD care

E1: Top five barriers to optimal CKD care (in descending importance)

1. Organizational factors
2. Political factors
3. Economic factors
4. General population's low awareness of early detection and prevention of CKD
5. Policymakers' low awareness of early detection and prevention of CKD

Political factors

CKD is not recognised as a politically important topic in the same way as diabetes, cancer or vascular disease. Politically the health care system is quite complex: lack of cooperation between Dutch- and French-speaking parts makes a national policy for CKD difficult to obtain.

Economic factors

Reimbursement for early CKD care is limited as most budgets are allocated to the care of ESRD patients.

Organizational factors

- Many parties are involved in the organization and delivery of care between and within regions, leading to poor coordination and lack of focus.
- Rivalries between organizations (hospitals, PCP practices) to attract patients to their centres are based mostly on economic factors.

CKD awareness

Overall, awareness of the importance of CKD is low among care providers, policymakers, patients and the general population. Some improvements were reported with the introduction of care trajectory in 2009.

F. CKD burden and risk factors

F1: Epidemiology of ESRD

In 2010, the number of adult patients starting RRT in Belgium was 2111; 1226 patients in Dutch Belgium equating to an incidence rate of 195.2 pmp and 885 patients with a rate of 191.7 pmp in French Belgium. Diabetes and vascular diseases are the leading causes of ESRD.[7]

As of December 31, 2010, there were 13,034 adult patients receiving RRT in Belgium. In Dutch Belgium the prevalence of RRT was 1161.1 pmp with an increase of 2.18% since 2009; correspondingly in French Belgium, 1237.4 pmp with an increase of 3.7%. From 2009 to 2010 the prevalence of HD patients increased by 2.9%, the prevalence of PD fell by 6.9%, and the prevalence of patients with a functioning transplant increased by 2.5% in Dutch Belgium; comparable changes in French Belgium were an increase of 3.7%, 3.2% and 4.2% respectively. Since 2009 the number of patients receiving home HD decreased from 19 to 16 in Dutch Belgium (−16%) and increased from 39 to 47 in French Belgium (+21%).

Transplantation was the second most common treatment modality (41%), HD was used in 54% of RRT patients and PD in 5% in all regions of Belgium. Transplant prevalence at the end of 2010 was 477.4 pmp in Dutch Belgium and 504.5 pmp in French Belgium.

F2: Epidemiology of CKD

A single study reported that the prevalence of CKD was 17.2% in an elderly population cohort.[8]

F3: CKD Cost Data

There are no data on CKD care cost.

F4: CKD risk factors

A high burden of risk factors is associated with CKD at the population level including increasing age, diabetes, hypertension, smoking, alcohol use and obesity (Table 2-4).

Table 2-4

Risk factor	*Prevalence (year)*
Age >65 years	17.1% (2009)
Diabetes	6.6% (2011)
Hypertension	41.2% (2011)
Smoking	20.5% (2009)
Alcohol	9.7 L* (2009)
Obesity	13.8% (2009)

*Mean annual consumption per capita.

G. Perceptions of care (providers, patients and policymakers)

G1: Efficiency in CKD care delivery

Efficiency was rated as above average by 25% and excellent by 45% of the KH4L respondents.

G2: Patient education

According to the CEAPIR European Kidney Patients' Federation 2011 survey results, about 75% patients say they have never received education to help them manage their CKD.[9] Patients at all stages of CKD lack educational materials.

G3: Patients' involvement in their care

Patients' involvement was rated as average in the KH4L survey. According to the CEAPIR European Kidney Patients' Federation 2011 survey results, about 77% of CKD patients felt they were involved in making decisions about their treatment.[9]

G4: Patients' perceptions of quality of care received

Perceived quality of care was rated as above average in the KH4L survey. According to CEAPIR European Kidney Patients' Federation, 2011 survey results about 88% of patients are very satisfied with care for their kidney disease, and another 12% are somewhat satisfied.[9]

H. Opportunities for and obstacles to improvement

H1: Opportunities

- Universal healthcare system and well-developed infrastructure.
- A recent initiative – "Trajectory" ("Trajectoire") established to care for patients with stage 3b to 5 CKD – aiming to promote collaboration between PCPs and specialists.

H2: Obstacles

- Limited funding and economic factors with increasing competing priorities.
- Limited workforce and multidisciplinary teams.
- Increased inappropriate referral to nephrology since the onset of the Trajectory initiative.
- Lack of coordination of care between PCPs and specialists.
- Lack of priority given by policymakers to early CKD care.

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Canada

COUNTRY OVERVIEW

Facts

Area	9,984,670 sq km
Total population	34,300,083 (2012)

CKD care plan

National plan/strategy for NCDs	Yes
National plan/strategy: CKD specific	Yes
Guideline/service framework	Yes
CKD (non-RRT) Registry	No
Planned actions	Yes

Disease burden

ESRD data	
Incidence/pmp	165.5 (2010)
Prevalence/pmp	1153.7 (2010)
CKD data	
Prevalence	12.5% (2013)
Costs data	
GDP (PPP)	$1.414 trillion (2011)
Total health expenditures (% of GDP)	11.4 (2010)
CKD costs data (as % total health expenditure)	Not available

Capacity and workforce

Hospital bed capacity	1.7 per 1000 population
Physicians supply	2.4 per 1000 population
Nurses supply	9.3 per 1000 population
Nephrologists supply	14 per 1000 ESRD patients
Renal units, N	121
Transplant centres, N	17

PPP = purchasing power parity.

A. Health systems, policies and structures

A1: Governance structure

Canada is a federation of ten provinces and three territories that share the responsibilities of governing the nation with the federal government. The provision of healthcare is within the mandate of the provinces and territories, while the federal government is responsible for legislation and regulation.[1]

A2: Healthcare system organization

A2.1: Coverage

Healthcare coverage is universal for all types of services including physician and diagnostic (imaging and laboratory) services and medications. Healthcare delivery is governed by the principles of the Canada Health Act of 1984, which has five key principles:

- Public administration of healthcare by provincial health insurance plans
- Comprehensiveness of healthcare coverage
- Universality (all Canadians receive coverage)
- Accessibility (insured services must be reasonably accessible to all Canadians)
- Portability (i.e., healthcare coverage is available to Canadians who move between provinces)

These conditions must be met by all provinces and territories, and the federal government is responsible for ensuring adherence to the governing principles of the Canada Health Act.[1]

A2.2: Individual copayment

There are copayments for outpatient prescriptions, but in most of the provinces, government-sponsored drug insurance is universal for patients over the age of 65 years. Most patients have private third-party insurance to cover these copayments or have the copayments subsidized. The copayment is 15% to 25% for patients with government-sponsored or private insurance; the government-sponsored programs have a yearly maximum limit for total copayments paid according to income level.

A2.3: Financing

Healthcare in Canada is publicly funded and privately delivered. Hospitals are almost entirely publicly funded not-for-profit institutions, while the majority of care providers (PCPs and specialists) are independent contractors who bill the provincial health insurance plans for health services rendered to patients. The total healthcare expenditure as a percentage of GDP was 11.4% in 2010 (above the 9.5% OECD average). Public funding by government covered 71% of total health expenditure. A single payer system provided by each province or territory contributes ~30% of total medication costs. Of note, all aspects of ESRD care, including dialysis and transplantation are fully covered (without copayment) by provincial government health plans.[2]

A2.4: Organization of care delivery

A2.4.1: Primary care

Primary care is delivered by PCPs, predominantly in private group practices. PCPs are the first point of contact with healthcare.

A2.4.2: Specialist care

Specialist care is accessed predominantly via public hospitals and private outpatient facilities. To access specialist care, referral is compulsory.

A3: Physician compensation

PCPs and specialists are paid predominantly by FFS.

A4: NCD policy and strategy

The Canadian NCD strategy is based on the WHO action plan for the prevention and control of NCDs for 2013–2020. Chronic disease screening and management programs are the responsibility of the Public Health Agency of Canada (PHAC).[3]

A5: CKD-specific policies, guideline and/or service frameworks

A5.1: Specific policies

There is no CKD-specific policy at national or provincial levels. There are individual regional programs in various parts of the country, funded by regional governments that are responsible for standardization and improvement in CKD care.

A5.2: Guidelines

There has been a national guideline since 2008, with variable implementation across the provinces. This guideline covers:

- Criteria for referral to specialist care.
- Management of progression risk (lifestyle factors, hypertension, diabetes, dyslipidemia, proteinuria), complications of CKD (anemia, mineral metabolism, malnutrition).
- Criteria for RRT initiation.
- Comprehensive conservative management.[4]

A5.3: Structures/systems for monitoring uptake of guideline

There are no national or provincial structures or systems for monitoring the uptake of the guideline.

A5.4: CKD as a healthcare priority

CKD is not recognized as healthcare priority at any level of government. Some provinces have “renal agencies” that help to coordinate and monitor renal care across the province; other provinces are served by multiple independent programs. There are scattered regional initiatives in Alberta, British Columbia, Manitoba and Ontario for early detection and management.

A5.5: CKD care advocacy

There is no advocacy group to raise the profile of CKD with government at any level.

B. Organization and structure of CKD care

There are no organized structures for early CKD care. Oversight of CKD care is by individual hospitals (Quebec, Manitoba, Saskatchewan and the Atlantic provinces) or provincial/regional programs (Alberta, British Columbia, and Ontario).

B1: Role of care providers

B1.1: PCPs and other specialists

Early CKD care is provided mainly by PCPs and other specialists (cardiologists, endocrinologists, etc) until stage 4 CKD. PCPs remain responsible for overall care even after nephrology referral.

B1.2: Nephrologists

Nephrologists care mostly for stages 4–5 CKD and RRT. High reimbursement for RRT services and low reimbursement for CKD prevention may limit nephrologist interest in CKD care.

B2: CKD care structures

Each province has a distinct leadership structure for CKD care, which varies from a single organization for a whole province as in British Columbia, Manitoba, New Brunswick, Newfoundland and Labrador, Nova Scotia and Prince Edward Island, Quebec and Saskatchewan, two organizations in Alberta and multiple organizations in Ontario.

B2.1: RRT care

RRT care is delivered in 121 renal hubs (mostly based in university and city hospitals) across the country; the majority are located in the more heavily populated provinces of Alberta, British Columbia, Quebec and Ontario. Of these hubs, 17 have functioning renal transplant programs (CORR, 2013).[5, 6] The delivery of RRT care has changed from a model dependent on dialysis services located in university or city hospitals to a model in which university or city hospitals continue as hubs while delivery of services is dispersed across satellite units that may or may not be staffed by on-site nephrologists. In many jurisdictions nephrologists work primarily at a hub unit but travel intermittently to (or use telehealth to remotely care for) patients dialyzing in satellite units. This need has been provoked by geographic factors and by the dispersion of dialysis to facilities that are too small to justify the presence of an on-site nephrologist. Over time roles have further evolved: nurse practitioners, technicians, licensed practical nurses and medical service aides are all now involved in the delivery of dialysis. Involvement of nurse practitioners, clinical associates, pharmacists and dieticians, and automation and protocol-guided care all have changed the roles that nephrologists play in delivering dialysis care in Canada.[7]

Care for patients with kidney transplants also varies across the country. In many places this care is shared with transplant surgeons. Some nephrologists are dedicated to care of transplant patients, while others spend no time on this aspect of nephrology.[7]

B2.2: CKD care (non-RRT)

No province has systems in place for early detection and management of CKD. However, because of the increasing general awareness and interest in CKD, specialized clinics dedicated to the care of patients with early CKD have continued to grow over the past 10 years. Many of these clinics are multidisciplinary, and the role of the nephrologist varies from centre to centre.[7]

B2.3: Regional variation in structures and practice patterns for CKD care

There is no nationally coordinated system for CKD care. However, because of the universal nature of healthcare, there are no major differences with the way that care is organized or delivered.

C. Access and quality of care

C1: Availability and access to care

CKD care and delivery including all forms of RRT are wholly covered and accessible to all residents. This includes all aspects of ambulatory and hospital care, inclusive of physician and diagnostic (laboratory and imaging) services. However, there is a small copayment for medications, which is not specific to CKD patients (see Section A2.2). Medications are publicly funded by the government; patients are responsible only for small copayments on medications and transportation to access specialized care services. Funding for certain medications such as cinacalcet is absent or varies between jurisdictions. All immunosuppressive medications except steroids and azathioprine are publicly funded and free at the point of delivery. Access to care is a major issue for patients in some territories and provinces because of remote residence location. Increasing use of telehealth and travel by nephrologists to remote or rural regions can mitigate some of the problems.

C2: Referral criteria

National criteria for referral of patients with CKD to a nephrologist are as follows:

- Stage 4 and 5 CKD
- Significant proteinuria (PCR ≥ 100 mg/mmol, ACR ≥ 70 mg/mmol)
- Rapid progression based on clinical evaluation
- Refractory hypertension
- Presence of proteinuria and hematuria

C3: Quality management programs

A national quality management program is available only for ESRD patients on RRT, and only through the national registry. There are no national quality indicators for CKD care. Differences in medication coverage across provinces were felt by some respondents to impede a national quality standard.

C4: CKD registry

There is no national registry for early CKD patients. In British Columbia, formal registration and full data collection of all patients with CKD followed by nephrologists have existed since 2003. British Columbia is the only province in Canada with this type of data.[8]

D. Capacity, workforce and access to multidisciplinary teams

D1: Physician workforce

There are currently 561 nephrologists practising in Canada (Table2-5).

D2: Multidisciplinary teams and other professionals

The care of CKD patients who require RRT is generally provided by nephrologists with support of a multidisciplinary team comprising vascular access practitioners, nurses, dieticians, pharmacists, social workers, etc. The nature and extent of multidisciplinary teams differ across Canada.

D3: Workforce limitations

Deficiencies are reported in the number of vascular access coordinators, PCPs and renal pharmacists (Table 2-5).

Table 2-5

Workforce	*Availability*
Physicians per 1000 population	2.2
Nephrologists per 1000 ESRD patients	14
Nephrologists per 1000 CKD patients	0.17
Nurses per 1000 population	9.3
Presence of multidisciplinary teams for CKD	Yes
Disciplines with most pronounced lack of capacity for CKD care, in the opinion of survey respondents	Vascular access coordinators, Primary care physicians, Renal pharmacists

E. Barriers to optimal CKD care

E1: Top five barriers to optimal CKD care (in descending importance)

1. Organizational factors
2. Economic factors
3. Political factors
4. Policymakers' awareness of early detection and prevention of CKD
5. General population's awareness of early detection and prevention of CKD

Political factors

CKD is not recognised by political leaders as a public health priority, in contrast to diabetes, cancer or CVD. This is perceived as a critical issue, since resources for healthcare delivery are felt to be allocated on the basis of political preference and/or expediency as well as need.

Economic factors

Different funding structures and priorities across provinces hinder national standardization in care practice patterns, delivery and quality. For example, not all provinces have funding structures in place for multidisciplinary teams for CKD. Some respondents felt that differences in roles and responsibilities between provinces also hindered attempts at national standardization: for example, in some provinces, renal dieticians might be responsible for both ward and clinic patients, whereas in other provinces, dieticians might be responsible for clinic patients only.

Organizational factors

The fact that CKD care (like all healthcare) is a provincial responsibility hampers attempts to achieve a national quality standard. A national healthcare system was perceived to have major advantages such as standardization of care, transparent and uniform funding models, the potential for comprehensive disease surveillance, and enhanced dissemination of guidelines to improve outcomes.

CKD awareness

Overall, awareness of the importance of CKD is low among care providers, policymakers, patients and the general population.

F. CKD burden and risk factors

F1: Epidemiology of ESRD

In 2010, the number of adult patients starting RRT in Canada was 5,646, equating to an incidence rate of 165.5 pmp. The incidence rate was stable from 2004 to 2010 but had increased from 154.9 pmp in 2000. Diabetes and vascular diseases are the leading causes of ESRD. As of December 31, 2010, there were 39,352 adult patients receiving RRT. The prevalence of RRT was 1153.7 pmp, an increase of 2.3% from 2009. From 2009 to 2010 the prevalence of HD patients increased by 2.0%, the prevalence of PD fell by 0.49%, and the prevalence of patients with a functioning transplant increased by 3.4%. The number of patients receiving home HD since 2009 increased by 6.1%, from 786 patients to 834 patients.[6]

Transplantation is the second most common treatment modality (43.1%) followed by HD in 46.4% of RRT patients and PD in 10.5%. Transplant prevalence at the end of 2010 was 473.9 pmp.[6]

F2: Epidemiology of CKD

Nationally representative data suggest that the prevalence of CKD is 12.5%.[9] These data are supplemented by reports using regional administrative databases.[10]

F3: CKD cost data

RRT care is funded exclusively through the public sector and consumed about 1.2% of total healthcare expenditures in Canada.[1]

F4: CKD risk factors

There is a high burden of risk factors associated with CKD at population level including increasing age, diabetes, hypertension, smoking, alcohol use and obesity (Table 2-6).

Table 2-6

Risk factors	*Prevalence (year)*
Age >65 years	13.9% (2009)
Diabetes	9.2% (2011)
Hypertension	33.6% (2011)
Smoking	16.2% (2009)
Alcohol use	8.2 L* (2009)
Obesity	24.2% (2009)

*Mean annual consumption per capita.

G. Perceptions of care (providers, patients and policymakers)

G1: Efficiency in CKD care delivery

This was rated as above average by 37% of respondents and average by 53%.

G2: Patient education

According to 32% of respondents, there were no nationally available tools or resources to educate patients about how to manage CKD. Primary care providers are not felt to have sufficient time to educate patients about CKD. The Kidney Foundation of Canada is felt to provide significant support with educational materials relevant to all stages of CKD.

G3: Patients’ involvement in their care

This was rated as average in the KH4L survey.

G4: Patients’ perceptions of quality of care received

This was rated as above average in the KH4L survey.

H. Opportunities for and obstacles to improvement

H1: Opportunities

- Universal healthcare system and well-developed infrastructures.
- The See Kidney Disease (SeeKD) targeted screening program (The Kidney Foundation of Canada has produced the first national targeted screening program in Canada for CKD). Its goal is to collect data and information about screening and prevention, early detection and management of CKD across Canada.
- Canadian Kidney Knowledge Translation and Generation Network (CANN-NET) initiative.

H2: Obstacles

- Lack of a national surveillance strategy for CKD prevention, earlier intervention and appropriate referral for patients. National care databases are needed to facilitate better comparative studies across provinces and care facilities.
- Limited workforce planning and guideline in terms of how hemodialysis units and CKD clinics are staffed and operated, and what intensity of resource should be applied.
- A major obstacle at the local or regional level is that nephrologists work as individual contractors. Typically, most of the workload for nephrologists is devoted to periodic hemodialysis care. A salary-based payment method for ESRD care may be more appropriate as nephrologists are working as a team and FFS is really unnecessary in this context.
- Poor marketing and branding of CKD as an important public health issue by all stakeholders (care providers, patients' organizations, and administrators).
- The healthcare systems of all provinces function in silos, and even within provinces huge variation exists between hospitals. There is a need for a national strategy and standardization of care organization (quality targets, structures, workforce needs).
- Culture of "we know it all" among physicians, who do not like to be guided on what to do; this inhibits guideline implementation and other quality improvement (QI) initiatives.
- Multidisciplinary teams differ across Canada and are not standardized.
- The approval process for certain medications needs to be streamlined by eliminating provincial barriers and by full uptake of a national approvals process.
- Multiple and varied care structures, and absence of electronic data capture systems in some provinces.

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Denmark

COUNTRY OVERVIEW

Facts

Area	43,094 sq km
Total population	5,543,453 (2012)

CKD care plan

National plan/strategy for NCDs	Yes
National plan/strategy: CKD-specific	No
Guideline/service framework	No
CKD (non-RRT) registry	No
Planned actions	No

Disease burden

ESRD data	
Incidence, pmp	120.1 (2010)
Prevalence, pmp	847.7 (2010)
CKD data	
Prevalence %	Not available
Costs data	
GDP (PPP)	$ 209.2 billion (2011)
Total health expenditures (% of GDP)	7.0 (2009)
CKD costs data (as % total health expenditure)	Not available

Capacity and workforce

Hospital bed capacity	3.57 per 1000 population (2008)
Physician supply	3.2 per 1000 population (2010)
Nurses supply	14.8 nurses per 1000 population (2009)
Nephrologist supply	26 per 1000 ESRD population
Renal units, N	14 (hubs)
Transplant centres, N	3

PPP = purchasing power parity.

A. Health systems, policies and structures

A1: Governance structure

Denmark is a parliamentary democracy and consists of three distinct administrative levels: the federal government, five regions and 98 municipalities. The Danish federal government is responsible for regulation, planning and supervision of health services. The regions are responsible for hospitals and independent care providers. The 95 municipalities are mainly responsible for primary care provision (disease prevention and health promotion).[1-4]

A2: Healthcare system organization

A2.1: Coverage

Healthcare coverage is universal for all types of services including physician and diagnostic (imaging and laboratory) services and medications.

A2.2: Individual copayment

There are fixed copayments for outpatients' prescription medications, which are usually reimbursable if an individual's annual expenditure on copayments exceed a certain threshold (usually >US$148). Municipalities provide means-tested social assistance (ie, reduced copayments) for those with low income, pensioners and patients with chronic diseases with high prescription medication usage/costs.

A2.3: Financing

All publicly funded healthcare is largely free at the point of delivery. The annual spending on healthcare averages 11.5% of GDP. Healthcare is financed predominantly from general taxation, which represents >85% of total healthcare expenditure.

Privately financed healthcare is relatively uncommon (16% of total health expenditure) and mostly involves medications and private hospital care.

A2.4: Organization of care delivery

A2.4.1: Primary care

Primary care is delivered by PCPs, predominantly in private group practices. The number of solo practices has decreased significantly over the last decade. PCPs are the first point of contact with healthcare. To access primary care, registration with a PCP is required.

A2.4.2: Specialist care

Specialist care is accessed predominantly via ambulatory clinics in public hospitals or self-employed specialists in privately owned clinics. Referrals are required for access; PCPs serve as the gatekeepers.

A3: Physician compensation

PCPs are private contractors paid using a mix of capitation (30%) and FFS (70%). Specialists are predominantly salaried employees of public hospitals or self-employed specialists paid through FFS.

A4: NCD policy and strategy

The Danish NCD strategy is based on the WHO action plan for the prevention and control of NCDs for 2013–2020. There are specific policies/programs for CVD, cancer, tobacco and alcohol; a department in the Ministry of Health is responsible for NCDs. The national diabetes care program, based on work done by the Steno group, is very strong.

A5: CKD-specific policies, guideline and/or service frameworks

A5.1: Specific policies

There are no specific policies, strategies or service frameworks.

A5.2: Guidelines

A national guideline for CKD management has been developed by the Danish Society of Nephrology and covers:

- Identification of patients with CKD.
- Assessment of kidney function and proteinuria.
- Management and referral of CKD.
- Criteria for RRT initiation.

A5.3: Structures/systems for monitoring uptake of guideline

No structures or systems are in place to monitor adherence to the guideline. The guideline is poorly disseminated across regions because it is perceived to increase nephrologists' workload.

A5.4: CKD as a healthcare priority

No level of government has recognized CKD as a healthcare priority.

A5.5: CKD care advocacy

There is no official advocacy group to raise the profile of CKD with government, media or the general public; however, there is an increasing interest with this, as for example the "Nyreforeningen" (www.nyreforeningen.dk), a group consisting of patients and their relatives, are advocating for patients with severe kidney disease (primarily ESRD).

B. Organization and structure of CKD care

CKD care is overseen by individual hospitals and is delivered mainly by primary care and other specialists until advanced stages of the disease.

B1: Role of care providers

B1.1: PCPs and other specialists

Early CKD care is provided mainly by PCPs and other specialists (cardiologists, endocrinologists, etc) until stage 3, 4 or 5 CKD.

B1.2: Nephrologists

Nephrologists care mostly for patients with CKD stages 4 and 5 and RRT but also, when clinically relevant, treat and follow up with patients with early CKD (stage 3).

B2: CKD care structures

B2.1: RRT care

Nephrology services are delivered chiefly by centralized hubs. There are 14 hub renal units in Denmark, which have on-site consultant nephrologists and inpatient beds for renal patients, and 2–3 satellite units attached to main centres. Transplantation is delivered by the three largest nephrology centres in the city areas of central Copenhagen (Copenhagen and Frederiksberg municipalities), Odense and Aarhus (including suburbs and surrounding municipalities).

B2.2: CKD care (non-RRT)

The national CKD management guideline supports the management of CKD in the community, and referral of appropriate individuals for specialist nephrology care as required. However, nephrologists felt that the guideline triggered many inappropriate referrals. Therefore, although the guideline is still technically in force, there has been poor dissemination and application particularly at the primary care level.

B2.3: Regional variation in structures and practice patterns for CKD care

There is no major practice variation across regions or municipalities.

C. Access and quality of care

C1: Availability and access to care

CKD care and delivery including all forms of RRT are wholly covered through the publicly funded healthcare system and are accessible to all Danish residents. These include all aspects of ambulatory or hospital care inclusive of physician and diagnostic (laboratory and imaging) services.

However, there are certain exemptions for medications as these are not wholly publicly funded by government for all CKD patients across Denmark. There is a small copayment which is not specific to CKD patients (see Section A2.2) except for those with low income, pensioners, or living with a chronic disease with high prescription medication usage/costs.

In general, patients on RRT receive free medications and transportation to access specialized care. There are no waiting lists for dialysis, placement of permanent vascular access for dialysis, or other treatment procedures related to ESRD treatment.

Kidney transplantation is free, and immunosuppressive medications are fully covered.

C2: Referral criteria

National published standards for referral of patients with CKD to a nephrologist are as follows:

- Stage 4 and 5 CKD
- Significant proteinuria (PCR ≥ 100 mg/mmol, ACR ≥ 70 mg/mmol)
- Rapid progression based on clinical evaluation
- Difficult to control hypertension
- Presence of proteinuria and hematuria

C3: Quality management programs

Quality management programs are available for ESRD, and administered by the Danish National Registry on Regular Dialysis and Transplantation (NRDT). The NRDT was established in 1990 and includes data on all Danish patients being actively treated for ESRD. The registry is used for quality assurance and supplies data to the regional ERA-EDTA Registry.

C4: CKD registry

There is no registry for early CKD patients. There is no plan to develop a national CKD registry; however, there is ample opportunity to develop this as a strong nationwide information technology system is being utilised at all levels of the healthcare system. All citizens in Denmark have a unique personal ID for identification in all public registries and health databases. Finally, all primary care clinics use electronic records for communication with regions, hospitals and pharmacies. Implementation of a national CKD registry would require collaboration between the Danish Society of Nephrology and PCPs.

D. Capacity, workforce and access to multidisciplinary teams

D1: Physician workforce

Care for patients with early CKD is provided by the PCPs. There are ~120 certified nephrologists across 14 renal centres in Denmark, mainly providing care for patients with advanced stages of CKD (stages 4 and 5 and those on RRT) (Table 2-7).

D2: Multidisciplinary teams and other professionals

There are multidisciplinary teams of nurses, dieticians, psychologists, and social workers, but no renal pharmacists.

D3: Workforce limitations

There are reported deficiencies in the number of vascular access coordinators, counsellors/ psychologists, renal social workers, dieticians and nephrologists (Table 2-7).

Table 2-7

Workforce	*Availability*
Physicians per 1000 population	3.2
Nephrologists per 1000 ESRD patients	26
Nephrologists per 1000 CKD patients	0.22
Nurses per 1000 population	14.8
Presence of multidisciplinary teams for CKD	Yes
Disciplines with most pronounced lack of capacity for CKD care, in the opinion of survey respondents	Nephrologists, Dieticians, Vascular access coordinators, Counselors/ psychologists, Renal social workers

E. Barriers to optimal CKD care

E1: Top five barriers to optimal CKD care (in descending importance)

1. Political factors
2. Economic factors
3. Organizational factors
4. Care providers' awareness of early detection and prevention of CKD
5. General population's awareness of early detection and prevention of CKD

Political factors

CKD is not recognised as a politically important topic in the same way as diabetes or CVD.

Economic factors

The 2008 global financial crisis reduced funding to most public services including healthcare for CKD.

Organizational factors

- There is perceived lack of coordination in primary and secondary care, and often lack of good relationships among providers. These factors are felt to impede efficient CKD care.
- Although progress has been made in educating primary care providers about the importance of CKD, case detection of CKD among people at risk continues to vary. The major barriers are thought to be lack of education and failure on the part of the PCPs, policymakers and the general public to appreciate the significance of CKD.

CKD awareness

Overall, awareness of the importance of CKD is low among care providers, policymakers, patients and the general population. Lack of media attention is felt to be an important but potentially reversible barrier.

F. CKD Burden and risk factors

F1: Epidemiology of ESRD

In 2010, the number of adult patients starting RRT in Denmark was 673, equating to an incidence of 120.1 pmp. Diabetes and vascular diseases are the leading causes of ESRD. As of December 31, 2010, there were 4,745 adult patients receiving RRT in Denmark. The prevalence of RRT was 846.7 pmp, an increase of 1% from 2009. From 2009 to 2010 the prevalence of HD patients decreased by 1.2%, the prevalence of PD fell by 4.1%, and the prevalence of patients with a functioning transplant increased by 4.6%. The number of patients receiving home HD decreased by 3.9% since 2009, from 128 to 123. Transplantation and HD were the most common treatment modalities (45% and 43%, respectively), and PD was used in 12% of RRT patients in 2010. The prevalence of patients with a functioning transplant at the end of 2010 was 380.1 pmp.[5, 6]

F2: Epidemiology of CKD

There are no nationally representative data on the prevalence of CKD. A small study reported the prevalence of albuminuria as 3% in the general population.[7]

F3: CKD cost data

ESRD care is funded exclusively through the public sector. About 1–2% of total healthcare expenditures are spent on ESRD care. There are no data on the cost of CKD care in Denmark.

F4: CKD risk factors

A high burden of risk factors is associated with CKD at the population level including increasing age, diabetes, hypertension, smoking, alcohol use and obesity (Table 2-8).

Table 2-8

Risk factors	*Prevalence (year)*
Age >65 years	16.1% (2009)
Diabetes	9.1% (2011)
Hypertension	41.0% (2011)
Smoking	19.1% (2009)
Alcohol use	10.1 L*(2009)
Obesity	13.4% (2009)

*Mean annual consumption per capita.

G. Perceptions of care (providers, patients and policymakers)

G1: Efficiency in CKD care delivery

Efficiency was rated as above average by 55% of the respondents and as average by 27%.

Strengths of the existing system are felt to be a universal healthcare system and excellent chronic disease programs involving CVD and diabetes.

G2: Patient education

The majority of the respondents (70%) felt there were no nationally available tools or resources to educate patients about how to manage CKD.

G3: Patients’ involvement in their care

Patients’ involvement was rated as average in the KH4L survey, across the spectrum of CKD patients.

G4: Patients’ perceptions of quality of care received

Perceived quality of care was rated as above average in the KH4L survey, across the spectrum of CKD patients.

H. Opportunities for and obstacles to improvement

H1: Opportunities

- Universal healthcare system and well-developed infrastructure.
- Renal association/community that could work in partnerships with other groups like the diabetes association to facilitate quality improvement initiatives.
- Information technology available to support national CKD surveillance.
- Integrated care model with major NCDs (CVD and diabetes) at the Ministry of Health.

H2: Obstacles

- Limited funding and economic factors with increasing competing priorities.
- Low political awareness and involvement. CKD is not seen as a politically important topic compared to CVD and diabetes.
- Complex nature of CKD, involving multiple comorbidities.
- Limited contact time between patients and PCPs.
- Limited media involvement.
- Poor coordination and clinical integration of primary and secondary care.
- Low awareness of CKD on the part of patients, policymakers and primary care practitioners.

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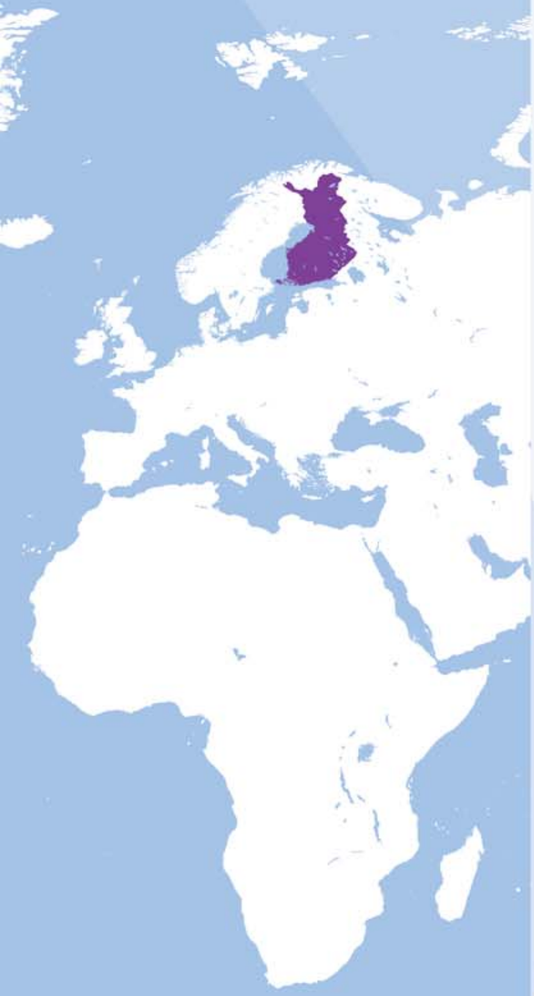
Finland



COUNTRY OVERVIEW

Facts

Area	338,145 sq km
Total population	5,262,930 (2012)

CKD care plan

National plan/strategy for NCDs	Yes
National plan/strategy: CKD-specific	No
Guideline/service framework	No
CKD (non-RRT) registry	No
Planned actions	No

Disease burden

ESRD data	
Incidence, pmp	81.5 (2010)
Prevalence, pmp	790.9 (2010)
CKD data	
Prevalence %	4.5 (stage 3–5 CKD, 2007)
Costs data	
GDP (PPP)	$198.2 billion (2011)
Total health expenditures (% of GDP)	11.7 (2009)
CKD costs data (as % total health expenditure)	Not available

Capacity and workforce

Hospital bed capacity	5.9 per 1000 population (2010)
Physicians supply	3.3 per 1000 population (2010)
Nurses supply	9.6 per 1000 population (2010)
Nephrologists supply	25 per 1000 ESRD population
Renal units, N	30
Dialysis centres, N	30 (main), 45 (satellite)
Transplant centres, N	1

PPP = purchasing power parity.

A. Health systems, policies and structures

A1: Governance structure

The Finnish governance structure consists of three levels: central, provincial and municipal. Finland is divided into five administrative provinces and the Åland Islands, the latter having autonomous status, and 440 self-governing municipalities. Municipalities are autonomous and responsible for delivering basic health services. There are three different publicly funded healthcare systems: municipal healthcare, private healthcare and occupational healthcare. The role of the central government (Ministry of Health) is mainly legislation and regulation. The administrative provinces play regulatory and supervisory roles.[1-3]

A2: Healthcare system organization

A2.1: Coverage

Universal and publicly funded coverage including 76–99% coverage for ambulatory PCP contacts, ambulatory specialist contacts, laboratory tests and diagnostic imaging; and 51–75% coverage for medications.

A2.2: Individual copayment

Small copayments for outpatient medications up to a maximum of €600/year; after that, all medications are free.

A2.3: Financing

There are different public financing mechanisms for healthcare services in Finland: municipal financing is based on taxes and NHI financing is based on compulsory insurance fees. Municipalities fund municipal healthcare services (except outpatient medications and transport costs) and NHI funds private healthcare, occupational healthcare, outpatient medications and transport costs. The dual public financing mechanism creates challenges for the overall efficiency of service, particularly for medication coverage where there is substantial potential for cost-shifting.[4]

A2.4: Organization of care delivery

A2.4.1: Primary care

Primary care is delivered by PCPs, who are the first points of contact with healthcare. However, to access primary care, registration with a PCP is not required.

A2.4.2: Specialist care

To access secondary care, residents need referral, and specialists are accessed mainly through hospitals and ambulatory community clinics.

A3: Physician compensation

PCP services are paid by a mix of FFS and salary and capitation, while outpatient specialist services are paid by salary.

A4: NCD policy and strategy

The NCD strategy is based in part on the WHO action plan for the prevention and control of NCDs for 2013–2020. The NCD strategy mainly covers CVD, cancer, diabetes, tobacco and alcohol. A department in the federal health ministry has specific responsibility for NCDs.

A5: CKD-specific policies, guidelines and/or service frameworks

A5.1: Specific policies

There is no CDK-specific policy.

A5.2: Guidelines

There is no national guideline for CKD management. Some regional guidelines exist (there are differences between regions), although these are not widely implemented. Guidelines for management of diabetes and CVD recommend checking for serum creatinine as part of routine assessment.

A5.3: Structures/systems for monitoring uptake of guidelines

This is not applicable, as a national guideline does not exist.

A5.4: CKD as a healthcare priority

No level of government recognizes CKD as a healthcare priority.

A5.5: CKD care advocacy

There is no advocacy group to raise the profile of CKD with any level of government.

B. Organization and structure of CKD care

There are no organized structures for early CKD care. Oversight of CKD care is provided in individual hospitals by PCPs and other specialists until advanced stages of CKD (stage 5 and RRT), when nephrologists take over.

B1: Role of care providers

B1.1: PCPs and other specialists

Early CKD care is provided mainly by PCPs and other specialists (cardiologists, endocrinologists, etc) until stages 4–5 CKD.

B1.2: Nephrologists

Nephrologists care mostly for patients with stages 4–5 CKD and RRT.

B2: CKD care structures

B2.1: RRT care

There are well-established programs for dialysis and transplantation: care is delivered through a total of 5 university hospitals, 20 central hospitals and 5 community hospitals. There are a total of 30 dialysis units and 45 satellite units. Kidney transplantation surgery takes place in only one centre (Helsinki University Hospital).

B2.2: CKD care (Non-RRT)

No organized clinical care pathway or program is in place for CKD patients.

B2.3: Regional variation in structures and practice patterns for CKD care

There is no regional variation across the country.

C. Access and quality of care

C1: Availability and access to care

CKD care and delivery including all forms of RRT are wholly covered and accessible to all residents. These include all aspects of ambulatory or hospital care inclusive of physician and diagnostic (laboratory and imaging) services. However, there is a small copayment for medications, which is not specific to CKD patients (see Section A2.2).

Kidney transplantation is free, and immunosuppressive medications are wholly covered by health insurance.

C2: Referral criteria

There are no nationally defined criteria for nephrology referrals. Regional criteria exist but are not widely used.

C3: Quality management programs

Quality management programs are available only for ESRD on RRT, and only through the national registry.

C4: CKD registry

There is no registry for early CKD patients.

D. Capacity, workforce and access to multidisciplinary teams

D1: Physician workforce

There are ~105 nephrologists in the country (Table 2-9).

D2: Multidisciplinary teams and other professionals

In general, multidisciplinary teams for CKD care are not widely available in Finland, although a few centres have started to use teams of varying composition.

D3: Workforce limitations

There are reported deficiencies in the number of dieticians, vascular access coordinators and nurses (Table 2-9).

Table 2-9

Workforce	*Availability*
Physicians per 1000 population	3.3
Nephrologists per 1000 ESRD patients	25
Nephrologists per 1000 CKD patients	0.20
Nurses per 1000 population	9.6
Presence of multidisciplinary teams for CKD	—
Disciplines with most pronounced lack of capacity for CKD care, in the opinion of survey respondents	Dieticians, Vascular access coordinators, Dialysis nurses

E. Barriers to optimal CKD care

E1: Top five barriers to optimal CKD care (in descending importance)

1. Political factors
2. Economic factors
3. Organizational factors
4. Care providers' awareness of early detection and prevention of CKD
5. General population's awareness of early detection and prevention of CKD.

Political factors

CKD is not recognised as a politically important topic in the same way as diabetes, cancer or vascular disease.

Economic factors

In the current economic climate, all health care is subject to challenges with funding, which are not specific to CKD.

Organizational factors

There is a perceived shortage of physicians in all parts of Finland; this is not specific to CKD or other NCDs.

CKD awareness

Overall, awareness of the importance of CKD is low among care providers, policymakers, patients and the general population.

F. CKD burden and risk factors

F1: Epidemiology of ESRD

In 2010, the number of adult patients starting RRT in Finland was 437, equating to an incidence rate of 81.5 pmp. The incidence rate in Finland was 95 pmp in 2000 and remained stable from 2000 to 2010. Diabetes and vascular diseases are the leading causes of ESRD. As of December 31, 2010, there were 4242 adult patients receiving RRT in Finland. The Finnish prevalence of RRT was 790.9 pmp, an increase of 1.4% from 2009. From 2009 to 2010 the prevalence of HD patients increased by 4.6%, the prevalence of PD fell by 13%, and the prevalence of patients with a functioning transplant increased by 1.8%. The number of patients receiving home HD increased by 6.2%, from 65 patients to 69 patients since 2009.[5]

Transplantation continued as the most common treatment modality (59.2%), HD was used in 33.3% and PD 7.5% of RRT patients. The prevalence of patients with a functioning transplant at the end of 2009 was 460 pmp.[5]

F2: Epidemiology of CKD

The national FINRISK Study reported the prevalence of CKD as 4.5% in the general population. In this study, only the prevalence of reduced kidney function (eGFR) was examined (albuminuria was not considered).[6]

F3: CKD cost data

There are no data on CKD care costs.

F4: CKD risk factors

A high burden of risk factors is associated with CKD at the population level, including increasing age, diabetes, hypertension, smoking, alcohol use and obesity (Table 2-10).

Table 2-10

Risk factors	*Prevalence (year)*
Age >65 years	16.9% (2009)
Diabetes	8.7% (2011)
Hypertension	49.2% (2011)
Smoking	18.6% (2009)
Alcohol use	9.7 L* (2009)
Obesity	20.2% (2009)

*Mean annual consumption per capita.

G. Perceptions of care (providers, patients and policymakers)

G1: Efficiency in CKD Care Delivery

This was rated as above average by most of the respondents.

G2: Patient education

According to the CEAPIR European Kidney Patients' Federation 2011 report, about 70% of patients say they have never received education to help them manage their CKD.[7]

G3: Patients' involvement in their care

This was rated as average in the KH4L survey. According to the CEAPIR European Kidney Patients' Federation 2011 Survey results, about 50% of CKD patients feel they were very involved in making decisions about their treatment.[8]

G4: Patients' perceptions of quality of care received

This was rated as average in the KH4L survey. According to the CEAPIR European Kidney Patients' Federation 2011 Survey results, about 70% of patients are very satisfied with care for their kidney disease, and another 28% are somewhat satisfied.[8]

H. Opportunities for and obstacles to improvement

H1: Opportunities

- Universal healthcare system and well-developed infrastructure.
- Consensus document of 10 societies on chronic disease care to be implemented by the federal government into a chronic disease care program for the nation.

H2: Obstacles

- Lack of awareness among the public about the importance of CKD.
- Poor collaboration between nephrologists, PCPs and other medical specialists.
- Absence of a national guideline specific to CKD.

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France

COUNTRY OVERVIEW

Facts

Area	643,801 sq km
Total population	65, 630,692 (2012)

CKD care plan

National plan/strategy for NCDs	Yes
National plan/strategy: CKD-specific	No
Guideline/service framework	Yes
CKD (non-RRT) registry	No
Planned actions	No

Disease burden

ESRD data	
Incidence, pmp	149.2* (2011)
Prevalence, pmp	1091.1* (2011)
CKD data	
Prevalence	12.9%
Costs data	
GDP (PPP)	$2.253 trillion (2011)
Total health expenditures (% of GDP)	11.7 (2009)
CKD costs data (as % total health expenditure)	Not available

Capacity and workforce

Hospital bed capacity	6.9 per 1000 population
Physicians supply	3.4 per 1000 population
Nurses supply	8.5 per 1000 population
Nephrologists supply	20 per 1000 ESRD population
Renal units, N	278
Dialysis centres, N	240
Transplant centres, N	38

PPP = purchasing power parity.

* 25 out of 26 regions.

A. Health systems, policies and structures

A1: Governance structure

France is a republic with 27 administrative regions that comprise 100 divisions and 36,679 municipalities. The central government deals with policy and regulation, and regional governments are responsible for planning and care delivery through the regional health agencies (agences régionales de santé; ARS).[1-3]

A2: Healthcare system organization

A2.1: Coverage

Universal healthcare coverage is available in France. All residents are eligible for this publicly financed healthcare, which covers hospital care, ambulatory care and medications.

A2.2: Individual copayment

There is no copayment for medications such as ACEi/ARBs that are classed as highly effective with regard to improvement in health or savings in the cost of treatment. There is a 40–85% copayment for non-effective medications. An exemption from copayment is applied to patients with chronic diseases, patients with low income and/or patients receiving work-injury benefits.

A2.3: Financing

The total health spending was 11.6% of GDP (above the 9.5% OECD average) in 2010. This amount was predominantly publicly funded by government (77% of total expenditure) and generated through social insurance contributions. About 92% of residents have access to voluntary health insurance, either through their employers or vouchers (couverture maladie universelle complémentaire; CMU-C).[4]

A2.4: Organization of care delivery

A2.4.1: Primary care

Médecin traitant is a voluntary gatekeeping system that was introduced for adults (aged 16 years and over) by a health financing reform law in 2004. Under this program, patients are not legally obliged to register with a PCP, but there are strong financial incentives for doing so, such as higher copayments for visits and medications without a referral from the gatekeeper (PCP). More than 85% of the French population has registered with a PCP.

A2.4.2: Specialist care

Specialist care is accessed predominantly via hospitals (this is true for nephrology, not for other specialities such as cardiology). Referrals are required for access; PCPs serve as the gatekeepers.

A3: Physician compensation

The predominant method of compensation for PCPs and specialists is FFS.

A4: NCD policy and strategy

The NCD strategy is based in part on the WHO action plan for the prevention and control of NCDs for 2013–2020. There are specific policies/programs for CVD, cancer, diabetes, tobacco and alcohol. A department in the health ministry has specific responsibility for NCDs.

A5: CKD-specific policies, guidelines and/or service frameworks

A5.1: Specific policies

There is no specific CKD policy.

A5.2: Guidelines

There is a national guideline for CKD management, but this is not widely implemented.

A5.3: Structures/systems for monitoring uptake of guideline

No structures or systems are in place to monitor adherence to the national guideline.

A5.4: CKD as a healthcare priority

CKD is not yet recognized as healthcare priority at any level of government, but this is changing because of a patient-initiated movement (RENALOO, see H1).

A5.5: CKD care advocacy

There is no advocacy group to raise the profile of CKD at any level of government. The Kidney Foundation of France focuses mainly on public information and research support for renal diseases.

B. Organization and structure of CKD care

Few structures are organized for early CKD care (renal care networks). CKD care is overseen by individual hospitals and occasionally by regional authorities through PCPs and other specialists until advanced stages of CKD (stage 5 and RRT), when nephrologists take over. There is no incentive for PCP to increase referral of CKD patients to nephrologists.

B1: Role of care providers

B1.1: PCPs and other specialists

Early CKD care is provided mainly by PCPs and other specialists (cardiologists, endocrinologists, etc) until stage 5 CKD.

B1.2: Nephrologists

Nephrologists care mostly for patients with stage 5 CKD and RRT (who overall account for 50% of the time spent by nephrologists).

B2: CKD care structures

B2.1: RRT care

There are well-established programs for dialysis and transplantation; care is delivered through a total of 240 dialysis centres and 38 transplant centres.

B2.2: CKD care (non-RRT)

No organized clinical care pathway or program is in place for CKD patients. There are no incentives to implement guidelines for early CKD management.

B2.3: Regional variation in structures and practice patterns for CKD care

The organization and delivery of CKD care vary widely across regions and hospitals.

C. Access and quality of care

C1: Availability and access to care

Medications are publicly funded by government with some fees at the point of delivery for patients with CKD, including those treated with RRT. Patients are responsible only for small copayments on medications and transportation to access specialized care (see Section A2.2).

C2: Referral criteria

There is a national guideline for referral and management, although it is not widely implemented.

C3: Quality management programs

Quality management programs are available for patients with ESRD on RRT, but only through the registry.

C4: CKD registry

There is no registry for early CKD patients.

D. Capacity, workforce and access to multidisciplinary teams

D1: Physician workforce

There were a total of 1325 nephrologists in January 2013. The number of nephrologists may have increased substantially since then, as ~100 trainees graduate from the training programs per year (Table 2-11).

D2: Multidisciplinary teams and other professionals

There are few multidisciplinary teams of nurses, dieticians, psychologists, social workers, nephrologists, vascular access and transplant coordinators for early CKD care.

D3: Workforce limitations

There are reported deficiencies in the number of nephrologists, dieticians, and nurses (Table 2-11).

Table 2-11

Workforce	*Availability*
Physicians per 1000 population	3.4
Nephrologists per 1000 ESRD patients	20
Nephrologists per 1000 CKD patients	0.2
Nurses per 1000 population	8.5
Presence of multidisciplinary teams for CKD	No
Disciplines with most pronounced lack of capacity for CKD care, in the opinion of survey respondents	Nephrologists, Dieticians, Dialysis nurses

E. Barriers to optimal CKD care

E1: Top five barriers to optimal CKD care (in descending importance)

1. Economic factors
2. Organizational factors
3. Care providers' awareness of early detection and prevention of CKD
4. General population's awareness of early detection and prevention of CKD
5. Patients' awareness of early detection and prevention of CKD

Political factors

CKD is not yet recognised as a politically important topic in the same way as are diabetes, cancer or vascular disease.

Economic factors

There are perceived challenges with ensuring appropriate funding for CKD care, as it must compete with many other priorities.

Organizational factors

- Poor coordination of care between PCPs and specialists.
- There are no incentives to ensure comprehensive chronic disease management, and no mechanisms for funding allied health professionals (nurses, dieticians) to provide care for CKD patients.
- Issues with workforce availability and planning: there are approximately 20 to 25 nephrologists to care for 1000 HD patients, but only 5 nephrologists to care for 1100 transplant patients, and there are 3000 transplants/year.
- Lack of capacity for management of early CKD or for pre-dialysis care.

CKD awareness

Overall, awareness of the importance of CKD is low among care providers, policymakers, patients and the general population.

F. CKD burden and risk factors

F1: Epidemiology of ESRD

In 2011, the number of adult patients starting RRT in France (25 out of 26 regions) was 9,584, equating to an incidence rate of 149 pmp. The incidence rate was stable from 2008 to 2010, having increased from 122.9 pmp in 2003. Diabetes and vascular diseases are the leading causes of ESRD. As of December 31, 2011, there were 70,332 adult patients receiving RRT: 39,183 on dialysis and 31,139 with a functioning graft. The prevalence of RRT was 1091 pmp. From 2009 to 2010 the prevalence of HD patients increased by 1.6%, the prevalence of PD fell by 1.2%, and the prevalence of patients with a functioning transplant increased by 7%. The number of patients receiving home HD decreased by 2.7% since 2009, from 256 to 249. Transplantation continued as the second most common treatment modality (44%), HD was used in 52% of RRT patients and PD in 3.7%. The prevalence of patients with a functioning transplant at the end of 2011 was 497 pmp.[5, 6]

F2: Epidemiology of CKD

There are no nationally representative data. Regional studies among high-risk groups estimated the prevalence of CKD as 12.9% among community-dwelling elderly patients older than 65 years.[7] Among patients with type 2 diabetes, the prevalence was reported to be 29%.[8] In the EPIRAN study conducted in the Nancy district (2004–2006) an annual incidence rate for CKD was reported as 1/1000 inhabitants (1.3/1000 for men and 0.7/1000 for women).[9]

F3: CKD cost data

The total cost of ESRD care was estimated to be around €4 billion in 2007. There are no data on CKD care costs.

F4: CKD risk factors

A high burden of risk factors is associated with CKD at the population level including increasing age, diabetes, hypertension, smoking, alcohol use and obesity (Table 2-12).

Table 2-12

Risk factors	*Prevalence (year)*
Age >65 years	16.7% (2009)
Diabetes	7.3% (2011)
Hypertension	42.7% (2011)
Smoking	26.2% (2009)
Alcohol use	12.3 L* (2009)
Obesity	11.2% (2008)

*Mean annual consumption per capita.

G. Perceptions of care (providers, patients and policymakers)

G1: Efficiency in CKD care delivery

Efficiency was rated as above average by most of the respondents.

G2: Patient education

There are excellent mechanisms for educating patients with stage 4–5 CKD, and many educational tools to guide them about RRT.

G3: Patients' involvement in their care

Patients' involvement was rated as below average by the majority (50%) of respondents to the KH4L survey. According to the CEAPIR European Kidney Patients' Federation 2011 survey results only about 50% of CKD patients feel they were very involved in making decisions about their treatment.[10]

G4: Patients' perceptions of quality of care received

Perceived quality of care was rated as above average in the KH4L survey.

H. Opportunities for and obstacles to improvement

H1: Opportunities

- Universal healthcare system and well-developed infrastructures.
- The patient organization RENALOO is preparing a white paper that makes the case to government for prioritizing CKD care.

H2: Obstacles

- Lack of compensation to PCPs for early CKD care.
- Lack of an organized system for efficient CKD care at primary care level.
- Lack of coordination of care across regions.
- Lack of a medical data communication system.
- Limited funding with increasing competing priorities.
- Absence of multidisciplinary teams.

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Germany

COUNTRY OVERVIEW

Facts

Area	357,022 sq km
Total population	81,305,856 (2012)

CKD care plan

National plan/strategy for NCDs	Yes
National plan/strategy: CKD-specific	No
Guideline/service framework	No
CKD (non-RRT) registry	No
Planned actions	No

Disease burden

ESRD data	
Incidence, pmp	213 (2006)
Prevalence, pmp	1114 (2006)
CKD data	
Prevalence %	14.6
Costs data	
GDP (PPP)	$3.139 trillion (2011)
Total health expenditures (% of GDP)	11.6 (2009)
CKD costs data (as % total health expenditure)	Not available

Capacity and workforce

Hospital bed capacity	8.17 per 1000 population (2008)
Physician supply	3.5 per 1000 population (2010)
Nurses supply	11.3 per 1000 population
Nephrologist supply	28 per 1000 ESRD patients
Renal units, N	1,192 (2004), 861 private
Transplant centres, N	40 (2007)

PPP = purchasing power parity.

A. Health systems, policies and structures

A1: Governance structure

Germany is a federal republic consisting of 16 states (Länders). There are three levels of government: federal, state and municipalities.[1-3] These levels of government have virtually no role in the direct delivery of health care. However, states own the vast majority of university hospitals. Municipalities play a role in public health activities and own about 50% of hospital beds. Most regulation is delegated to the self-governing corporatist bodies (sickness funds and provider associations). Health insurance is mandatory and is provided by competing, not-for-profit, nongovernmental funds called the “sickness funds” via the statutory health insurance scheme (SHI) or voluntary private health insurance (PHI).[4]

A2: Healthcare system organization

A2.1: Coverage

Healthcare coverage is universal for all types of services including physician encounters, diagnostic imaging, laboratory tests and medications.

A2.2: Individual copayment

Patients pay fixed copayments of 10% for services (ambulatory office visits to PCPs and specialists) and medications. This is usually US$13 per outpatient medication or visit to care providers per quarter. Exemptions apply to certain categories of the population with low income (social assistance beneficiaries and unemployed) and patients with chronic diseases.

A2.3: Financing

All publicly funded health care is free at the point of delivery and is financed by general taxation and social insurance contributions. All individuals must purchase a basic package insurance plan, for which the costs are shared equally by individual and employer. The annual spending on healthcare averages 11.6% of GDP. Comprehensive and statutory health insurance (SHI) covers about 85%; the remainder is covered by private providers. All employed citizens and low-income groups such as pensioners have mandatory coverage free of charge. Individuals with income above the threshold can choose to remain in the public scheme (75%) or buy private insurance (25%).[5]

A2.4: Organization of care delivery

A2.4.1: Primary care

Primary care is delivered by PCPs, predominantly in private solo practices. PCPs are the patient’s first point of contact with healthcare. However, registration with a PCP is not required to access primary care, and PCPs have no formal gatekeeping function. To improve compliance with gatekeeping rules, sickness funds have been trying to encourage registration with PCPs and offer incentives (eg, exemption from medication copayment if a medication is prescribed by a PCP).

A2.4.2: Specialist care

Specialist care is accessed predominantly via acute hospitals and outpatient facilities. Residents have free access (without referral) to specialists unless enrolled in a gatekeeping managed care plan.

A3: Physician compensation

Most PCPs and specialists are private contractors paid using FFS, which is negotiated between sickness funds and physicians. Providers receive a weekly reimbursement for care of dialysis patients (personnel, facilities and medications). For CKD patients, providers receive only €20 per quarter (every 3 months) per patient irrespective of the number of encounters – this compensation, however, is currently under negotiation and may be increased.

A4: NCD policy and strategy

The NCD strategy is based on the WHO action plan for the prevention and control of NCDs for 2013–2020. The NCD strategy mainly covers CVD, cancer, diabetes, tobacco and alcohol.

A5: CKD-specific policies, guideline and/or service frameworks

A5.1: Specific policies

There is no specific CKD policy.

A5.2: Guidelines

There is no national or regional guideline for referral and management of CKD. Screening for CKD is integrated in the national diabetes guideline (Versorgungsleitlinie) but is not well implemented nationally. The international guideline on CKD (KDIGO) has been translated into German and approved by the German Guideline Institute but is not widely implemented.

A5.3: Structures/systems for monitoring uptake of guidelines

This is not applicable as a guideline does not exist.

A5.4: CKD as a health care priority

No level of government recognizes CKD as a healthcare priority.

A5.5: CKD care advocacy

There is no advocacy group to raise the profile of CKD with any level of government.

B. Organization and structure of CKD care

There are no organized structures for early CKD care. Oversight of CKD care is by individual hospitals and occasionally by regional authorities.

B1: Role of care providers

B1.1: PCPs and other specialists

Early CKD care is provided mainly through PCPs and other specialists (cardiologists, endocrinologists, etc) until stage 5 CKD.

B1.2: Nephrologists

Nephrologists care mostly for patients with stage 5 CKD and RRT.

B2: CKD care structures

B2.1: RRT care

There are well-established programs for dialysis and transplantation: care is delivered through a total of 35 university centres and 200 hospitals, each with a renal division and several ambulatory renal clinics (N = ~600). There are ~1200 dialysis units, of which ~900 are satellite units. Most dialysis centres in Germany are privately owned. Public hospital-based dialysis units treat only a small proportion of the dialysis population (10–12%). Transplantation services are provided mostly in university hospital facilities.[6-8]

B2.2: CKD care (non-RRT)

No organized clinical care pathway or program is in place for CKD patients.

B2.3: Regional variation in structures and practice patterns for CKD care

There is no important regional variation in terms of structures, workforce or patient characteristics. Respondents felt that because practice variation is difficult to measure and compare between regions it is uncertain whether differences exist.

C. Access and quality of care

C1: Availability and access to care

CKD care and delivery including all forms of RRT and all aspects of ambulatory and hospital care are wholly covered and accessible to all residents. In general, RRT patients receive medications and transportation to access specialized care, which are free aside from small copayments. Kidney transplantation is free and immunosuppressive medications are covered wholly through the health insurance coverage.

C2: Referral criteria

There are no defined national criteria for nephrology referrals.

C3: Quality management programs

No defined quality management program is available for early CKD patients; only patients on RRT are covered by quality control on dialysis adequacy and anemia management.

C4: CKD registry

There is no national registry for CKD patients, even those on RRT. A registry involving 59 participating nephrology clinics with 6,187 patients is being developed as part of the CKD Outcomes and Practice Patterns Study (CKDopps).

A national RRT registry closed in 2006 because the government discontinued funding in response to concerns over the quality of data being collated. Since that year, Germany has not participated in the ERA-EDTA registry.

D. Capacity, workforce and access to multidisciplinary teams

D1: Physician workforce

PCPs provide early CKD care, while nephrologists care for patients with advanced stage 5 CKD or patients on RRT. There are ~2500 nephrologists in the country (Table 2-13).

D2: Multidisciplinary teams and other professionals

There are no multidisciplinary teams of nurses, dieticians, psychologists, social workers, nephrologists, vascular access and transplant coordinators for early CKD care.

D3: Workforce limitations

There are reported deficiencies in the number of vascular access coordinators, nurse practitioners and counsellors. In fact, even in major centres only nurses, dieticians and doctors are generally available (Table 2-13).

Table 2-13

Workforce	*Availability*
Physicians per 1000 population	3.5
Nephrologists per 1000 ESRD patients	28
Nephrologists per 1000 CKD patients	0.30
Nurses per 1000 population	11.3
Presence of multidisciplinary teams for CKD	No
Disciplines with most pronounced lack of capacity for CKD care, in the opinion of survey respondents	Nurse practitioners, Renal social workers, Renal pharmacists

E. Barriers to optimal CKD care

E1: Top five barriers to optimal CKD care (in descending importance)

1. Economic factors
2. Organizational factors
3. Care providers' awareness of early detection and prevention of CKD
4. General population's awareness of early detection and prevention of CKD
5. Patients' awareness of early detection and prevention of CKD

Economic factors

The 2008 global financial crisis reduced funding generally to most public services including healthcare for CKD. Second, reimbursement policies are perceived to strongly influence the practice patterns of care providers – leading to more emphasis on RRT care than on prevention.

Organizational factors

- Heterogeneous and independent healthcare systems across the 16 Länders, making a nationally coordinated approach to CKD very challenging.
- A perceived lack of coordination in primary and secondary care, and often lack of good relationships among providers.
- Although progress has been made in educating primary care providers about the importance of CKD, case detection of CKD among people at risk continues to vary. The major barriers are thought to be lack of education and failure of PCPs, policymakers and the general populace to appreciate the significance of CKD.
- The increased workload for PCPs and specialists to incorporate new information (such as guidelines) into practice is viewed as a barrier to behaviour change.
- Politicians and policymakers view nephrology as a minor specialty, reducing the chance that policy will be drafted to address the needs of CKD patients.

CKD awareness

Overall, awareness of the importance of CKD is low among care providers, policymakers, patients and the general population.

F. CKD burden and risk factors

F1: Epidemiology of ESRD

Data are limited because Germany has no nationwide registry and does not participate in the regional ERA-EDTA registry. The latest RRT estimates available for Germany are for the year 2006. In 2006, the number of adult patients starting RRT in Germany was 17,548, equating to an incidence rate of 213 pmp, which was up from 186 pmp in 2003; the incidence rate pmp had been stable from 2000 to 2002. Diabetes and vascular diseases are the leading causes of ESRD. As of December 31, 2006, there were 91,718 adult patients receiving RRT. The prevalence of RRT was 1114.2 pmp, an increase of 5.4% from 2005. From 2005 to 2006 the prevalence of HD patients increased by 4.9%, the prevalence of PD increased by 6.3%, and the prevalence of patients with a functioning transplant increased by 6.4%. The number of patients receiving home HD increased by 7.8% since 2005, from 477 to 514. Transplantation continued as the second most common treatment modality (27.5%), followed by HD in 69% of RRT patients, whereas PD was used in only 3.5%. The prevalence of patients with a functioning transplant at the end of 2006 was 306.3 pmp.[9]

F2: Epidemiology of CKD

There are no nationally representative data on the prevalence of CKD. In a study of 9,806 high-risk patients (elderly and with diabetes and/or hypertension) the overall prevalence of CKD (Modification of Diet in Renal Disease [MDRD] formula for eGFR < 60 ml/min/1.73m2) was 17.4% (Table 2-14).[10] The MONICA (Monitoring Trends and Determinants in Cardiovascular Diseases) project was conducted in the city of Augsburg and two adjacent counties.[11] An independent random sample of 6,640 individuals was drawn from the Augsburg population aged 25–74 years in 1994. The age-standardized prevalence of microalbuminuria was 8.0% and 7.5% in males and females, respectively.

Table 2-14 CKD prevalence, Saarland, Southwest Germany, July 2000–December 2002

		*CKD (%)**
Male		640 (15.4)
Female		1066 (19.8)
Total		17.4
Age (years)	50–54	221 (13.2)
	55–59	257 (15.4)
	60–64	434 (16.2)
	65–69	425 (18.9)
	70–74	369 (24.0)
Diabetes		168 (15.7)
Hypertension		784 (19.0)
Hyperlipidemia		732 (18.4)

* CKD defined by estimated glomerular filtration rate (eGFR) <60 mL/min/1.73 m2.

F3: CKD cost data

ESRD care is funded exclusively through the public sector. About 1–2% of total health care expenditures are spent on ESRD care. There are no data on the costs of CKD care.

F4: CKD risk factors

A high burden of risk factors is associated with CKD at population level including increasing age, diabetes, hypertension, smoking, alcohol use and obesity (Table 2-15).

Table 2-15

Risk factors	*Prevalence (year)*
Age >65 years	20.5% (2009)
Diabetes	8.0% (2011)
Hypertension	47.2% (2011)
Smoking	21.9% (2009)
Alcohol use	9.7 L* (2009)
Obesity	14.7% (2009)

*Mean annual consumption per capita.

G. Perceptions of care (providers, patients and policymakers)

G1: Efficiency in CKD care delivery

This was rated as above average by 40% of respondents.

G2: Patient education

No tools for patient education are available nationally or locally except for patients treated with RRT. From the CEAPIR survey results (2011), ~80% of patients reported never having received education or rehabilitation to help them manage their CKD.[12]

G3: Patients' involvement in their care

This was rated as average in the KH4L survey. According to the CEAPIR European Kidney Patients' Federation 2011 Survey results, about 50% of CKD patients feel they were very involved in making decisions about their treatment.[12]

G4: Patients' perceptions of quality of care received

This was rated as above average in the KH4L survey. In the CEAPIR report about 79% of patients were very satisfied with care for their kidney disease, and another 28% were somewhat satisfied.[12]

H. Opportunities for and obstacles to improvement

H1: Opportunities

- Universal healthcare system and well-developed infrastructure.
- Large nephrology workforce.
- Absence of government interference with care organization and delivery.

H2: Obstacles

- Clinical care is driven by anticipated economic benefits to the providers.
- Low political awareness and involvement. CKD is not seen as a politically important topic compared to cancer, CVD and dementia.
- Complex nature of CKD, involving multiple comorbidities.
- Poor coordination in CKD management between primary and secondary care.
- Low awareness of CKD on the part of patients, policymakers and primary care practitioners.
- Different quality control measures across the government (hospital) and private sectors.
- Greater emphasis on cost rather than quality of care for CKD.
- Historical disunity among nephrologists, who had three societies with different objectives (scientific society of nephrology, clinical society of nephrology, association of private nephrologists) until about 5 years ago, when these societies merged. A more focused, representative and unified approach can now be expected.
- Lack of effective means for government to influence provider behaviour, since many are private and independent.
- High workload for PCPs.

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Greece

COUNTRY OVERVIEW

Facts

Area	131,957 sq km
Total population	10,767,827 (2012)

CKD Care plan

National plan/strategy for NCDs	Yes
National plan/strategy: CKD-specific	No
Guideline/service framework	No
CKD (non-RRT) registry	No
Planned actions	No

Disease burden

ESRD data	
Incidence/pmp	190.5 (2010)
Prevalence/pmp	1080 (2010)
CKD data	
Prevalence/pmp	—
Costs data	
GDP (PPP)	$298.1 billion (2011)
Total health expenditures (% of GDP)	7.4 (2009)
CKD costs data (as % total health expenditure)	—

Capacity and workforce

Hospital bed capacity	4.7 per 1000 population (2008)
Physicians supply	5.4 per 1000 population
Nurses supply	3.3 per 1000 population
Nephrologists supply population	46 per 1000 ESRD
Renal units, N	165
Transplant centres, N	5

PPP = purchasing power parity.

A. Health systems, policies and structures

A1: Governance structure

Greece is a parliamentary republic consisting of 13 administrative divisions (regions) and 1 autonomous monastic state (part of Greek state located on the peninsula of Athos).[1-4] The Greek healthcare system is a blend of public and private sectors. The public sector is a UK-style NHS system established in 1983, and coexists with a social health insurance model. The social insurance system comprises several schemes under the Ministry of Employment and Social Protection. Each insurance scheme is subject to different legislation, and there are substantial differences between and within schemes in contribution rates, coverage, benefits and eligibility for benefits, resulting in inequalities in access to and financing of services. The Ministry of Health and Social Solidarity is responsible for planning and regulation; some responsibilities are delegated to regional health authorities. The private sector includes profit-making hospitals, diagnostic centres and independent practices. A major focus of the private sector is to provide primary care on behalf of the insurance funds.[4]

A2: Healthcare system organization

A2.1: Coverage

Health is enshrined in the Greek constitution as a social right. The two main principles of entitlement are based on citizenship and occupational status. A system is in place for delivery of services and free access to care for the poor. Coverage for medications is universal, and all prescription-only medications are reimbursed by social insurance according to a recovery price.[4]

A2.2: Individual copayment

A copayment of 25% for prescription medications is mandatory; however, patients with chronic conditions such as CKD are exempted from copayment.

A2.3: Financing

Total health spending is 10.2% of GDP, which is above the OECD average of 9.5%. Out of the total expenditure, 59.4% is publicly funded.

A2.4: Organization of care delivery

A2.4.1: Primary care

Primary care services provide care through private solo practices. Registration with a primary care physician is not required.

A2.4.2: Specialist care

Specialist care services are offered though private solo practices. To access secondary care, referral is not compulsory.

A3: Physician compensation

Payment for PCP services is through salary and for outpatient specialist services is by FFS/salary.

A4: NCD policy and strategy

The NCD strategy is based on the WHO action plan for the prevention and control of NCDs for 2013–2020. There are specific policies/programs for CVD, cancer, diabetes, tobacco and alcohol. A department in the federal health ministry has specific responsibility for NCDs.

A5: CKD-specific policies, guidelines and/or service frameworks

A5.1: Specific policies

There is no specific CKD policy. However, the Hellenic Society of Nephrology has developed or translated protocols for management of common renal disorders, which are available to all Greek nephrologists (www.ene.gr/THERAPEFTIKA_PROROKOLLA).[5]

A5.2: Guidelines

There is no national or regional guideline available for CKD management. However, KDIGO and/or European Best Practice guidelines are often used in clinical practice and are widely accepted by the Greek nephrology community, since the Hellenic Society of Nephrology has endorsed, translated, and posted these guidelines on its website. The Society has also prepared protocols for the treatment of CKD mineral and bone disorder, anemia and dialysis adequacy, which essentially summarize KDIGO and NKF-K/DOQI guidelines on these topics.

A5.3: Structures/systems for monitoring uptake of guidelines

This is not applicable as national guidelines do not exist.

A5.4: CKD as a healthcare priority

Among survey respondents, 58% felt that CKD is not recognized as a healthcare priority by government. Respondents felt that this was primarily due to lack of political awareness and financial limitations (due to the recent economic crisis) rather than structural or legal deficiencies. The Hellenic Nephrology Society would be the most appropriate organization to lobby the federal MOH to include CKD in the NCD agenda.

A5.5: CKD care advocacy

There is no advocacy group to raise the profile of CKD at any level of government.

B. Organization and structure of CKD care

CKD care is overseen by individual hospitals. All ESRD patients are managed mostly in government hospitals, and some private institutions provide hemodialysis services.

B1: Role of care providers

B1.1: PCPs and other specialists

Early CKD care is provided mainly by PCPs and non-nephrologist specialists until advanced stages (stage 5 and RRT), when nephrologists take over. There is no primary care involvement after nephrology referral.

B1.2: Nephrologists

Nephrologists care mostly for stage 5 CKD and RRT.

B2: CKD care structures

B2.1: RRT care

CKD care is provided in government hospitals and private institutions. Out of 77 renal units, the majority (n = 61; 80%) are owned by the government (NHS). Of these, 35 are comprehensive state units with clinical nephrology clinics, HD and PD units. Only five units provide transplantation services. The remaining 42 units are HD units only. Two state units serve pediatric patients. There are 165 HD units (93 in public hospitals and 72 private). However, PD and transplantation are provided only by public (NHS) facilities.[5-9]

B2.2: CKD care (non-RRT)

CKD care is organized at the level of individual renal centres or hospitals. Pre-dialysis patients receive treatment in public hospital and outpatient clinics. No centrally coordinated system is in place.

B2.3: Regional variation in structures and practice patterns for CKD care

Respondents did not identify significant variation across different regions.

C. Access and quality of care

C1: Availability and access to care

Medications for CKD patients are publicly funded by government with no fees at the point of delivery (copayments are waived for patients with CKD stages 3–5). Patients receive financial support for transportation to access specialized care, including HD. ESRD facilities are universally available, and all NHS dialysis (HD/PD) is free of charge to all patients.

C2: Referral criteria

There are no national published standards for referral of patients with CKD to a nephrologist.

Recently the PRESTAR Study demonstrated that 65–70% of CKD patients in Greece do not visit a nephrologist until stage 3b/4.

C3: Quality management programs

Quality management programs are available for patients with ESRD on dialysis only through the RRT registry.

C4: CKD registry

There is no registry for early CKD patients.

D. Capacity, workforce and access to multidisciplinary teams

D1: Physician workforce

PCPs remain responsible for overall care before nephrology referral. There are 550 nephrologists in the 165 centres (93 public hospitals, 72 private HD units) (Table 2-16).

D2: Multidisciplinary teams and other professionals

There are no multidisciplinary teams of nurses, dieticians, psychologists, social workers, vascular access coordinators or transplant coordinators for early CKD care.

D3: Workforce limitations

There are perceived deficiencies in the number of renal nurses, dieticians and psychologists across the renal units (Table 2-16).

Table 2-16

Workforce	*Availability*
Physicians per 1000 population	5.4
Nephrologists per 1000 ESRD patients	46
Nephrologists per 1000 CKD patients	0.5
Nurses per 1000 population	3.3
Presence of multidisciplinary teams for CKD	No
Disciplines with most pronounced lack of capacity for CKD care, in the opinion of survey respondents	Dieticians, Vascular access coordinators, Counselors/Psychologists

E. Barriers to optimal CKD care

E1: Top five barriers to optimal CKD care (in descending importance)

1. Economic factors
2. Political factors
3. Organizational factors
4. Care providers' awareness of early detection and prevention of CKD
5. General population's and patients' awareness of early detection and prevention of CKD

Political factors

CKD is not recognised as a politically important topic in the same way as diabetes, cancer or vascular disease, perhaps because of the lack of an established advocacy effort targeting policymakers (Ministry of Health, Center for Disease Control and Prevention).

Economic factors

The 2008 global financial crisis reduced funding for most public services, including healthcare for CKD. In the current financial climate, it is uncertain if the government can invest in a national CKD program; employ doctors, nurses or dieticians; or fund campaigns about CKD.

Organizational factors

- Limited workforce capacity (PCPs and nurses) in the remote/rural areas.
- Most renal units are located in urban centres, making it difficult for some patients to access specialized renal care.
- The recent recession and resulting high levels of unemployment have negatively affected the general health of the populace.

CKD awareness

Overall, awareness of the course and importance of CKD is low among care providers, policymakers, patients and the general population. Respondents felt that knowledge among physicians was also suboptimal (eg, eGFR is not widely used; most physicians including nephrologists rely on serum creatinine to estimate kidney function; referral to nephrologists often occurs only in the later stages of CKD).

F. CKD burden and risk factors

F1: Epidemiology of ESRD

In 2010, the number of adult patients starting RRT in Greece was 2154, equating to an incidence rate of 190.5 pmp. The incidence rate has been stable from 2004 to 2010. Diabetes and vascular diseases are the leading causes of ESRD. As of December 31, 2010, there were 12212 adult patients receiving RRT. The prevalence of RRT was 1080 pmp, an increase of 1.4% from 2009. From 2009 to 2010, the prevalence of HD patients increased by 2.3%, the prevalence of PD fell by 1.0%, and the prevalence of patients with a functioning transplant decreased by 1.1%. Transplantation continued as the second most common treatment modality (19.7% of RRT patients), while HD was used in 74.1% and PD 6.2%. The prevalence of patients with a functioning transplant at the end of 2010 was 213 pmp.[6, 7]

F2: Epidemiology of CKD

There are no nationally representative data, and estimates of prevalence are unreliable because of lack of infrastructure. Respondents to the KH4L survey estimated CKD prevalence at 5–10%, but this was not based on high-quality data.

F3: CKD cost data

There are no data on the costs of CKD care. The costs of annual HD care were estimated at 0.3% of the national healthcare budget.

F4: CKD risk factors

A high burden of risk factors is associated with CKD at the population level including increasing age, diabetes, hypertension, smoking, alcohol use and obesity (Table 2-17).

Table 2-17

Risk factors	*Prevalence (year)*
Age >65 years	18.8% (2009)
Diabetes	7.0% (2011)
Hypertension	42.6% (2011)
Smoking	39.7% (2009)
Alcohol use	9.2 L*(2009)
Obesity	18.1% (2009)

*Mean annual consumption per capita.

G. Perceptions of care (providers, patients and policymakers)

G1: Efficiency in CKD care delivery

In the KH4L survey, 50% of respondents rated the efficiency of the healthcare system for delivering CKD care as average, and 34% (n = 17) rated it above average.

G2: Patient education

The majority of the respondents (76%) felt there were no nationally available tools/resources to educate patients about how to manage their CKD. Educational materials are available only for patients on RRT.

G3: Patients' involvement in their care

Patients' involvement was rated as average by most respondents. ESRD patients are perceived to be more involved in their care. They usually participate in decision-making about the time of RRT initiation and type of RRT.

G4: Patients' perceptions of quality of care received

In the KH4L survey, 46% of respondents rated the quality of care provided to non-RRT CKD patients as average, and 38% rated it as above average.

H. Opportunities for and obstacles to improvement

H1: Opportunities

- Universal healthcare system and well-developed infrastructure.
- It has been proposed to the federal MOH by the Helenic Nephrology Society (Scientific Committee) that both public and private laboratories should begin mandatory reporting of eGFR (CKD-EPI) when serum creatinine is ordered.
- A very well-established CVD prevention policy in the country, which the nephrology community can use as a template. This is a national action plan for CVD (public campaigns, healthy eating, health checks, etc) developed by the Ministry of Health.

H2: Obstacles

- Poorly organized primary healthcare structures.
- Limited knowledge and low awareness about CKD among PCP and specialists.
- Late referral of patients with CKD to nephrologists.
- Lack of multidisciplinary teams (renal nurses, dieticians, surgeons and psychologists specializing in CKD patients).
- Poor collaboration between specialists and PCP.
- Current financial situation.

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Ireland

COUNTRY OVERVIEW

Facts

Area	70,273 sq km
Total population	4,585,400 (2012)

CKD care plan

National plan/strategy for NCDs	Yes
National plan/strategy: CKD-specific	Yes
Guideline/service framework	Yes
CKD (non-RRT) registry	No
Planned actions	Yes

Disease burden

ESRD data	
Incidence, pmp	92 (2012)
Prevalence, pmp	845 (2012)
CKD data	
Prevalence	21.3% (in those aged 45 or older) (2012)
Costs data	
GDP (PPP)	$200 billion (2012)
Total health expenditures (% of GDP)	9.2 (2010)
CKD costs data (as % total health expenditure)	—

Capacity and workforce

Hospital bed capacity	2.3 per 1000 population
Physicians supply	3.2 per 1000 population
Nurses supply	13.1 per 1000 population
Nephrologists supply	5.7 per 1000 ESRD population
Renal units, N	13
Transplant centres, N	1

PPP = purchasing power parity.

A. Health systems, policies and structures

A1: Governance structure

Ireland is a parliamentary republic consisting of 26 counties and 5 cities. The Republic of Ireland is situated in northwestern Europe. One-quarter of the population lives in the capital of Dublin. Overall responsibility for the healthcare system lies with the central government, exercised through the Department of Health and Children. Extensive healthcare reforms in 2005 led to the establishment of a single body (Health Service Executive; HSE) that is responsible for providing healthcare and social services to all of Ireland.[1-4]

A2: Healthcare system organization

A2.1: Coverage

All citizens have access to hospital-based care independent of income if they choose to avail themselves of it. Access to primary care services is based on income and is means-tested. Some citizens access almost their entire healthcare privately. Notably, all RRT services are universally accessible irrespective of income.

A2.2: Individual copayment

The patients within the General Medical Scheme pay only a prescribing charge; others also pay both for the cost of the medications and a prescription charge, capped at €144/month.

A2.3: Financing

Total health spending is 9.2% of GDP (below the 9.5% OECD average). There is a mix of public, private not-for-profit and private profit-making providers. Public funding constituted 69.5% of total expenditure (down from 75.5% in 2007); the decrease was a result of the economic crisis and led to higher out-of-pocket payments, especially for medications. Less than 50% of the population has voluntary private health insurance, which is administered through a mix of insurance providers. These insurance organizations are regulated by the government via the Health Insurance Authority (HIA).[3, 5]

A2.4: Organization of care delivery

A2.4.1: Primary care

Primary care is delivered by PCPs, predominantly in private solo practices and increasingly in group practices. PCPs are the first point of contact with healthcare. However, to access primary care, registration with a PCP is not required.

A2.4.2: Specialist care

Specialist care is accessed predominantly via public hospitals. To access secondary care, referral from PCPs is encouraged.

A3: Physician compensation

Most PCPs are paid using FFS, and outpatient specialist services are paid predominantly by salary, with some specialist services accessed by private fee.

A4: NCD policy and strategy

The NCD strategy is based in part on the WHO action plan for the prevention and control of NCDs for 2013–2020. There are specific policies/programs for CVD, cancer, diabetes, tobacco and alcohol. A department in the government health ministry has specific responsibility for NCDs.

A5: CKD-specific policies, guidelines and/or service frameworks

A5.1: Specific policies

A National Renal Care Program is administered by the establishment of the National Renal Office (NRO) under the leadership of Dr Liam Plant. The NRO is responsible for the strategic development and integration of kidney disease care across Ireland. The initial focus of the NRO is ESRD care, but in the next few years increased emphasis will be devoted to early CKD care.

A5.2: Guidelines

There is a national guideline for referral and management of CKD. There is no targeted active or passive surveillance system to identify early CKD in Ireland; efforts are underway to develop a National Kidney Disease Surveillance System to capture AKI/CKD patients.

A5.3: Structures/systems for monitoring uptake of guidelines

There are no structures or systems for monitoring CKD guideline uptake.

A5.4: CKD as a healthcare priority

CKD is now part of the existing NCD program in the country, and the establishment of the NRO is evidence that the government views CKD as an important health condition.

A5.5: CKD care advocacy

There is no advocacy group to raise the profile of CKD at any level of government. In the KH4L survey, 88% (n = 7) of respondents did not identify any advocacy group working to raise the profile of CKD and its prevention with government; the Irish Kidney Association is an advocacy group that has traditionally focused on the ESKD population.

B. Organization and structure of CKD care

CKD care is overseen by the NRO within the Health Service Executive. There are 11 adult renal centres and 2 children units supervising a network of 21 hemodialysis facilities.

B1: Role of care providers

B1.1: PCPs and other specialists

For many patients early CKD care is provided mainly by PCPs and other specialists (cardiologists, endocrinologists, etc) until they reach stages 4–5 CKD and are referred on to Renal Services. Earlier referral is common (stage 3 and earlier) especially for younger patients and those with specific kidney disorders (multisystem disorders, hereditary kidney disease, etc).

B1.2: Nephrologists

Nephrologists focus predominantly on providing care for patients with ESKD and stages 4–5 CKD but also manage patients with a variety of kidney diseases caused by conditions such as glomerulonephritides, autosomal dominant polycystic kidney disease, hereditary disorders and multi-system disorders.

B2: CKD care structures

B2.1: RRT care

There are 11 adult renal centres (supervising 21 hemodialysis facilities) and 2 pediatric renal centres that provide care to patients. A process of reconfiguration is currently underway to establish 6 hospital groups (or trusts). There is a single centre for adult kidney transplantation in Ireland.

B2.2: CKD care (non-RRT)

No organized clinical care pathway or program is in place for CKD patients.

B2.3: Regional variation in structures and practice patterns for CKD care

There is regional variation in capacity, configuration and governance across Ireland. Renal practices in the country are organized into four clinical regions, between which there are certain variations in practices, particularly in:

- Workforce capacity (staffing ratios for nephrologists and nurses).

- Infrastructure (eg, some units have dedicated inpatient facilities for kidney patients, while others do not).
- Service provision (some offer facilities for home therapies, while others do not).
- Clinical information systems (some units have no electronic care facilities).

C. Access and quality of care

C1: Availability and access to care

CKD care and delivery including all forms of RRT are wholly covered and accessible to all residents; dialysis units are available in all regions. Medications are subject to a copayment as described in a previous section (A2.2), which is waived for people with certain chronic diseases. There is a current effort to have CKD recognized (like diabetes) as a qualifying condition for this waiver. Kidney transplantation is free, and medications are covered.

C2: Referral criteria

There are no national published standards for referral of patients with CKD to a nephrologist. A working group has been established to develop this in 2014.

C3: Quality management programs

Quality management programmes are being developed by the NRO with an initial target to focus on ESRD care utilising the Kidney Disease Clinical Patient Management System (KDCPMS).

C4: CKD registry

There is no registry for early CKD patients. The National Renal Strategy Review placed a high priority on capturing clinical information on ESKD and CKD patients treated at kidney clinics across the country. As a result, a fully integrated kidney-specific information system is currently being rolled out across all centres to capture patients with advanced CKD and those attending CKD clinics. This system will contribute data on CKD to a planned national renal registry. Substantial progress has been made, and the registry is expected to be operational in 2015.

D. Capacity, workforce and access to multidisciplinary teams

D1: Physician workforce

There are 43 individual nephrologists in Ireland, but they have additional responsibilities besides clinical care and may be required to provide non-nephrology clinical services, especially in smaller units. PCPs and other referring physicians "share care responsibilities" after referral to nephrologists, whose role becomes more prominent as CKD progresses or ESRD develops (Table 2-18). The number of whole time equivalent specific to nephrology was estimated by the NRO at 21.9.

D2: Multidisciplinary teams and other professionals

There are multidisciplinary teams of nurses, dieticians, psychologists, social workers, vascular access and transplant coordinators, who work with nephrologists to provide early CKD care.

D3: Workforce limitations

There are perceived to be shortages of nephrologists, dieticians, and access coordinators, especially in certain regions (Table 2-18).

Table 2-18

Workforce	*Availability*
Physicians per 1000 population	3.2
Nephrologists per 1000 ESRD patients	5.7
Nephrologists per 1000 CKD patients	0.06
Nurses per 1000 population	13.1
Presence of multidisciplinary teams for CKD	Yes
Disciplines with most pronounced lack of capacity for CKD care, in the opinion of survey respondents	Nephrologists, Dieticians, Vascular access coordinators

E. Barriers to optimal CKD care

E1: Top five barriers to optimal CKD care (in descending importance)

1. Economic factors
2. Political factors
3. Organizational factors
4. Providers' and policymakers' awareness of early detection and prevention of CKD
5. General population's and patients' awareness of early detection and prevention of CKD

Political factors

Changes in government and political direction have led to multiple changes in health policy that directly and indirectly affect the care of CKD patients.

Economic factors

- Resource limitations and reduced funding from government across the board.
- The adequacy of funding is perceived to vary between units.

Organizational factors

- Variations in human resources (staffing ratios for nephrologists and nursing staff) between units, with some units perceived to be substantially understaffed.
- Infrastructure supports (eg, information technology support) are perceived to be inadequate for certain units.
- Certain centres do not offer all clinical services (eg, home dialysis).
- Absence of a coordinated system for providing CKD care (such as the UK QoF) leads to variable clinical practices across regions (eg, different serum creatinine assays are used in different regions, as there is no national standard). The NRO should help with this but until recently has been focused on ESRD care.

CKD awareness

Overall, awareness of the importance of CKD is low among care providers, policymakers, patients and the general population.

F. CKD burden and risk factors

F1: Epidemiology of ESRD

In 2012, the number of adult patients starting RRT in Ireland was 423, equating to an incidence rate of 92 pmp. The incidence rate has varied between 86 and 101 pmp since 2007. Diabetes and glomerulonephritis are the leading causes of ESRD.[6]

On December 31, 2012, there were 3,876 adults receiving RRT. Prevalence was 845 pmp, an increase of 24% from 2007 (or 4.8% p.a.). From 2007 to 2012 the prevalence of dialysis increased by 18% (or 3.6% p.a.) while the prevalence of having a functioning transplant increased by 29% (or 5.8% p.a.). The number of patients using home hemodialysis increased by 154% (from 11 to 28) between 2010 and 2012. Transplant remains the commonest modality of RRT at 54% of patients, while 40% use centre HD and 6% use home therapies (PD/HHD). The prevalence of a functioning transplant at the end of 2012 was 453 pmp.

F2: Epidemiology of CKD

CKD prevalence was estimated using a population-based cross-sectional study of 1,098 adults aged 45 years and older from the 2007 Survey of Lifestyle, Attitudes and Nutrition (SLÁN). The overall prevalence of CKD in the population was 21.3% of which 11.6% had eGFR<60mls/min. This was the first population-based study of the prevalence of CKD in Ireland, using a randomly selected, nationally representative sample of middle-aged and older adults) (Table 2-19).[7]

Table 2-19: Prevalence of CKD in the general population in Ireland

CKD	*Prevalence* (%)*
Stage 1	3.8
Stage 2	6.3
Stage 3A	9.2
Stage 3B	2.3
Stage 4–5	0.36
Total percent	21.9
Weighted population estimate	21.3

*Based on the CKD-EPI equation.

F3: CKD cost data

There are no data on the costs of early CKD care. About €100 million is spent annually on ESRD care and provision of RRT. The costs of additional elements of this programme including transplantation add a further €25 million to this.

F4: CKD risk factors

A high burden of risk factors is associated with CKD at the population level including increasing age, diabetes, hypertension, smoking, alcohol use and obesity (Table 2-20).

Table 2-20

Risk factors	*Prevalence (year)*
Age >65 years	11.1% (2009)
Diabetes	6.1% (2011)
Hypertension	42.4% (2011)
Smoking	27.4% (2009)
Alcohol use	11.3 L* (2009)
Obesity	23.0% (2009)

*Mean annual consumption per capita.

G. Perceptions of care (providers, patients and policymakers)

G1: Efficiency in CKD care delivery

Efficiency was rated as average by most of the respondents. All regions have renal clinics, and care is universal without any financial barriers to access services.

G2: Patient education

According to the CEAPIR European Kidney Patients' Federation 2011 survey, about 75% of patients say they have never received education to help them manage their CKD.[8] Educational booklets and videos are available in English and in Irish – and although these have traditionally focused on ESKD, new CKD patient guides have recently been produced.

G3: Patients' involvement in their care

According to the CEAPIR European Kidney Patients' Federation 2011 survey, about 53% of CKD patients feel that they were very involved in making the decision about their treatment. About 8% felt they were not involved in the process.[8]

According to provider respondents, those with advanced kidney disease will probably be involved with their care, but the extent of involvement may depend on the unit. Patients with earlier stages of CKD were perceived to be less well engaged, perhaps because they are receiving their care in primary care. The patients who were perceived to be least engaged were patients who had mild CKD and were managed in diabetes mellitus, cardiovascular or lipid clinics.

G4: Patients' perceptions of quality of care received

According to the CEAPIR European Kidney Patients' Federation 2011 survey results, about 69% of patients are very satisfied with care for their CKD, and another 28% are somewhat satisfied.[8]

H. Opportunities for and obstacles to improvement

H1: Opportunities

- Universal healthcare system and well-developed infrastructure.
- NSF/policy development for CKD under development.
- Small community of nephrologists, making collaborations easier.

H2: Obstacles

- Lack of a common national information technology platform to facilitate surveillance.
- Poor coordination and communication between nephrologists and PCPs.
- Lack of resources to fund adequate numbers of nephrologists, nurses and other allied health professionals.
- Continuous changes in political direction leading to haphazard policymaking and implementation.
- Poor implementation of CKD-relevant guidelines due to lack of resources.
- Relatively lower priority placed on CKD as compared to CVD, diabetes and cancer.

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Israel

COUNTRY OVERVIEW

Facts

Area	20,770 sq km
Total population	8,120,300 (2013)

CKD care plan

National plan/strategy for NCDs	Yes
National plan/strategy: CKD specific	No
Guideline/Service framework	No
CKD (non-RRT) Registry	No
Planned actions	No

Disease burden

ESRD data	
Incidence, pmp	186.3 (2010)
Prevalence, pmp	1109 (2010)
CKD data	
Prevalence %	10%
Costs data	
GDP (PPP)	$238.2 billion (2011)
Total health expenditures (% of GDP)	7.4 (2012)
CKD costs data (as % total health expenditure)	3.4%

Capacity and workforce

Hospital bed capacity	5.8 per 1000 population (2008)
Physician supply	3.6 per 1000 population (2009)
Nurses supply	5.8 per 1000 population (2011)
Nephrologist supply	27 per 1000 ESRD population
Renal units, N	73 (hubs)
Transplant centres, N	6

PPP = purchasing power parity.

A. Health systems, policies and structures

A1: Governance structure

Israel is a parliamentary democracy, and consists of six administrative districts (divisions).[1-6] The Ministry of Health has overall responsibility for population health and effective functioning of the health care system. In addition to its regulatory, planning and policy-making roles, the Ministry of Health also owns and operates about half of the nation's acute care hospitals beds. In 1995, the National Health Insurance Law made it compulsory for all citizens to belong to one of the four health maintenance organizations (HMOs), namely, Clalit, Maccabi, Meuhedet and Leumit. The largest health plan (Clalit) has a market share of 53% and provides community-based services, primarily via salaried physicians working in clinics that it owns and operates. The next largest plan (Maccabi) has a market share of 24% and provides care primarily through a network of mostly independent (contracted) physicians (IPs).[4]

A2: Healthcare system organization

A2.1: Coverage

Healthcare coverage is universal for all types of services including physician and diagnostic (imaging and laboratory) services and medications. However, participation in a medical insurance plan is compulsory, and to be eligible, a resident must pay health insurance tax.

A2.2: Individual copayment

There are fixed copayments for non-essential services and outpatients prescriptions, which may also be funded by cost-sharing with employers or private health insurance programs.

A2.3: Financing

The healthcare system is financed primarily through taxation and statutory national health insurance (NHI) fees administered by Bituah Leumi (National Insurance Institute; NII). The Government distributes these funds among the health plans according to a capitation formula that accounts for the number of members within each plan and their age mix.[4] Recently the member's distance from the centre has been factored into the capitation formula. The HMOs also receive direct financial subventions from the government.

The privately financed health care system is relatively small compared to the public systems via the HMOs. Private health care focuses mostly on medications, dentistry and private hospital care. Approximately 28% of total health services are provided by private providers, while 40% of the national expenditure on health is "out of pocket" money.

A2.4: Organization of care delivery

A2.4.1: Primary care

Primary care is delivered by PCPs, predominantly in the HMOs' public clinics. PCPs are the first point of contact with health care. To access primary care, registration with a PCP is required. The main coordinating bodies are the Ministry of Health and the four HMOs. Each HMO runs its own CKD care program independently; all take slightly different approaches.

A2.4.2: Specialist care

Specialist care is accessed predominantly via ambulatory clinics in public hospitals or provided through the HMO-owned clinics. General surgeons, gynecologists, dermatologists, ENT specialists, orthopaedic surgeons and general ophthalmologists are considered by most HMOs to be PCPs. To access all other specialists, referrals are required; PCPs serve as the gatekeepers.

A3: Physician compensation

Physicians (PCPs and specialists) are predominantly salaried employees of public hospitals and the large HMO, Clalit. Additionally there are capitation payments for PCPs and fee-for-service for specialists, which vary across the HMOs.

A4: NCD policy and strategy

The Israel NCD strategy is based in part on the WHO action plan for the prevention and control of NCDs for 2013–2020. There are specific national policies/programs for CVD and diabetes.

A5: CKD specific policies, guidelines and/or service frameworks

A5.1: Specific policies

There are no specific policies, strategies and/or service frameworks.

A5.2: Guidelines

There is no existing national or regional guideline for CKD management. However, a national guideline is being developed by the Israeli Society of Nephrology (in conjunction with the national professional organization for PCPs) and will include:

- Identification of patients with CKD.
- Assessment of kidney function and proteinuria.
- Management and referral of CKD.
- Criteria for RRT initiation.

A5.3: Structures/systems for monitoring uptake of guidelines

No structures or systems are in place to monitor adherence to the forthcoming guideline.

A5.4: CKD as a healthcare priority

No level of government has recognized CKD as a healthcare priority.

A5.5: CKD care advocacy

There are advocacy groups to raise the profile of CKD with government, media or the general public. They are engaged mainly with guarding RRT patients' social, pecuniary and regulatory rights rather than with the clinical or organizational aspects of CKD and ESRD care.

B. Organization and structure of CKD care

CKD care is overseen by individual HMOs.

B1: Role of care providers

B1.1: PCPs and other specialists

Early CKD care is provided mainly by PCPs and other specialists (cardiologists, endocrinologists, etc) until stage 4 or 5 CKD.

B1.2: Nephrologists

Nephrologists care mostly for patients with stage 3b–5 CKD and RRT.

B2: CKD care structures

B2.1: RRT care

Nephrology services are chiefly delivered through the centralized centres and HMOs. There are 73 “hub” renal units in Israel, which have on-site consultant nephrologists and inpatient beds for renal patients, managing about 5,795 dialysis patients.

B2.2: CKD care (non-RRT)

No organized clinical care pathway or program is in place for CKD patients. CKD care is delivered mainly at the primary care level (PCPs) and HMOs until advanced stages, when a referral is made to nephrology services.

B2.3: Regional variation in structures and practice patterns for CKD care

There is no major perceived practice variation across the administrative regions (districts). Between-HMO differences are the source of most practice variation within Israel.

C. Access and quality of care

C1: Availability and access to care

CKD care and delivery including all forms of RRT are wholly covered by the publicly funded healthcare system and accessible to all residents. These include all aspects of ambulatory and hospital care, inclusive of physician and diagnostic (laboratory and imaging) services.

A small fixed copayment, which is not specific to CKD patients (see Section A2.2), covers non-essential services only. In general, RRT patients receive free medications and transportation to access specialized care. There are no waiting lists for dialysis, placement of permanent vascular access for dialysis, or other treatment procedures related to ESRD treatment. Kidney transplantation is free, and immunosuppressive medications are covered wholly through the publicly funded healthcare system.

C2: Referral criteria

There are no national published standards for referral of patients with CKD to a nephrologist. Such standards are expected to be included in the forthcoming guidelines.

C3: Quality management programs

Quality management programs are available for patients with ESRD on RRT, and only through the RRT registry.

C4: CKD registry

There is no registry for early CKD patients. There is no plan to develop a national CKD registry. The Israeli Society of Nephrology could lead an effort to establish such a registry but would require cooperation and support from the Ministry of Health and the four HMOs. The main limiting factor is a perceived reluctance of the various HMOs to share data with each other and with other organizations.

D. Capacity, workforce and access to multidisciplinary teams

D1: Physician workforce

There are ~150 certified nephrologists, who mainly provide care for advanced CKD (Stage 3b–5) (Table 2-21) across the renal centres in each of the 24 general hospitals and 6 pediatric centres.

D2: Multidisciplinary teams and other professionals

There are no multidisciplinary teams of nurses, dieticians, psychologists and social workers, and no renal pharmacists.

D3: Workforce limitations

There are perceived deficiencies in the number of nephrologists, vascular access coordinators and dialysis nurses (Table 2-21).

Table 2-21

Workforce	*Availability*
Physicians per 1000 population	3.6
Nephrologists per 1000 ESRD patients	27
Nephrologists per 1000 CKD patients	0.20
Nurses per 1000 population	4.8
Presence of multidisciplinary teams for CKD	No
Disciplines with most pronounced lack of capacity for CKD care, in the opinion of survey respondents	Nephrologists, Vascular access coordinators, Dialysis nurses

E. Barriers to optimal CKD care

E1: Top five barriers to optimal CKD care (in descending importance)

1. Organizational factors
2. PCPs' awareness of early detection and prevention of CKD
3. Policymakers' awareness of early detection and prevention of CKD
4. Economic factors
5. General population's awareness of early detection and prevention of CKD

Economic factors

The current financial crisis has led to reduced funding for most public services, including healthcare generally and CKD care specifically.

Organizational factors

- There is perceived lack of coordination between primary and secondary care.
- National policy on CKD is lacking.
- Although progress has been made in educating primary care providers about the importance of CKD, case detection of CKD among people at risk continues to vary. The major barriers are thought to be lack of education and failure of PCPs, policymakers and the general populace to appreciate the significance of CKD.

CKD awareness

Overall, awareness of the importance of CKD is low among care providers, policymakers, patients and the general population.

F. CKD burden and risk factors

F1: Epidemiology of ESRD

In 2010, the number of adult patients starting RRT in Israel was 1,423, equating to an incidence rate of 186.3 pmp. Having increased from 165 pmp in 2000, the incidence rate remained stable from 2003 to 2010. Diabetes and vascular diseases are the leading causes of ESRD. The prevalence of RRT was 1109 pmp in 2010. From 2009 to 2010 the prevalence of HD patients increased by 3.2% and the prevalence of PD fell by 7.6%. No patients received home HD.[7, 8]

F2: Epidemiology of CKD

There are no nationally representative data on the prevalence of CKD, and a recent study estimated this at 10.3%.

F3: CKD cost data

ESRD care is funded exclusively through the public sector. About 3.4% of total health care expenditures are spent on ESRD care.

F4: CKD risk factors

A high burden of risk factors is associated with CKD at the population level including increasing age, diabetes, hypertension, smoking, alcohol use and obesity (Table2-22).

Table 2-22

Risk factors	*Prevalence (year)*
Age >65 years	9.8% (2009)
Diabetes	8.5% (2011)
Hypertension	35.8% (2011)
Smoking	20.3% (2009)
Alcohol use	2.5 L* (2009)
Obesity	13.8% (2009)

*Mean annual consumption per capita.

G. Perceptions of care (providers, patients and policymakers)

G1: Efficiency in CKD care delivery

Efficiency was rated as above average by 75% of the respondents and as average by 25%.

Strengths of the existing system are felt to be a universal health care system and excellent chronic disease programs involving CVD and diabetes.

G2: Patient education

Half of respondents felt there were no nationally available tools/resources to educate patients about how to manage CKD.

G3: Patients' involvement in their care

Patients' involvement was rated as average by respondents to the KH4L survey, for all severities of CKD.

G4: Patients' perceptions of quality of care received

Perceived quality of care was rated as above average by respondents to the KH4L survey, for all severities of CKD.

H. Opportunities for and obstacles to improvement

H1: Opportunities

- Universal healthcare system and well-developed infrastructure.
- Cohesive renal community that could work in partnerships with other groups like the diabetes association to facilitate quality care.
- Presence of well-structured provider organizations (hospitals and HMOs).
- Good communication between nephrologists.

H2: Obstacles

- Limited funding and economic factors with multiple competing priorities.
- Complex nature of CKD, involving multiple comorbidities.
- PCPs have limited time to spend with patients.
- Poor coordination between primary and secondary care.
- Low awareness of CKD on the part of patients, policymakers and PCPs.
- Reliance on PCPs for CKD care due to inadequate number of nephrologists.
- Nephrology is not an attractive specialty for trainees because of long hours of work and low pay.

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Italy

COUNTRY OVERVIEW

Facts

Area	301,340 sq km
Total population	61,261,254 (2012)

CKD care plan

National plan/strategy for NCDs	Yes
National plan/strategy: CKD-specific	Yes
Guideline/service framework	No
CKD (non-RRT) registry	No
Planned actions	No

Disease burden

ESRD data	
Incidence, pmp	160.5 (2010)
Prevalence, pmp	905.9 (2010)
CKD data	
Prevalence, %	13.2
Costs data	
GDP (PPP)	$1.871 trillion (2011)
Total health expenditures (% of GDP)	9.3
CKD costs data (as % total health expenditure)	—

Capacity and workforce

Hospital bed capacity	3.7 per 1000 population (2008)
Physicians supply	3.7 per 1000 population (2010)
Nurses supply	6.4 per 1000 population (2009)
Nephrologists supply	94 per 1000 ESRD patients
Renal units, N	681 (2008)
Transplant units, N	41 (2012)

PPP = purchasing power parity.

A. Health systems, policies and structures

A1: Governance structure

Italy is a republic consisting of 15 administrative divisions (regions) and 5 autonomous regions. The public health care system (Servizio Sanitario Nazionale, SSN) covers all citizens and legal foreign residents of Italy.[1-4] The healthcare system was modelled after the UK NHS. It provides universal health care through general taxation. The federal government provides oversight and legislation; the 20 regions are responsible for implementation, planning, financing and monitoring of health care. Each region has a local health unit (LHU) that is responsible for population health. In 2001, the central government defined the minimum national benefits package that must be provided to all residents – known as "essential levels of care" (livelli essenziali di assistenza; LEAs). The elements of LEAs are based on criteria (periodically reviewed) related to medical necessity, effectiveness and efficiency and include medications, inpatient care and preventive medicine. Regions can also provide non-LEA services, but they cannot use national resources to fund these non-essential services.

A2: Healthcare system organization

A2.1: Coverage

Health care is largely free at the point of delivery. There is 100% coverage for ambulatory PCP consultations and medications, and 76–99% coverage for ambulatory specialist contacts, laboratory tests and diagnostic imaging.

A2.2: Individual copayment

All government-approved medications are fully covered and free for nearly all people. Only patients with high income or no chronic disease might pay a fixed amount for medications. For initial nephrology consultations, patients must pay a fixed amount (~€30) based on their income. This is not specific to nephrology and applies to all other specialists' visits/consultations.

A2.3: Financing

Total health spending in terms is 9.3% of GDP (slightly below the 9.5% OECD average).

There is a mix of public, private not-for-profit and private profit-making players. In total, 79.6% of total expenditure comes from public funding by government.

A2.4: Organization of care delivery

A2.4.1: Primary care

Primary care services are provided by PCPs. To receive care from a primary care physician, registration is required.

A2.4.2: Specialist care

Specialist care services are provided in both public and accreditated private hospitals. To access specialist care, referral is compulsory.

A3: Physician compensation

Payment for PCPs services is predominantly by capitation, and payment for outpatient specialist services is by salary.

A4: NCD policy and strategy

The NCD strategy is based in part on the WHO action plan for the prevention and control of NCDs for 2013–2020. There are specific policies/programs for CVD, cancer, diabetes, tobacco and alcohol. A department in the federal health ministry has specific responsibility for NCDs.

A5: CKD specific-policies, guideline and/or service frameworks

A5.1: Specific policies

A CKD public health policy is being developed by the Ministry of Health, although the exact details are not yet clear.

A5.2: Guidelines

Under the umbrella of the National Institute of Health (Istituto Superiore di Sanità, ISS), a national guideline has been issued (January 2012) jointly by the Italian Society of Nephrology and several other societies (laboratory medicine, diabetology, hypertension, cardiology, endocrinology). This guideline is based on the UK NICE Guideline. However, uptake of the guideline has been low, and several regions have local CKD guidelines, which also are implemented unevenly.

A5.3: Structures/systems for monitoring uptake of guidelines

No structures or systems are in place to monitor adherence to the national guideline.

No investment has been made by most regional authorities to educate PCPs about the relevance of the national or regional guidelines to the care of CKD patients.

A5.4: CKD as a healthcare priority

The government in Italy does not recognize CKD as a healthcare priority, perhaps because of inadequate lobbying by key stakeholders (nephrologists and patients). Nephrologists and nephrology societies have made attempts to join forces with other professional societies (such as cardiology, hypertension, diabetes) to increase the effectiveness of advocacy efforts, but these efforts have not produced tangible results to date.

A5.5: CKD care advocacy

There is no advocacy group to raise the profile of CKD at any level of government. In the KH4L survey, 85% (n = 105) of respondents did not identify any advocacy group that was working to raise the profile of CKD with the general public.

B. Organization and structure of CKD care

CKD care is overseen by individual hospitals.

B1: Role of care providers

B1.1: PCPs and other specialists

Early CKD care is provided mainly by PCPs and other specialists (cardiologists, endocrinologists, etc) until stage 5 CKD. There is no incentive for PCPs to increase referral of CKD patients to nephrologists; there is no primary care involvement after nephrology referral.

B1.2: Nephrologists

Nephrologists care for patients with stages 4–5 CKD and RRT. ESRD patients are managed mostly in public hospitals. Private institutions provide hemodialysis services only.

B2: CKD care structures

B2.1: RRT care

The public system pays for ESRD and RRT care in Italy. Private HD treatment covers 25% of the demand for RRT in the country and receives reimbursements from the public health care system. As of 2004, there were 363 renal clinics/divisions in Italy. There were 758 dialysis units (hubs) which comprised 363 public and 295 private facilities. There are approximately 303 satellite HD units, which are attached to hospital-based HD facilities. The majority of satellite units have limited medical support; nephrologists supervise ESRD patients by phone or intermittent visits, but most dialysis care in these units is provided by nurses.[5, 6]

B2.2: CKD care (non-RRT)

No organized clinical care pathway or program is in place for CKD patients, although some regions have pilot projects to develop care pathways between PCPs and nephrologists.[6]

B2.3: Regional variation in structures and practice patterns for CKD care

There are substantial inequalities between levels of service provision in renal care in the Northern and Southern parts of Italy. The fact that each region (n = 20) has its own health system and policies has created substantial between-region differences in the delivery and organization of care patterns. These differences are magnified by substantial economic disparities between the various regions of Italy, which translate into major differences in available facilities and infrastructures. Some regions have enormous resources (eg, Lombardy has a GDP like that of Germany), while others are limited in resources (eg, Calabria has a GDP like that of Greece). These disparities translate also into major organizational and managerial differences.

C. Access and quality of care

C1: Availability and access to care

CKD care including all forms of RRT is wholly covered and accessible to all residents. This includes all aspects of ambulatory and hospital care inclusive of physician and diagnostic (laboratory and imaging) services. Some patients must pay small copayments for medications (Section A2.2). Kidney transplantation is free, and immunosuppressive medications are wholly covered.

C2: Referral criteria

There are no national standard criteria for referral of CKD patients to nephrologists.

C3: Quality management programs

Quality management programs are available for patients with ESRD on RRT, and only through the RRT registry.

C4: CKD registry

There is no registry for early CKD patients. A registry for patients in stage 5 (not yet on RRT) is under development through local and regional initiatives and currently covers approximately 20–30% of people with stage 5 CKD. The main challenge for increased uptake of the registry is adequate funding. Additional local registries have been started by individual units, but the quality and coverage of these initiatives is unknown.

D. Capacity, workforce and access to multidisciplinary teams

D1: Physician workforce

As of 2004, there were 3278 nephrologists in Italy (Table 2-23). The number of nephrologists has decreased in recent years because of attrition due to retirement compared to graduation of new trainees.

D2: Multidisciplinary teams and other professionals

There are no multidisciplinary teams of nurses, dieticians, psychologists, social workers, vascular access and transplant coordinators for early CKD care. Multidisciplinary teams are available in some centres for ESRD care.

D3: Workforce limitations

There are reported deficiencies in vascular access coordinators, counsellors/psychologists and dieticians (Table 2-23). No renal pharmacists are available in Italy.

Table 2-23

Workforce	*Availability*
Physicians per 1000 population	3.7
Nephrologists per 1000 ESRD patients	94
Nephrologists per 1000 CKD patients	0.54
Nurses per 1000 population	6.4
Presence of multidisciplinary teams for CKD	Yes (some centres)
Disciplines with most pronounced lack of capacity for CKD care, in the opinion of survey respondents	Dieticians, Vascular access coordinators, Counselors/ psychologists

E. Barriers to optimal CKD care

E1: Top five barriers to optimal CKD care (in descending importance)

1. Organizational factors
2. Political factors
3. Economic factors
4. Care providers' and policymakers' awareness of early detection and prevention of CKD
5. General population's awareness of early detection and prevention of CKD

Political factors

CKD is not recognised as a politically important topic in the same way as diabetes, cancer or vascular disease. To increase the profile of CKD care, effective lobbying of regional health authorities and other policymakers, as well as liaison with other societies, is essential.

Economic factors

- The 2008 global financial crisis reduced funding for most public services including healthcare for CKD.
- CKD registries are a high priority but lack adequate funding.
- The current reimbursement system may constitute a barrier to effective collaboration between nephrologists and PCPs.

Organizational factors

- The fact that each region (n = 20) has its own health plan translates into substantial variation in the quality of CKD care across Italy.
- Poor communication between PCPs and nephrologists.
- Absence of framework of quality indicators to measure the performance and benchmark for PCPs.

CKD awareness

Overall, awareness of the importance of CKD is low among care providers, policymakers, patients and the general population. The nephrology community is well aware of the epidemic nature of CKD, but in most Italian regions this awareness has not been sufficiently communicated to local/regional governments or to PCPs.

F. CKD burden and risk factors

F1: Epidemiology of ESRD

Data are available only for certain regions of Italy. In 2010, the number of adult patients starting RRT in Italy (estimates based on 88.7% coverage only, as not all regions report data to the registry) was 6,167, equating to an incidence rate of 160.5 pmp, up from 150.3 pmp in 2003. Diabetes and vascular diseases are the leading causes of ESRD. As of December 31, 2010, there were 34,809 adult patients receiving RRT. The prevalence of RRT was 905.9 pmp. The number of patients receiving home HD decreased by 98% since 2009, from 965 to 11. Transplantation is the second most common RRT modality (29% of RRT patients), HD was used in 64% and PD in 7% (in the 8 out of 20 regions of Italy for which there are data). The prevalence of patients with a functioning transplant at the end of 2010 was 307.8 pmp.[7, 8]

F2: Epidemiology of CKD

The Italian Society of Nephrology has submitted a proposal (awaiting approval) to the Ministry of Health for a national CKD prevalence survey (2012). Three published studies have reported on prevalence of CKD, although these were not nationally representative: the Gubbio study (1989–1992; only CKD stages 3–5) 6.6% in men and 6.2% in women,[9] SIN-HS (CKD stages 3–5) 9.3%[10] and the INCIPE study (CKD stages 1–5) 13.2%.[11]

F3: CKD cost data

ESRD care including RRT consumed about 1.5–2% of the total healthcare budget. There are no data on the costs of CKD care.

F4: CKD risk factors

A high burden of risk factors is associated with CKD at the population level including increasing age, diabetes, hypertension, smoking, alcohol use and obesity (Table 2-24).

Table 2-24

Risk factors	*Prevalence (year)*
Age >65 years	20.4% (2009)
Diabetes	7.8% (2011)
Hypertension	46.1% (2011)
Smoking	23.3% (2009)
Alcohol use	8.0 L* (2009)
Obesity	10.3% (2009)

*Mean annual consumption per capita.

G. Perceptions of care (providers, patients and policymakers)

G1: Efficiency in CKD care delivery

Efficiency was rated as above average by 45% of respondents.

G2: Patient education

According to the CEAPIR European Kidney Patients' Federation 2011 survey results, about 67% patients say they have never received educational materials to help them manage their CKD.[12] Existing educational materials apply chiefly to ESRD patients.

G3: Patients' involvement in their care

Patients' involvement was rated as average in the KH4L survey. According to the CEAPIR European Kidney Patients' Federation 2011 survey results, about 50% of CKD patients feel they were very involved in making decisions about their treatment. Transplant, dialysis and pre-dialysis (stage 4) patients are perceived to be more involved in their care.[12]

G4: Patients' perceptions of quality of care received

Perceived quality of care was rated as average in the KH4L survey. According to the CEAPIR European Kidney Patients' Federation 2011 survey results, about 44% of patients are very satisfied with care for their kidney disease, and another 46% are somewhat satisfied.[12]

H. Opportunities for and obstacles to improvement

H1: Opportunities

- Universal healthcare system and well-developed infrastructure.
- CKD public health policy document in development by the Ministry of Health.
- Italian Society of Nephrology recently submitted a proposal to the MoH for a national CKD prevalence survey.

H2: Obstacles

- Fragmentation of health care planning and policy across regions.
- Competing needs with other chronic diseases.
- Lack of effective collaboration between scientific societies and practitioners (nephrologists and PCPs).
- Nephrologists have historically not been effective advocates for early CKD care or helped to educate local PCPs about CKD.
- Most (regional) health authorities do not recommend or implement early detection of CKD.
- Absence of specific recommendations at regional levels for eGFR reporting by laboratories.

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Netherlands

COUNTRY OVERVIEW

Facts

Area	41,543 sq km
Total population	16,730,632 (2012)

CKD care plan

National plan/strategy for NCDs	Yes
National plan/strategy: CKD-specific	Yes
Guideline/service framework	Yes
CKD (non-RRT) registry	No
Planned actions	Yes

Disease burden

ESRD data	
Incidence/pmp	118.0 (2010)
Prevalence/pmp	925.8 (2010)
CKD data	
Prevalence	10.4% (PREVEND, Groningen)
Costs data	
GDP (PPP)	$713.1 billion (2011)
Total health expenditures (% of GDP)	12
CKD costs data (as % total health expenditure)	—

Capacity and workforce

Hospital bed capacity	4.2 per 1000 population
Physicians supply	3.9 per 1000 population
Nurses supply	8.4 per 1000 population
Nephrologists supply	56 per 1000 ESRD population
Renal units, N	89
Transplant centres, N	8 (academic centres)

PPP = purchasing power parity.

A. Health systems, policies and structures

A1: Governance structure

Netherlands is a constitutional monarchy consisting of 12 administrative divisions (provinces). The central government has overall responsibility for regulation of the health care system, and private health care providers are primarily responsible for providing services.[1-5] Health care coverage is statutory and regulated under the Health Insurance Act (Zorgverzekeringswet); insurance is provided by private companies that must provide a standard benefit package (primary and specialist care, hospital visits and medications). Private health insurance funds serve as payers and receive government-rated health premiums from the populace. The health care system is financed in three ways: (1) a compulsory SHI scheme for long-term care, which is financed through income-dependent contributions, (2) a SHI for the whole population (basic health insurance) funded through flat-rate (nominal) premiums and/or income-dependent employer contributions and (3) complementary voluntary health insurance (VHI) for services not covered by the SHI systems.

A2: Healthcare system organization

A2.1: Coverage

Health care coverage is universal. There is 100% coverage for ambulatory PCP services, ambulatory specialist services, laboratory tests, diagnostic imaging and medications. This also applies to inpatient care.

A2.2: Individual copayment

Patient copayments do not exceed €300 per year for ambulatory, inpatient care and/or medications. Expensive medications such as rituximab are not covered by insurance but are provided free of charge by government for inpatients.

A2.3: Financing

The Dutch statutory national health insurance system is financed through defined income-related contributions and community-rated premiums set by insurers. Total health spending is 12% of GDP (above the 9.5% OECD average), and mainly from public funding (85.7% of total expenditure).

A2.4: Organization of care delivery

A2.4.1: Primary care

Primary care is delivered by PCPs, who serve as the gatekeepers for specialist care. All citizens are registered with a PCP of their choice, usually in their own neighbourhood. PCPs operate predominantly in private group practices.

A2.4.2: Specialist care

Hospital care and specialist care (except emergency care) are accessible only on referral from a PCP. Specialist care services are provided in hospitals and also in private group practices.

A3: Physician compensation

PCPs are private contractors and receive payments as capitations and FFS. Specialists are usually hospital-based and salaried or in group practice and paid by FFS.

A4: NCD policy and strategy

The NCD strategy is based in part on the WHO action plan for the prevention and control of NCDs for 2013–2020. There are specific policies/programs for CVD, cancer, diabetes, tobacco and alcohol. A department in the federal health ministry has specific responsibility for NCDs.

A5: CKD-specific policies, guideline and/or service frameworks

A5.1: Specific policies

There is no specific CKD policy.

A5.2: Guideline

There is a national guideline for CKD management (diagnosis, referral and treatment) that was developed by the Dutch Nephrology Federation (NfN).

A5.3: Structures/systems for monitoring uptake of guideline

No system or structure monitors uptake of the national guideline. However, an initiative of the NfN in partnership with the Hans Mak Institute is monitoring compliance with the guideline as part of a quality improvement (QI) project.

A5.4: CKD as a healthcare priority

No level of government recognizes CKD as a healthcare priority. Government addresses CKD through its policies on other diseases such as diabetes and hypertension, which are felt to include most people with CKD.

A5.5: CKD care advocacy

The Dutch Kidney Foundation (together with the Heart & Diabetes Association) is a strong advocate for CKD care (ESRD and prevention or early detection of CKD), and is promoting the CKD care agenda to the government.

B. Organization and structure of CKD care

There are no organized structures for early CKD care. CKD care is overseen by individual hospitals and NGOs.

B1: Role of care providers

B1.1: PCPs and other specialists

Early CKD care is provided mainly by PCPs and other specialists (cardiologists, endocrinologists, etc) until referral by the standard criteria (See C2 below), when nephrologists take over.

B1.2: Role of care providers: Nephrologists

There is no incentive for PCPs to increase referral of CKD patients to nephrologists. Nephrologists provide care to stage 3–5 CKD and RRT patients.

B2: CKD care structures

B2.1: RRT care

ESRD care is provided in 8 academic centres, 80 peripheral hospitals and 80 HD satellite units.

B2.2: CKD care (non-RRT)

No organized clinical care pathway or program is in place for CKD patients.

B2.3: Regional variation in structures and practice patterns for CKD care

There is no perceived major variation between regions in available structures, organization or care delivery systems.

C. Access and quality of care

C1: Availability and access to care

CKD care and delivery including all forms of RRT are wholly covered and accessible to all residents. These include all aspects of ambulatory or hospital care inclusive of physician and diagnostic (laboratory and imaging) services. However, medications are subject to copayments (Section A2.2). Kidney transplantation is free, and immunosuppressive medications are covered wholly through the health insurance coverage.

C2: Referral criteria

There are published national standards for referral of patients with CKD to a nephrologist (Dutch National Transmural Agreement (LTA) for “Chronic renal failure”).

C3: Quality management programs

Quality management programs are available for patients with ESRD on RRT, and only through the registry. A new initiative through the Hans Mak Institute measures quality of care for CKD patients (Section A5.3).

C4: CKD registry

There is no registry for early CKD patients. The Hans Mak Institute recently changed its mission statement to include the establishment of an early stage CKD registry.

D. Capacity, workforce and access to multidisciplinary teams

D1: Physician workforce

PCPs and other specialists (cardiologist, endocrinologists) remain responsible for overall care before nephrology referral. There are 300 nephrologists across the country’s main renal centres (academic centres and peripheral hospitals), which also supervise peripheral satellite units (Table 2-25).

D2: Multidisciplinary teams and other professionals

There is no defined multidisciplinary team for early CKD care. Patients with more advanced disease (CKD stages 4/5) receive multidisciplinary management. The barrier is limited workforce capacity and lack of funding, as insurance companies do not reimburse expenses for multidisciplinary care.

D3: Workforce limitations

There are reported issues in the number of nurse practitioners, dialysis nurses and renal pharmacists (Table 2-25).

Table 2-25

Workforce	*Availability*
Physicians per 1000 population	3.9
Nephrologists per 1000 ESRD patients	56
Nephrologists per 1000 CKD patients	0.19
Nurses per 1000 population	8.4
Presence of multidisciplinary teams for CKD	Yes
Disciplines with most pronounced lack of capacity for CKD care, in the opinion of survey respondents	Nurse practitioners, Dialysis nurses, Renal pharmacists

E. Barriers to optimal CKD care

E1: Top five barriers to optimal CKD care (in descending importance)

1. Economic factors
2. Political factors
3. Organizational factors
4. Care providers' and policymakers' lack of awareness about the potential benefits of early detection and prevention of CKD
5. General population's and patients' lack of awareness about the potential benefits of early detection and prevention of CKD

Economic factors

Funding for early detection and prevention of CKD is lacking.

Political factors

CKD is not recognized as a politically important topic in the same way as diabetes, cancer, hypertension, COPD, or vascular disease.

Organizational factors

- PCPs are perceived to have a high threshold for making changes to their practice, including the incorporation of new evidence.
- Most CKD patients receive care outside hospitals, and coordination between PCPs and nephrologists in the care of CKD patients is lacking.

CKD awareness

Overall, awareness of the importance of CKD is low among care providers, policymakers, patients and the general population. There are now media strategies to educate the general public about the importance of CKD, eg, through the television program Grote Donorshow.

F. CKD burden and risk factors

F1: Epidemiology of ESRD

In 2010, the number of adult patients starting RRT in Netherlands was 1,960, equating to an incidence rate of 118 pmp. Diabetes and vascular diseases are the leading causes of ESRD. As of December 31, 2010, there were 15,383 adult patients receiving RRT. The prevalence of RRT was 925.8 pmp, an increase of 3.4% from 2009. From 2009 to 2010 the prevalence of HD patients decreased by 1%, the prevalence of PD fell by 1.3% and the prevalence of patients with a functioning transplant increased by 6.9%. The number of patients receiving home HD increased by 9.7% since 2009, from 155 to 170. Transplantation was the most common treatment modality (59% of prevalent RRT patients), 34% used HD and 7% used PD. The prevalence of patients with a functioning transplant at the end of 2010 was 543.2 pmp.[6, 7]

F2: Epidemiology of CKD

There are no national data on the prevalence of CKD. The prevalence of CKD was reported as 10.4% based on data published by the population-based PREVEND study, in the city of Groningen.[8, 9]

F3: CKD cost data

There are no data on the costs of CKD care. ESRD care costs ~1.5–2% of the total healthcare budget.

F4: CKD risk factors

A high burden of risk factors is associated with CKD at the population level including increasing age, diabetes, hypertension, smoking, alcohol use and obesity (Table 2-26).

Table 2-26

Risk factors	*Prevalence (year)*
Age >65 years	15.2% (2009)
Diabetes	7.3% (2011)
Hypertension	42.4% (2011)
Smoking	22.6% (2009)
Alcohol use	9.4 L* (2009)
Obesity	11.8% (2009)

*Mean annual consumption per capita.

G. Perceptions of care (providers, patients and policymakers)

G1: Efficiency in CKD care delivery

Efficiency was rated as above average by most of the respondents.

G2: Patient education

Although most material is applicable to ESRD, some educational material is available for every stage of CKD, prepared as pamphlets and websites (developed by the Dutch Kidney Foundation). The Dutch Kidney Foundation has produced a book that explains different RRT methods, diet and other aspects. There is also a workbook that CKD patients can use to increase their self-management skills. For patients with earlier stages of CKD, nurse practitioners provide information regarding lifestyle, management, etc.

G3: Patients' involvement in their care

Patients' involvement was rated as above average by respondents to the KH4L survey. People with more advanced CKD are perceived to be more involved in their care.

G4: Patients' perceptions of quality of care received

Perceived quality of care was rated as above average in the KH4L survey.

H. Opportunities for and obstacles to improvement

H1: Opportunities

- Universal healthcare system and well-developed infrastructure.
- An electronic preventive medicine program was initiated in 2012 with the focus on risk communication and lifestyle intervention for chronic diseases including CKD (https://www.testuwrisico.nl/ and http://www.testuwleefstijl.nl/). This program was set up by three non-governmental patient organizations (focused respectively on CKD, heart disease and diabetes). Patients fill in their clinical information via the Internet and receive a report summarizing their risk status and making recommendations (green: no action, yellow: may consult PCP for chronic disease care, red: must consult PCP for chronic disease care).
- The Kidney Foundation is a strong partner for advocacy with government.
- Disease management programs.

H2: Obstacles

- Providing care for people with early CKD is viewed as preventive in nature, which PCPs in the Netherlands view as out of scope for their practice. This makes it challenging to incorporate early CKD care in primary care.
- Absence of an organized multidisciplinary team approach to early CKD care.
- Lack of priority for CKD in the political agenda at the same level as diabetes, CVD and cancer.

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Norway

COUNTRY OVERVIEW

Facts

Area	323,802 sq km
Total population	4,707,270 (2012)

CKD care plan

National plan/strategy for NCDs	Yes
National plan/strategy: CKD-specific	Yes
Guideline/service framework	Yes
CKD (non-RRT) registry	No
Planned actions	No

Disease burden

ESRD data	
Incidence, pmp	104 (2010)
Prevalence, pmp	858 (2010)
CKD data	
Prevalence, %	11.2 (HUNT study)
Costs data	
GDP (PPP)	$269.3 billion (2011)
Total health expenditures (% of GDP)	9.4
CKD costs data (as % total health expenditure)	—

Capacity and workforce

Hospital bed capacity	3.5 per 1000 population
Physicians supply	3.9 per 1000 population
Nurses supply	8.7 per 1000 population
Nephrologists supply	21 per 1000 ESRD population
Renal units, N	19
Transplant centres, N	1 (Oslo)

PPP = purchasing power parity.

A. Health systems, policies and structures

A1: Governance structure

Norway is a constitutional monarchy consisting of 19 administrative divisions (counties) and three levels of healthcare: federal, regional and local. Overall responsibility for the healthcare sector rests at the federal level, with the Ministry of Health and Care Services. The regional level is represented by five regional health authorities, with responsibility for specialist healthcare; and the local level is represented by 434 municipalities with responsibility for primary healthcare.[1-4]

A2: Healthcare system organization

A2.1: Coverage

Healthcare coverage is universal for all, based on need and protected by public commitment and political interest in continuous improvement of the healthcare system. Coverage includes hospital care, ambulatory care and medications.

A2.2: Individual copayment

There is a specified list of covered medications (the "blue list"), which covers a maximum of US$95 for any medication. Medication copayment is related to reference price; there is an annual maximum limit for total copayment (1880 NOK, or US$339 at 2010 exchange rates). However, there are no limits on copayments for those medications not in the blue list.

Exemption from the usual copayment policies applies to children under age of 16 years, who get access to essential medication on the blue list; residents eligible for minimum retirement pension or on disability pensions, who receive free essential medications; and people with serious communicable diseases such as HIV, who receive free medications.

A2.3: Financing

The total annual health expenditure in terms of GDP is 9.4% (close to the 9.5% OECD average). There is a mix of public and private profit-making players: public funding by government constitutes 85.5% of total expenditure, private funding carries out only 5% of total expenditure, and the remainder is mostly out-of-pocket expenditure.

A2.4: Organization of care delivery

A2.4.1: Primary care

Primary care is delivered by PCPs, predominantly in private solo practices. PCPs are the first point of contact with healthcare, and to access primary care, registration with a PCP is required.

A2.4.2: Specialist care

Specialist care is accessed predominantly via private solo practices (ambulatory care) and hospitals. To access specialist care, referral is compulsory.

A3: Physician compensation

PCPs services and outpatient specialist services are paid by FFS/capitation. Hospital-based physicians are generally salaried.

A4: NCD policy and strategy

The NCD strategy is based in part on the WHO action plan for the prevention and control of NCDs for 2013–2020. There are specific policies/programs for CVD, cancer, diabetes, tobacco and alcohol. A department in the federal health ministry has specific responsibility for NCDs.

A5: CKD-specific policies, guidelines and/or service frameworks

A5.1: Specific policies

The Ministry of Health in Norway has started to create a national action plan for CKD, including secondary prevention, dialysis and kidney transplantation (National Action Plan, 2011).

A5.2: Guidelines

There is a national guideline for CKD management, but limited uptake of it by care providers is due to poor awareness and concrete implementation strategies.

A5.3: Structures/systems for monitoring uptake of guidelines

No structures or systems are in place to monitor adherence to the national guideline.

A5.4: CKD as a healthcare priority

The government recognizes CKD as a healthcare priority, as reflected by the development of a national action plan.

A5.5: CKD care advocacy

There is no advocacy group to raise the profile of CKD at any level of government.

B. Organization and structure of CKD care

CKD care is overseen by individual hospitals and regional authorities. All ESRD patients are managed exclusively in government hospitals.[5]

B1: Role of care providers

B1.1: PCPs and other specialists

Early CKD care is provided mainly through PCPs and other specialists (cardiologists, endocrinologists, etc) until stage 5 CKD, when nephrologists take over. PCPs remain involved after nephrology referral.

B1.2: Nephrologists

Nephrologists care mostly for patients with stages 4–5 CKD and RRT. There is no incentive for PCPs to increase referral of CKD patients to nephrologists.

B2: CKD care structures

B2.1: RRT care

There is at least one county hospital in each of the 19 counties; each constitutes a renal division that provides dialysis and transplant care. Some divisions (mainly in less populated northern regions) have satellite units for HD that are primarily managed by telemedicine with a physical visit from a nephrologist every 7–10 days. Kidney transplantation is carried out only at the Rikshospitalet Hospital in Oslo, where patients receive immediate transplant care, and later on follow up with their local nephrologist in any of the 19 county hospitals.

B2.2: CKD care (non-RRT)

No organized clinical care pathway or program is in place for CKD patients.

B2.3: Regional variation in structures and practice patterns for CKD care

Geography is perceived to significantly influence practice patterns, especially when comparing northern and southern Norway. Recruitment of health personnel, particularly doctors and specialized nurses, is difficult in rural areas, particularly in the north. A national strategy for addressing inequalities in health and healthcare has recently been issued.

C. Access and quality of care

C1: Availability and access to care

CKD care and delivery including all forms of RRT are wholly covered and accessible to all residents without charge. CKD care is provided by the 19 divisions. Most medications require a copayment; there are some exemptions (Section A2.2). Kidney transplantation is free, and immunosuppressive medications are fully covered.

C2: Referral criteria

Currently, every county or hospitals has its own criteria. There are no nationally agreed criteria for referral in either the guideline or the action plan.

C3: Quality management programs

The Norwegian Directorate for Health is responsible for ensuring quality improvement in the health system. The Directorate focuses on safety and efficiency, patient-centred care, coordination and continuity. Eliminating socioeconomic inequalities, health promotion and disease prevention are also priority areas. However, no specific elements of quality improvement are directed at CKD patients specifically – except patients treated with RRT, who are covered by the national RRT registry's quality improvement scheme.

C4: CKD registry

There is no CKD registry for patients who do not require RRT.

D. Capacity, workforce and access to multidisciplinary teams

D1: Physician workforce

There are 85 nephrologists across the 19 renal divisions in the country (Table 2-27).

D2: Multidisciplinary teams and other professionals

There are no multidisciplinary teams of nurses, dieticians, psychologists, social workers, nephrologists, vascular access and transplant coordinators for early CKD care.

D3: Workforce limitations

There are limited numbers of dieticians, psychologists and social workers for kidney patients (Table 2-27). Psychology services are available but are very expensive in Norway as they are predominantly accessed via the private sector due to limited capacity in the public system.

Table 2-27

Workforce	*Availability*
Physicians per 1000 population	3.9
Nephrologists per 1000 ESRD patients	21
Nephrologists per 1000 CKD patients	0.18
Nurses per 1000 population	8.7
Presence of multidisciplinary teams for CKD	No
Disciplines with most pronounced lack of capacity for CKD care, in the opinion of survey respondents	Nephrologists, Dieticians, Renal social workers

E. Barriers to optimal CKD care

E1: Top five barriers to optimal CKD care (in descending importance)

1. Organizational factors
2. Political factors
3. Care providers' and policymakers' awareness of early detection and prevention of CKD
4. General population's awareness of early detection and prevention of CKD
5. Patients' awareness of early detection and prevention of CKD

Political factors

CKD is not perceived to be a priority among political leaders, who appear to be more aware of other NCDs (diabetes, cancer, vascular diseases). On the other hand, the establishment of the national action plan suggests that at least some policy makers are aware of the importance of CKD.

Economic factors

Economic factors are not perceived to be a major barrier at present.

Organizational factors

- Coordinated systems and structures for care of patients with different severities of CKD are lacking.
- There is wide variation in practice patterns across the counties.
- There are perceived to be poor relationships (with lack of communication) between hospital-based (salaried) specialists and those in the private sector.
- Pay for performance programs to enhance quality improvement are lacking.

CKD awareness

Overall, awareness of the course of CKD and its importance is low among care providers, policymakers, patients and the general population.

F. CKD burden and risk factors

F1: Epidemiology of ESRD

In 2010, the number of adult patients starting RRT in Norway was 509, equating to an incidence rate of 104.1 pmp. Diabetes and vascular diseases are the leading causes of ESRD. As of December 31, 2010, there were 4,195 adult patients receiving RRT. The prevalence of RRT was 858 pmp, an increase of 1.9% from 2009. From 2009 to 2010 the prevalence of HD patients increased by 0.14%, the prevalence of PD fell by 4.7% and the prevalence of patients with a functioning transplant increased by 3%. The number of patients receiving home HD increased by 33% since 2009, from 6 to 8. Transplantation was the most common treatment modality (71% of RRT patients), HD was used in 24% and PD was used in 5%. The prevalence of patients with a functioning transplant at the end of 2010 was 608.5 pmp.[1, 6]

F2: Epidemiology of CKD

The overall prevalence of CKD was reported as 11.2% based on national data published by the HUNT study (Table 2-28).[7, 8]

F3: CKD cost data

There are no data on the costs of CKD care. ESRD care costs ~1.5–2% of the total healthcare budget.

F4: CKD risk factors

A high burden of risk factors is associated with CKD at the population level including hypertension, smoking, alcohol use and obesity (Table 2-29).

Table 2-29

Risk factors	*Prevalence (year)*
Age >65 years	12.8% (2009)
Diabetes	5.9% (2011)
Hypertension	46.8% (2011)
Smoking	21.0% (2009)
Alcohol use	6.7 L*(2009)
Obesity	10.0% (2009)

*Mean annual consumption per capita.

Table 2-28 CKD Prevalence, Norway, 1995–1997*

		Percentage by Stage									
		1		*2*		*3*		*4*		*5*	
Reduced kidney function		56.7		38.6		4.5		0.16		—	
Albuminuria (micro/macro)		4.9	0.5	8.2	0.6	21	5.6	—	—	—	—
CKD		3.1		3.4		4.5		0.16		—	
Age groups (yrs)	20–39	82.5		17.3		0.2		0.02			
	40–59	58.2		40.4		1.4		0.02			
	60–69	36.7		56.9		6.1		0.22			
	≥70	23.2		58.1		17.9		0.71			
Gender	Male	62.4		34.0		3.4		0.17			
	Female	51.6		42.7		5.5		0.16			
Diabetes	Yes	35.9		49.4		13.6		0.83			
	No	57.6		38.2		4.0		0.12			
Hypertension	Treated	28.2		55.6		15.5		0.61			
	Untreated	50.0		44.7		5.2		0.13			
	No	67.2		30.9		1.8		0.10			

CKD = chronic kidney disease, eGFR = estimated glomerular filtration rate.

*Percentage of total population with CKD.

G. Perceptions of care (providers, patients and policymakers)

G1: Efficiency in CKD care delivery

Efficiency was rated as above average by all (100%) respondents to the KH4L survey.

G2: Patient education

Patients with advanced CKD are referred to nephrologists and receive information on living with kidney disease via the patients' kidney schools available in each county. This program, taught by nephrologists and/or renal nurses, includes 20 hours of instruction relevant to the patients' perspective on kidney disease management.

G3: Patients' involvement in their care

Patients' involvement was rated as above average by most (50%) of respondents in the KH4L survey, but mainly for patients with advanced CKD (stages 4–5).

G4: Patients' perceptions of quality of care received

Perceived quality of care was rated as above average by 50% of respondents.

H. Opportunities for and obstacles to improvement

H1: Opportunities

- Universal healthcare system and well-developed infrastructure.
- The pending national action plan for CKD, which will cover secondary prevention, dialysis and kidney transplantation.
- The patients' kidney school.

H2: Obstacles

- Poorly organized referral system and lack of accepted criteria for referral.
- Limited availability of workforce: nephrologists, dieticians, social workers and psychologists.
- Wide variation in healthcare policy across counties.
- Poor communication between PCPs and specialists in the care of CKD patients.
- Lack of private sector, thereby eliminating competition and limiting potential for improvement.

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Portugal

COUNTRY OVERVIEW

Facts

Area	92,090 sq km
Total population	10,781,459 (2012)

CKD care plan

National plan/strategy for NCDs	Yes
National plan/strategy: CKD-specific	In preparation
Guideline/service framework	Yes
CKD (non-RRT) registry	No
Planned actions	No

Disease burden

ESRD data	
Incidence, pmp	220 (2012)
Prevalence, pmp	1670 (2012)
CKD data	
Prevalence, %	> 6.1 (2011)*
Costs data	
GDP (PPP)	$252.2 billion
Total health expenditures (% of GDP)	10.7
CKD costs data (as % total health expenditure)	–

Capacity and workforce

Hospital bed capacity	3.4 per 1000 population (2008)
Physicians supply	3.8 per 1000 population (2009)
Nurses supply	5.34 per 1000 population (2009)
Nephrologists supply	15 per 1000 ESRD population
Renal units, N	19 main divisions (100 HD units)
Transplant centres, N	8

PPP = purchasing power parity.

* No albuminuria included in survey.

A. Health systems, policies and structures

A1: Governance structure

Portugal is a parliamentary republic consisting of 5 regions with 18 administrative divisions (districts) and 2 autonomous regions.[1-5] The federal government is responsible for planning and healthcare regulation through the MoH. Each region has a board that is responsible for administration and delivery of healthcare services (contracting services with hospitals and private sector providers). The NHS coverage has been universal, comprehensive and free at the point of use since 1979. The healthcare delivery system in Portugal consists of a network of public and private healthcare providers, all of whom are linked to the MoH. The public NHS provides direct acute hospital and primary care. Specialized services such as RRT are commonly provided in the public and private sector; outpatient hemodialysis is mainly performed by the private sector, while peritoneal dialysis and transplantation are exclusively at the public level. All RRT is totally funded by the NHS. Diagnostics, dialysis and physiotherapy are performed by private providers who are under contract to the NHS.[6]

A2: Healthcare system organization

A2.1: Coverage

Coverage is universal for ambulatory PCP contacts, ambulatory specialist contacts, laboratory tests and diagnostic imaging. However, there is only 1–50% coverage for medications (except for RRT – see below).

A2.2: Individual copayment

The required copayment for prescribed medication varies based on effectiveness criteria: higher levels of copayment are required for medications with lower clinical effectiveness (copayments ~20–75%).

A2.3: Financing

The total annual health expenditure is 10.7% of GDP (above the 9.5% OECD average). The NHS is funded chiefly by general taxation. There is a mix of universal (public) NHS, private insurance schemes (25%) and private voluntary health insurance (10–20%).[6]

A2.4: Organization of care delivery

A2.4.1: Primary care

Primary care is delivered by PCPs, predominantly in public centres. PCPs are the first point of contact with healthcare, and to access primary care, registration with a PCP is required.

A2.4.2: Specialist care

Specialist care is accessed predominantly via public hospitals. To access specialist care, referral by a PCP is required.

A3: Physician compensation

The predominant mode of compensation for both PCPs and specialists is salary.

A4: NCD policy and strategy

The NCD strategy is based in part on the WHO action plan for the prevention and control of NCDs for 2013–2020. There are specific policies/programs for CVD, cancer, diabetes, tobacco and alcohol. A department in the federal health ministry has specific responsibility for NCDs.

A5: CKD-specific policies, guidelines and/or service frameworks

A5.1: Specific policies

There is no specific CKD policy at any level of government. A national CKD policy is under preparation.

A5.2: Guidelines

There is a national guideline for referral and management of CKD. There is no targeted active or passive surveillance system to identify and detect early CKD.

A5.3: Structures/systems for monitoring uptake of guidelines

There are no structures for monitoring uptake of the CKD guideline. There is a monitoring system (audit) for dialysis quality parameters.

A5.4: CKD as a healthcare priority

The Portuguese government does not currently recognize CKD as a healthcare priority.

A5.5: CKD care advocacy

There is no advocacy group to raise the profile of CKD at any level of government

B. Organization and structure of CKD care

CKD care is overseen by individual hospitals.

B1: Role of care providers

B1.1: PCPs and other specialists

Early CKD care is provided mainly through PCPs up to CKD stage 3b. Most patients are refered to nephrologists before stage 5. There is moderate continuation of PCP involvement after nephrology referral.

B1.2: Nephrologists

Nephrologists care for most patients on stage 5 CKD and RRT, although patients are usually referred earlier. There is no incentive for PCPs to increase referral of CKD patients to nephrologists.

B2: CKD care structures

B2.1: RRT care

There are 19 nephrology services that manage RRT patients. There are approximately 100 dialysis units; 80% of these are private and are satellites of the main units in the public hospitals.

B2.2: CKD care (non-RRT)

No organized clinical care pathway or program is in place for CKD patients.

B2.3: Regional variation in structures and practice patterns for CKD care

There is no significant perceived variation in practice across the regions. Currently access to specialist care is good, better in urban areas than in rural ones.

C. Access and quality of care

C1: Availability and access to care

CKD care and delivery including all forms of RRT are wholly covered and accessible to all residents and are free of charge with the exception of medications, for which most CKD patients must pay a copayment (Section A2.2). In general, patients on RRT receive free medications and transportation to access specialized care. Patients with a dialysis access (even if not yet on dialysis) also receive free medications and transportation to access specialized care.

C2: Referral criteria

There are no published standards for referral of CKD patients to a nephrologist, but a national policy is under preparation.

C3: Quality management programs

Quality management programs are available for patients with ESRD on RRT, only through the national registry.

C4: CKD registry

There is no CKD registry for patients who do not require RRT.

D. Capacity, workforce and access to multidisciplinary teams

D1: Physician workforce

There are 250 nephrologists and 120 trainees (according to the nephrology division of the Portuguese Medical Association) across the country (Table 2-30).

D2: Multidisciplinary teams and other professionals

At the hospital level there are multidisciplinary teams of nurses, dieticians, psychologists, social workers, nephrologists, vascular access and transplant coordinators for early and late CKD care. However, there are important regional differences.

D3: Workforce limitations

There are reported deficiencies in the number of nurse practitioners, dialysis nurses and renal pharmacists (Table 2-30).

Table 2-30

Workforce	*Availability*
Physicians per 1000 population	3.5
Nephrologists per 1000 ESRD patients	15
Nephrologists per 1000 CKD patients	0.23
Nurses per 1000 population	5.7
Presence of multidisciplinary teams for CKD	Yes
Disciplines with most pronounced lack of capacity for CKD care, in the opinion of survey respondents	Vascular access coordinators, General practitioners/ primary care physicians, Renal social workers

E. Barriers to optimal CKD care

E1: Top five barriers to optimal CKD care (in descending importance)

1. Economic factors
2. Political factors
3. Organizational factors
4. Care providers' and policymakers' awareness of early detection and prevention of CKD
5. General population's and patients' awareness of early detection and prevention of CKD

Political factors

CKD is not recognised as a politically important topic in the same way as diabetes, cancer or vascular disease.

Economic factors

Since 2008, RRT care has been funded by a care bundle that includes HD, medication and vascular access; this system is perceived to be comprehensive and very efficient. The 2008 global financial crisis reduced funding to most public services including healthcare for CKD. Limited funding is the major perceived barrier to better quality of CKD care.

Organizational factors

An organized system for early CKD care is lacking, and communication between PCPs and specialists is perceived to be poor.

CKD awareness

Overall, awareness of the importance of CKD is low among care providers, policymakers, patients and the general population.

F. CKD burden and risk factors

F1: Epidemiology of ESRD

In 2010, the number of adult patients starting RRT in Portugal was 2,519, equating to an incidence rate of 237 pmp. Diabetes and vascular diseases are the leading causes of ESRD. As of December 31, 2010, there were 16,788 adult patients receiving RRT. The prevalence of RRT was 1579.7 pmp, an increase of 4.9% from 2009. From 2009 to 2010 the prevalence of HD patients increased by 5.2%, the prevalence of PD increased by 15.6%, and the prevalence of patients with a functioning transplant increased by 3.2%. No patients receive home HD. Transplantation was the second most common treatment modality (35.6% of RRT patients), HD was used in 60.5% and PD in 3.9%. The prevalence of patients with a functioning transplant at the end of 2010 was 562.3 pmp (602 pmp in 2012).[7-9]

F2: Epidemiology of CKD

From January 2008 to January 2009, a large, population-based, nationally representative, cross-sectional study was conducted to assess the prevalence of diabetes in Portugal. A total of 5,167 subjects aged between 20 and 79 year were evaluated.[10] The overall CKD prevalence was estimated to be 6.1%, based on eGFR criteria (but not including albuminuria).

F3: CKD cost data

There are no data on the costs of CKD care.

F4: CKD risk factors

A high burden of risk factors is associated with CKD at the population level including increasing age, diabetes, hypertension, smoking, alcohol use and obesity (Table 2-31).

Table 2-31

Risk factors	*Prevalence (year)*
Age >65 years	17.8% (2009)
Diabetes	12.7% (2011)
Hypertension	47.9% (2011)
Smoking	18.6% (2009)
Alcohol use	10.0 L* (2009)
Obesity	15.2% (2009)

*Mean annual consumption per capita.

G. Perceptions of care (providers, patients and policymakers)

G1: Efficiency in CKD care delivery

Efficiency was rated as above average by most (53%) respondents to the KH4L survey. Every patient is felt to have access to treatment appropriate to the stage of CKD.

G2: Patient education

According to the CEAPIR European Kidney Patients' Federation 2011 survey, about 67% of patients say they have never received education or rehabilitation to help them manage their CKD.[11] Both early and advanced CKD patients are perceived to lack relevant educational material.

G3: Patients' involvement in their care

Patients' involvement was rated as average in the KH4L survey. According to the CEAPIR European Kidney Patients' Federation 2011 survey, about 42% of CKD patients feel they were very involved in making the decision about their treatment. About 8% felt they were not involved in the process.[11]

G4: Patients' perceptions of quality of care received

Perceived quality of care was rated as average in the KH4L survey. According to the CEAPIR European Kidney Patients' Federation 2011 survey, about 40% of patients are very satisfied with care for their kidney disease, and another 50% are somewhat satisfied.[11] Patients would be more satisfied if they had better access to educational material.

H. Opportunities for and obstacles to improvement

H1: Opportunities

- Universal healthcare system and well-developed infrastructure.
- Portuguese Society of Nephrology, which is felt to be a very committed organization, with the mandate to improve CKD care in Portugal.

H2: Obstacles

- Limited funding with increasing competing priorities.
- Lack of specific system for CKD care, with poor coordination of care between PCPs and specialists.
- Low awareness of the importance of CKD among policymakers.
- Low average education level and literacy among CKD patients.

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Spain

COUNTRY OVERVIEW

Facts

Area	505,370 sq km
Total population	47,042,984 (2012)

CKD care plan

National plan/strategy for NCDs	Yes
National plan/strategy: CKD-specific	No
Guideline/Service framework	Yes
CKD (non-RRT) registry	No
Planned actions	No

Disease burden

ESRD data	
Incidence, pmp	121 (2011)
Prevalence, pmp	1,078 (2011)
CKD data	
Prevalence %	9.2
Costs data	
GDP (PPP)	$1.432 trillion (2011)
Total health expenditures (% of GDP)	9.7 (2009)
CKD costs data (as % total health expenditure)	2.5 %

Capacity and workforce

Hospital bed capacity	3.2 per 1000 population (2008)
Physicians supply	3.7 per 1000 population (2009)
Nurses supply	4.9 per 1000 population
Nephrologists supply	40 per 1000 ESRD population
Renal units, N	125
Transplant centres, N	41

PPP = purchasing power parity.

A. Health systems, policies and structures

A1: Governance structure

Spain is a parliamentary monarchy consisting of 19 administrative divisions (17 autonomous regions and 2 autonomous cities).[1-3] Since 2002, health administration has been devolved to 17 regional health ministries with primary jurisdiction over the organization and delivery of health services in their territory. The federal MoH still holds authority over certain strategic areas such as legislation and as guarantor of the equitable functioning of health services across the country. Private voluntary insurance schemes play a relatively minor role in the Spanish healthcare system; these private schemes are independent of the public system (opting out of the public system is not possible) and complementary in nature (mainly to gain access to services for which there are waiting times in the public system). The private insurance schemes cover ~13% of the population, with considerable regional variation.[4]

A2: Healthcare system organization

A2.1: Coverage

There is 100% coverage for ambulatory PCP contacts, ambulatory specialist contacts, laboratory tests and diagnostic imaging; 100% for hospitalizations and 76–99% coverage for medications. Except for medications prescribed to people aged <65 years, which require a 40% copayment, healthcare provision is free of charge at the point of delivery.[1, 2, 5]

A2.2: Individual copayment

For people aged <65 years, medications are subject to a 40% copayment; there is no copayment for those aged ≥65 years or who have retired for other reasons such as chronic illness. However, from July 1, 2012, additional copayments are imposed based on annual income at <€18,000, €18,000–€100,000 and >€100,000 with 40%, 50% and 60% copayments for medications respectively. For the retired, the copayment is 0–20% up to a maximum of 60 euros per month.

A2.3: Financing

The Spanish healthcare system is funded via taxation and operates predominantly in the public sector. The total annual healthcare expenditure is 9.6% of GDP (close to the 9.5% OECD average). Public funding constitutes 83.6% of total expenditure. Private, complementary, voluntary insurance schemes account for 16.4%.

A2.4: Organization of care delivery

A2.4.1: Primary care

Primary care is delivered by PCPs. PCPs are the first point of contact with healthcare, and to access primary care, registration with a PCP is required.

A2.4.2: Specialist care

Specialist care is accessed predominantly via public hospitals. Residents need to have a referral from PCPs to access specialist care.

A3: Physician compensation

PCP services are paid by salary/capitation, and outpatient specialist services are paid by salary. Inpatient specialist services are included in the NHS assistance. Physicians have no additional compensation for these services, which are included in their salary.

A4: NCD policy and strategy

The NCD strategy is based in part on the WHO action plan for the prevention and control of NCDs for 2013–2020. There are specific policies/programs for CVD, cancer, diabetes, tobacco and alcohol, and a department in the federal health ministry with specific responsibility for NCDs. Currently the Ministry of Health, in contact with the respective scientific societies, is preparing a specific strategy for chronic diseases, including CKD. This strategy has been defined as “Quality Commitment of the Spanish Medical Societies.”

A5: CKD-specific policies, guidelines and/or service frameworks

A5.1: Specific policies

There is no specific CKD policy.

A5.2: Guidelines

An existing national guideline for referral and management of CKD has been approved by at least 10 societies (cardiac, diabetic, endocrinology societies) and is very much similar to the international KDIGO guideline. Efforts are also in progress to adapt the KDIGO CKD guideline (which is felt to be most relevant to specialists) to guide PCPs. There is no targeted active or passive surveillance system to identify and detect early CKD, but currently almost 100% of the primary care laboratories are implementing CKD-EPI GFR estimation and urine albumin/creatinine ratio.

A5.3: Structures/systems for monitoring uptake of guidelines

There is no defined system to monitor uptake of the guideline.

A5.4: CKD as a healthcare priority

CKD is a part of the national NCD strategy (including vascular risk reduction) but is not specifically recognized as a health priority by any level of government. The "Quality Commitment of the Spanish Medical Societies" has been designed to include CKD as a priority for the next years.

A5.5: CKD care advocacy

There is no advocacy group to raise the profile of CKD at any level of government but the Subdivision for Health Quality and Coherence of the Ministry of Health is preparing a specific document for the care of CKD for all 17 of the autonomous communities based on the "Ten Societies Consensus Document for the Care of CKD."

B. Organization and structure of CKD care

Oversight of CKD care is by individual hospitals and regional authorities. All ESRD patients are managed exclusively in government hospitals. In some regions private institutions may provide care to early CKD patients.

B1: Role of care providers

B1.1: PCPs and other specialists

Early CKD care is provided mainly through PCPs and other specialists (cardiologists, endocrinologists, etc) until stage 5 CKD, when nephrologists take over. There is no PCP involvement after nephrology referral, but the new consensus document implemented from December 2012 provides criteria for multifactorial and integrated management of patients with CKD stages 2–5 and gives specific counsel to the PCP.

B1.2: Nephrologists

Nephrologists care mostly for patients with stage 4 CKD, and intensively for stage 5 CKD and RRT. PCPs have no incentive to increase referral of CKD patients to nephrologists, but neither are there disincentives for PCPs to increase referral of CKD patients to nephrologists. Simply there are no incentives.

B2: CKD care structures

B2.1: RRT care

There are well-established programs for dialysis and transplantation. Care is delivered by 366 centres: 60% operated by the private sector and 40% by the public sector, according to the 2009 estimates. In practice, all the inpatient care is public, because almost all the CKD stage 5 complications are managed in public hospitals; only a few exceptions are managed in private hospitals in liaison with the public system.[6]

B2.2: CKD care (non-RRT)

No organized clinical care pathway is in place for CKD patients.

B2.3: Regional variation in structures and practice patterns for CKD care

Each of the 17 regions has its own health department, and thus there is considerable perceived variation between regions in the policies, structures and systems for delivery of chronic disease care (including CKD).

C. Access and quality of care

C1: Availability and access to care

CKD care and delivery including all forms of RRT are wholly covered and accessible to all residents. Coverage includes all aspects of ambulatory and hospital care inclusive of physician and diagnostic (laboratory and imaging) services, but not medications (Section A2.2). However, most CKD patients are exempt from copayments as they have retired because of age or to illness. Kidney transplantation is free and provided exclusively in public facilities; immunosuppressive medications are wholly covered by health insurance.

C2: Referral criteria

There are defined criteria for nephrology referral with variation across regions. A national strategy for referral criteria is under development (eg, PCPs' use of eGFR < 30 for referral of patients to nephrology units).

C3: Quality management programs

Quality management programs are available for patients with ESRD on RRT, and only through the national RRT registry.

C4: CKD registry

There is no registry for early CKD patients.

D. Capacity, workforce and access to multidisciplinary teams

D1: Physician workforce

There are ~1900 nephrologists in Spain (Table 2-32).

D2: Multidisciplinary teams and other professionals

With a few exceptions in some public hospitals, there are generally no multidisciplinary teams of nurses, dieticians, psychologists, social workers, nephrologists, vascular access and transplant coordinators for CKD care.

D3: Workforce limitations

There is a perceived lack of involvement of dieticians, social workers and psychologists in the care of CKD patients (Table 2-32). Fistula placement is felt to be unduly delayed because of lack of access to CV surgeons, who are thought to be very busy. Encouraging private surgeons to create fistulas has been proposed as a possible solution.

Table 2-32

Workforce	*Availability*
Physicians per 1000 population	3.7
Nephrologists per 1000 ESRD patients	40
Nephrologists per 1000 CKD patients	0.4
Nurses per 1000 population	4.9
Presence of multidisciplinary teams for CKD	No (Yes in some public hospitals)
Disciplines with most pronounced lack of capacity for CKD care, in the opinion of survey respondents	Dieticians, Vascular access coordinators, (increasing in public hospitals), Renal social workers

E. Barriers to optimal CKD care

E1: Top five barriers to optimal CKD care (in descending importance)

1. Economic factors
2. Political factors
3. Organizational factors
4. Care providers' and policymakers' awareness of early detection and prevention of CKD
5. General population' and patient's awareness of early detection and prevention of CKD

Political factors

CKD is not felt to be recognised as a politically important topic in the same way as diabetes, cancer or vascular disease. Rivalries or differing political directions are felt to block uptake of effective strategies or development of a national strategy.

Economic factors

The 2008 global financial crisis reduced funding to most public services including healthcare for CKD.

Organizational factors

Existence of the 17 different regions is felt to contribute to fragmentation of care and between-region variations in practice.

CKD awareness

Overall, awareness of the importance of CKD is low among care providers, policymakers, patients and the general population. The Spanish Society of Nephrology has tried to inform these actors through its Strategies for Renal Care. World Kidney Day is celebrated each year with the specific messages and in close contact with patient organizations, media, other medical societies and the Ministry of Health. Many campaigns to pay attention to early detection of CKD are in progress on the radio or television.

F. CKD burden and risk factors

F1: Epidemiology of ESRD

In 2010, the number of adult patients starting RRT in (18 out of 19 regions of) Spain was 5,518, equating to an incidence rate of 121 pmp. Diabetes and vascular diseases are the leading causes of ESRD. As of December 31, 2010, there were 47,230 adult patients receiving RRT in 18 regions in Spain. The prevalence of RRT was 1036.6 pmp, an increase of 0.3% from 2009. From 2009 to 2010 the prevalence of HD patients decreased by 2.5%, the prevalence of PD increased by 6%, and the prevalence of patients with a functioning transplant increased by 2.5%. The number of patients receiving home HD decreased by 100% since 2009, from 41 to none. Transplantation and HD were the most common treatment modalities (50.1% and 45.6% of RRT patients, respectively) and PD was used in 5.3%. The prevalence of patients with a functioning transplant at the end of 2010 was 507.9 pmp. In 2011 the incidence rate of adult patients starting RRT was 121 pmp; 82.2% of them entered into HD, 15.1% in PD and 2.7% received a preemptive kidney transplant. The prevalence rate was 1078 pmp, of which 50.1% have a functioning graft, 4.6% received HD and 5.3% received PD.[7-9]

F2: Epidemiology of CKD

According to the EPIRCE study, the overall CKD prevalence in Spain was 9.2% (Table 2-33).[10]

F3: CKD cost data

There were estimates only for the costs of dialysis and transplantation. Each patient on HD costs €60,000 per year, PD ~€45,000 per year and transplantation €45,000 in the first year, €12000–€19,000 in the second year and €10000 per year from the third year onwards. RRT care represents ~2.5% of the nation's annual healthcare costs. No cost data on CKD care are available.

Table 2-33 CKD prevalence in Spain (overall, and across age groups and sex)

	EPIRCE study					
	By Stage (%)					
	*1**	*2*	*3a*	*3b*	*4*	*5*
Overall	0.99	1.3	5.4	1.1	0.27	0.03
Age groups						
20–39 yrs	0.86	0.97	0.1	–	–	–
40–64 yrs	1.0	1.8	2.8	0.37	0.09	0.07
>64 yrs	1.1	1.1	16.8	3.7	0.92	–
Sex						
Male	1.4	1.3	4.7	0.79	0.39	
Female	0.58	1.3	6.2	1.3	0.16	0.05

*with proteinuria

F4: CKD risk factors

A high burden of risk factors is associated with CKD at the population level including increasing age, diabetes, hypertension, smoking, alcohol use and obesity (Table 2-34).

Table 2-34

Risk factors	*Prevalence (year)*
Age >65 years	16.7% (2009)
Diabetes	8.1% (2011)
Hypertension	41.7% (2011)
Smoking	26.2% (2009)
Alcohol use	10.0 L* (2009)
Obesity	16.0% (2009)

*Mean annual consumption per capita.

G. Perceptions of care (providers, patients and policymakers)

G1: Efficiency in CKD care delivery

This was rated as above average by most of the respondents to the KH4L survey. Renal transplantation is felt to be highly efficient (excellent). Early CKD care and early detection of CKD are both felt to be below average.

G2: Patient education

Educational materials for CKD patients are not widely available but are well known by nephrologists. The “Election Project” (Proyecto Elección) is a document implemented under the auspices of the Spanish Nephrology Society (SEN) to provide adequate information to patients and their families about the importance of CKD and possible treatments.

And now an interesting project of the SEN is in development, the P.A.R. project – “Plan de Atención Renal” – to help patients with stage 3 CKD to comply adequately with their diet, self-care and medications. The patient can contact a “call centre” with the assistance of a PCP, a nurse, a dentist, a psychologist and in close contact with the nephrologist in charge of the patient. This is a pilot program started in June 2013 in eight Spanish hospitals.

G3: Patients’ involvement in their care

This was rated as average by respondents to the KH4L survey.

G4: Patients’ perceptions of quality of care received

This was rated as above average by respondents to the KH4L survey. Patients are generally satisfied because care is free, and they generally perceive the quality of systems, doctors and nurses to be adequate – especially for advanced CKD.

H. Opportunities for and obstacles to improvement

H1: Opportunities

- Universal healthcare system and well-developed infrastructure.
- Promising national initiative to adapt the KDIGO guideline for primary care management of CKD in the Spanish setting.
- Estimated GFR (eGFR) is now reported in every hospital and every outpatient laboratory.
- Excellent relationships between nephrologists and PCPs.

H2: Obstacles

- Lack of a national CKD registry.
- Low awareness of CKD among policymakers and the general population.
- Lack of patient educational materials about CKD.
- Limited funding with increasing competing priorities.
- Multiple priorities across the 17 health regions have complicated development and implementation of a national strategy.
- Poor implementation of existing CKD guideline by PCPs.

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Sweden

COUNTRY OVERVIEW

Facts

Area	450,295 sq km
Total population	9,103,788 (2012)

CKD care plan

National plan/strategy for NCDs	Yes
National plan/strategy: CKD-specific	No
Guideline/service framework	No
CKD (non-RRT) registry	No
Planned actions	No

Disease burden

ESRD data	
Incidence, pmp	121 (2010)
Prevalence, pmp	909 (2010)
CKD data	
Prevalence, pmp	—
Costs data	
GDP (PPP)	$386.6 billion (2011)
Total health expenditures (% of GDP)	9.6
CKD costs data (as % total health expenditure)	—

Capacity and workforce

Hospital bed capacity	2.7 per 1000 population
Physicians supply	3.8 per 1000 population
Nurses supply	11 per 1000 population
Nephrologists supply	23 per 1000 ESRD population
Renal units, N	60
Transplant centres, N	4

PPP = purchasing power parity.

A. Health systems, policies and structures

A1: Governance structure

Sweden is a parliamentary monarchy with three levels of government: federal, 21 county councils (regions) and 290 municipalities. All three levels have important roles in healthcare organization and delivery. The federal government focuses on strategy and regulation, while the regional and municipal governments focus on service delivery based on local needs and priorities.[1-4]

A2: Healthcare system organization

A2.1: Coverage

Healthcare coverage in Sweden is universal and comprehensive. All residents are entitled to publicly financed healthcare, which covers clinical preventive services, inpatient and outpatient hospital care, primary healthcare, inpatient and outpatient medications, patient transport support services, home care, and long-term and nursing home care.

A2.2: Individual copayment

There is a copayment for most publicly financed services, but the maximum amount of paid out-of-pocket individual expenditure per year is US$140 for all types of health services.

A2.3: Financing

The total healthcare expenditure is 9.6% of GDP (just above the 9.5% OECD average). Universal healthcare is mandatory. There is a mixed of publicly and privately owned healthcare facilities. Public funding constitutes 81% of total expenditure.

A2.4: Organization of care delivery

A2.4.1: Primary care

Primary care is delivered by PCPs, predominantly in public centres. PCPs are the first point of contact with healthcare, but registration with a PCP is not required to access primary care.

A2.4.2: Specialist care

Specialist care is accessed predominantly via public hospitals. Residents have free access (without referral) to specialists unless enrolled in a gatekeeping managed care plan; all kidney patients are under this plan, and thus need referrals to see nephrologists.

A3: Physician compensation

PCP services and specialist services are paid by salary.

A4: NCD policy and strategy

The NCD strategy is based in part on the WHO action plan for the prevention and control of NCDs for 2013–2020. There are specific policies/programs for CVD, cancer, diabetes, tobacco and alcohol. A department in the federal health ministry has specific responsibility for NCDs.

A5: CKD-specific policies, guidelines and/or service frameworks

A5.1: Specific policies

There is no specific CKD policy.

A5.2: Guidelines

Since 2007 there has been a national guideline about specialist referral and management of CKD. However, implementation across counties is perceived to be variable. The 2007 guideline is felt to be outdated, but there is disagreement about how best to adapt newer international or European guidelines to the Swedish setting.

A5.3: Structures/systems for monitoring uptake of guidelines

There is no structure or system to facilitate guideline uptake and implementation.

A5.4: CKD as a healthcare priority

No level of government recognizes CKD as a healthcare priority.

A5.5: CKD care advocacy

There is no advocacy group to raise the profile of CKD at any level of government.

B. Organization and structure of CKD care

CKD care is overseen by regional (county) authorities and delivered by individual hospitals. All ESRD patients are managed mostly in government hospitals, and some private institutions provide hemodialysis services.

B1: Role of care providers

B1.1: PCPs and other specialists

Early CKD care is provided mainly by PCPs and other specialists (cardiologists, endocrinologists, etc) until stages 4–5 CKD, when nephrologists take over. There is continuous PCP involvement after nephrology referral.

B1.2: Nephrologists

Nephrologists care mostly for stages 4–5 CKD and RRT. There is no incentive for a PCP to increase referral of CKD patients to nephrologists.

B2: CKD care structures

B2.1: RRT care

There are well-established programs for dialysis and transplantation: care is delivered by 60 renal divisions, approximately 55 hub dialysis units, approximately 8 associated satellite units and 4 kidney transplant centres.[5]

B2.2: CKD care (non-RRT)

No organized clinical care pathway or program is in place for CKD patients.

B2.3: Regional variation in structures and practice patterns for CKD care

There is substantial perceived variation in the organization and delivery of primary care among the 21 county councils. It is unclear how the perceived variation affects the quality of CKD care, as there are no data comparing outcomes across regions.

C. Access and quality of care

C1: Availability and access to care

CKD care and delivery including all forms of RRT are wholly covered and accessible to all residents. In general, patients on RRT or with a dialysis access receive free medications and transportation to access specialized care. Kidney transplantation is free, and immunosuppressive medications are wholly covered through health insurance.

C2: Referral criteria

There are defined criteria for nephrology referrals, although the extent to which these criteria are followed is perceived to vary.

C3: Quality management programs

Quality management programs are available for patients with ESRD on RRT, only through the national RRT registry.

C4: CKD registry

There is a registry for CKD patients who do not require RRT. It began operations in the Stockholm area approximately 5 years ago and has expanded to include other regions over time, although not all regions currently participate. Most of the patients included in the registry have stage 4–5 CKD and are followed by nephrologists.

D. Capacity, workforce and access to multidisciplinary teams

D1: Physician workforce

There are about ~180 nephrologists; an additional 20 semi-retired nephrologists work exclusively in dialysis units (Table 2-35).

D2: Multidisciplinary teams and other professionals

Some units have multidisciplinary teams for early CKD care. Most units have "uremia coordinators," whose chief function is to prepare for ESRD care (access, anemia, mineral and bone disorder, and nutrition management) in patients with advanced CKD.

D3: Workforce limitations

There are reported deficiencies in the number of nephrologists, dieticians, dialysis nurses and renal pharmacists (Table 2-35).

Table 2-35

Workforce	*Availability*
Physicians per 1000 population	3.6
Nephrologists per 1000 ESRD patients	23
Nephrologists per 1000 CKD patients	0.22
Nurses per 1000 population	11.0
Presence of multidisciplinary teams for CKD	Yes
Disciplines with most pronounced lack of capacity for CKD care, in the opinion of survey respondents	Nephrologists, Dieticians, Dialysis nurses

E. Barriers to optimal CKD care

E1: Top five barriers to optimal CKD care (in descending importance)

1. Organizational factors
2. Economic factors
3. Political factors
4. Care providers' and policymakers' awareness of early detection and prevention of CKD
5. Patients' awareness of early detection and prevention of CKD

Political factors

Awareness of the importance of CKD is low among policymakers and political leaders.

Economic factors

Funding is limited in the context of competing priorities.

Organizational factors

- Care facilities (particularly the number of beds for inpatient care) are limited.
- The workforce capacity (especially for nephrologists, dieticians, dialysis nurses and renal pharmacists) is limited.
- Care coordination between PCPs and specialists is lacking.

CKD awareness

Overall, awareness of the importance of CKD is low among care providers, policymakers, patients and the general population.

F. CKD burden and risk factors

F1: Epidemiology of ESRD

In 2010, the number of adult patients starting RRT in Sweden was 1,135, equating to an incidence rate of 121 pmp. Diabetes and vascular diseases are the leading causes of ESRD. As of December 31, 2010, there were 8,525 adult patients receiving RRT. The prevalence of RRT was 909 pmp, an increase of 2.1% from 2009. From 2009 to 2010 the prevalence of HD patients increased by 3.96%, the prevalence of PD fell by 2.4%, and the prevalence of patients with a functioning transplant increased by 1.83%. The number of patients receiving home HD increased by 6% since 2009, from 98 to 104. Transplantation was the most common treatment modality (56%); HD was used in 34% and PD in 10% of RRT patients. The prevalence of patients with a functioning transplant at the end of 2010 was 506.1 pmp.[6]

F2: Epidemiology of CKD

There are no nationally representative data on the prevalence of CKD. Estimated prevalence based on the opinion of the respondents was ~5.1–10%.

F3: CKD cost data

ESRD care is funded exclusively through the public sector. About 1–2% of total healthcare expenditures are spent on ESRD care. There are no data on CKD care costs.

F4: CKD risk factors

A high burden of risk factors is associated with CKD at the population level including increasing age, diabetes, hypertension, smoking, alcohol use and obesity (Table 2-36).

Table 2-36

Risk factors	*Prevalence (year)*
Age >65 years	17.9% (2009)
Diabetes	5.7% (2011)
Hypertension	46.0% (2011)
Smoking	14.3% (2009)
Alcohol use	7.4 L* (2009)
Obesity	11.2% (2009)

*Mean annual consumption per capita.

G. Perceptions of care (providers, patients and policymakers)

G1: Efficiency in CKD care delivery

Efficiency was rated as above average by most (63%) of the respondents to the KH4L survey.

G2: Patient education

According to 46% of respondents, there were no nationally available tools or resources to educate patients about how to manage CKD. Educational materials are available for patients with different stages of CKD, including RRT.

G3: Patients’ involvement in their care

Patients’ involvement was rated as average by 33% and above average by 54% respondents in the KH4L survey.

G4: Patients’ perceptions of quality of care received

Perceived quality of care was rated as above average in the KH4L survey. Patients are very satisfied with the care that they receive.

H. Opportunities for and obstacles to improvement

H1: Opportunities

- Universal healthcare system and well-developed infrastructure.
- Strong patient advocacy organization and nephrology society.
- A registry for early CKD.

H2: Obstacles

- Limited funding with increasing competing priorities.
- Lack of adequate supply of nephrologists and nurses.
- Limited availability of electronic infrastructure, which hampers effective data collation for registry and surveillance. All regions were invited to participate in the registry; however, geographically coverage is not 100%, the challenge being the lack of personnel to register and extract the data.
- Differences in focus and priorities of the 29 county councils, making a national strategy difficult to implement.
- Shortage of PCPs in some counties and increased travel distance to access specialist care.

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Switzerland

COUNTRY OVERVIEW

Facts

Area	41,277 sq km
Total population	7,925,517 (2012)

CKD care plan

National plan/strategy for NCDs	Yes
National plan/strategy: CKD-specific	No
Guideline/service framework	No
CKD (non-RRT) registry	No
Planned actions	No

Disease Burden

ESRD data	
Incidence, pmp	—
Prevalence, pmp	309 (2012)
CKD data	
Prevalence, %	13% (Stages 3–5)
Costs data	
GDP (PPP)	$344.2 billion (2011)
Total health expenditures (% of GDP)	11.3 (2009)
CKD costs data (as % total health expenditure)	—

Capacity and workforce

Hospital bed capacity	5.3 per 1000 population (2009)
Physician supply	4.7 per 1000 population (2010)
Nurses supply	16 per 1000 population
Nephrologist supply	72 per 1000 ESRD population
Renal units, N	25
Dialysis units, N	80
Transplant centres, N	5

PPP = purchasing power parity.

A. Health systems, policies and structures

A1: Governance structure

Switzerland is a federation that consists of 26 administrative divisions (cantons). The federal government is responsible for legislation and oversight of healthcare across the country. The cantons are responsible for the provision, organization and financing of health services, as well as for the development and implementation of health policy. There are thus 26 autonomous healthcare systems in Switzerland, one for each canton.[1-5]

A2: Healthcare system organization

A2.1: Coverage

Healthcare coverage is universal for all types of services including physician and diagnostic (imaging and laboratory) services and medications.

A2.2: Individual copayment

There is a fixed copayment of 10% for all services and medications to a maximum of US$580 per year. There are exemptions for people with low income (social assistance beneficiaries) and recipients of old age and disability benefits.

A2.3: Financing

All publicly funded healthcare is free at the point of delivery, and financed by general taxation and social insurance contributions (all individuals must purchase a basic package insurance plan). The annual spending on healthcare averages 11.4% of GDP (above the 9.5% OECD average). Privately financed healthcare, mostly involving dentistry and long-term care, accounts for about 40% of the annual total health expenditure.

A2.4: Organization of care delivery

A2.4.1: Primary care

Primary care is delivered by PCPs, predominantly in private solo practices. PCPs are the first point of contact with healthcare, but registration with a PCP is not required to access primary care.

A2.4.2: Specialist care

Specialist care is accessed predominantly via acute hospitals. Residents have free access (without referral) to specialists unless enrolled in a gatekeeping managed care plan.

A3: Physician compensation

Most PCPs and specialists are private contractors paid using FFS. A few physicians (PCPs and specialists) involved in managed care plans are paid by capitation.

A4: NCD policy and strategy

The NCD strategy is based in part on the WHO action plan for the prevention and control of NCDs for 2013–2020. There are specific policies/programs for CVD, cancer, diabetes, tobacco and alcohol. A department in the federal health ministry has specific responsibility for NCDs.

A5: CKD-specific policies, guidelines and/or service frameworks

A5.1: Specific policies

There is no specific CKD policy.

A5.2: Guidelines

There is no national or regional guideline for CKD management.

A5.3: Structures/systems for monitoring uptake of guidelines

This is not applicable as no national guideline exists. In general, there are no established procedures for assessing adherence to quality standards for CKD or ESRD patients.

A5.4: CKD as a healthcare priority

No level of government recognizes CKD as a healthcare priority.

A5.5: CKD care advocacy

There is no advocacy group to raise the profile of CKD at any level of government.

B. Organization and structure of CKD care

CKD care is overseen by individual hospitals.

B1: Role of care providers

B1.1: PCPs and other specialists

Early CKD care is provided mainly through PCPs and other specialists (cardiologists, endocrinologists, internists) until stage 4–5 CKD when nephrologists take over.

B1.2: Nephrologists

Nephrologists care mostly for patients with stage 5 CKD and RRT. They also manage earlier stages in cases in specific renal diseases (eg, nephrotic syndromes).

B2: CKD care structures

B2.1: RRT care

There are well-established programs for dialysis and transplantation. Care is delivered by 70 renal divisions comprising 5 university hospitals (dialysis and transplant care) and 50 peripheral hospitals with 86 dialysis units.

B2.2: CKD care (non-RRT)

No organized clinical care pathway or program is in place for CKD patients.

B2.3: Regional variation in structures and practice patterns for CKD care

There is some perceived variation in the organization of CKD care across cantons.

C. Access and quality of care

C1: Availability and access to care

CKD care and delivery including all forms of RRT are wholly covered and accessible to all residents, although there is a copayment for medications (Section A2.2). In general, patients on RRT or with a dialysis access receive free medications but have to pay for transportation to receive specialized care. Kidney transplantation is free, and immunosuppressive medications are wholly covered.

C2: Referral criteria

There are no national standards for referral of patients with CKD to a nephrologist.

C3: Quality management programs

Quality management programs are available for patients with ESRD on hemodialysis only. There are no existing programs for patients using other modalities such as transplant or PD.

C4: CKD registry

There is no CKD registry for patients who do not require RRT and no plan to develop one, although a national diabetes registry is available. Interviewees believed that development of a registry should be led by the PCPs and coordinated by the national renal association. This effort would be facilitated by a national e-health initiative that should be completed by 2015. The main obstacle is lack of funds, as there is no apparent interest from either government or the private sector.

D. Capacity, workforce and access to multidisciplinary teams

D1: Physician workforce

There are ~180 nephrologists in the country (Table 2-37).

D2: Multidisciplinary teams and other professionals

There are no multidisciplinary teams of nurses, dieticians, psychologists, social workers, nephrologists, vascular access and transplant coordinators except in major centres in Lausanne, Geneva, Zurich and Bern and Basel.

D3: Workforce limitations

There are reported deficiencies in the number of vascular access coordinators, nurse practitioners and PCPs (Table 2-37).

Table 2-37

Workforce	*Availability*
Physicians per 1000 population	3.9
Nephrologists per 1000 ESRD patients	98
Nephrologists per 1000 CKD patients	0.5
Nurses per 1000 population	16.0
Presence of multidisciplinary teams for CKD	—
Disciplines with most pronounced lack of capacity for CKD care, in the opinion of survey respondents	Vascular access coordinators, Nurse practitioners, General practitioners/ primary care physicians

E. Barriers to optimal CKD care

E1: Top five barriers to optimal CKD care (in descending importance)

1. Organizational factors
2. Political factors
3. Economic factors
4. General population's awareness of early detection and prevention of CKD
5. Care providers' and policymakers' awareness of early detection and prevention of CKD

Political factors

CKD is not recognised as a politically important topic in the same way as diabetes, cancer or vascular disease.

Economic factors

The 2008 global financial crisis reduced funding to most public services including healthcare for CKD.

Organizational factors

- Heterogeneous and independent healthcare systems across the 26 cantons make a nationally coordinated approach to CKD very challenging.
- A perceived lack of coordination in primary and secondary care and often a lack of good relationships among providers may impede efficient CKD care.
- Although progress has been made in educating primary care providers about the importance of CKD, case detection of CKD among people at risk continues to vary. The major barrier is thought to be failure of PCPs, policymakers and general population to appreciate the significance of CKD.

CKD awareness

Overall, awareness of the importance of CKD is low among care providers, policymakers, patients and the general population. Lack of media attention is felt to be an important but potentially reversible barrier.

F. CKD burden and risk factors

F1: Epidemiology of ESRD

Data are incomplete, as there is no national registry and Switzerland does not participate in the regional ERA-EDTA registry. Respondents believed that there are approximately 2,500 HD patients in Switzerland, and RRT prevalence of ~309 pmp (2012).[6]

F2: Epidemiology of CKD

There are no nationally representative data on the prevalence of CKD. There is an ongoing national study to evaluate the prevalence of CKD in the Swiss population and compare data across cantonal systems (August 2009–December 2013). The 2006 SAPALDIA study reported a prevalence of CKD of 13% in a cohort of elderly Swiss people aged 65 years and above.[7] There are some data from regional surveys, eg, the COLAUS study in the French area with 6,000 people from the general population.[8]

F3: CKD Cost Data

ESRD care is funded exclusively through the public sector and accounts for about 1–2% of total healthcare expenditures. There are no data available on CKD care costs.

F4: CKD risk factors

A high burden of risk factors is associated with CKD at the population level including increasing age, diabetes, hypertension, smoking, and obesity (Table 2-38).

Table 2-38

Risk factors	*Prevalence (year)*
Age >65 years	17.2% (2009)
Diabetes	7.4% (2011)
Hypertension	40.4% (2011)
Smoking	27.0% (2009)
Alcohol use	1.5 L* (2009)
Obesity	15.2% (2009)

*Mean annual consumption per capita.

G. Perceptions of care (providers, patients and policymakers)

G1: Efficiency in CKD care delivery

Efficiency was rated as excellent by most (67%) of the respondents to the KH4L survey.

G2: Patient education

None of the KH4L survey respondents believed that there were nationally available tools or resources to educate patients about how to manage CKD.

G3: Patients' involvement in their care

Patients' involvement was rated as above average by respondents to the KH4L survey. According to CEAPIR European Kidney Patients' Federation 2011 survey results about 50% of CKD patients feel they were very involved in making decisions about their treatment.[9]

G4: Patients' perceptions of quality of care received

Perceived quality of care was rated as above average by respondents to the KH4L survey.

H. Opportunities for and obstacles to improvement

H1: Opportunities

- Universal healthcare system and well-developed infrastructures.
- A national e-health service (eHealth Suisse) with personal identifiers (to be fully implemented by 2015).

H2: Obstacles

- Limited funding with increasing competing priorities.
- Complex nature of CKD, involving multiple comorbidities.
- PCPs' limited contact time with patients.
- Heterogeneous organizational system across the 26 cantons.
- Poor coordination between primary and specialist care.
- Low awareness of CKD among patients, policymakers and PCPs.

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Turkey

COUNTRY OVERVIEW

Facts

Area	783,562 sq km
Total population	79,749,461 (2012)

CKD care plan

National plan/strategy for NCDs	Yes
National plan/strategy: CKD-specific	No
Guideline/service framework	No
CKD (non-RRT) registry	No
Planned actions	No

Disease burden

ESRD data	
Incidence, pmp	252 (2010)
Prevalence, pmp	847 (2010)
CKD data	
Prevalence, %	15.7
Costs data	
GDP (PPP)	$1.087 trillion (2011)
Total health expenditures (% of GDP)	6.7 (2009)
CKD costs data (as % total health expenditure)	Not available

Capacity and workforce

Hospital bed capacity	2.71 per 1000 population (2010)
Physicians supply	1.7 per 1000 population (2010)
Nurses supply	1.6 per 1000 population (2010)
Nephrologists supply	7 per 1000 ESRD population
Renal units, N	871 (2011)
Transplant centres, N	61 (2012)

PPP = purchasing power parity.

A. Health systems, policies and structures

A1: Governance structure

Turkey is a parliamentary republic consisting of 81 administrative divisions (provinces). The central government is responsible for policy and legislation, and the provinces deal with healthcare administration and delivery. The municipalities are concerned mainly with public health and preventive services. In addition, universities and the Ministry of National Defense own healthcare facilities in the public sector, and a few private providers work under contract to the public healthcare system.[1-4]

A2: Healthcare system organization

A2.1: Coverage

There is 76–99% coverage for ambulatory PCP and specialist contacts and medications; and 100% coverage for laboratory tests and diagnostic imaging.

A2.2: Individual copayment

There are copayments for outpatient medications (employed individuals pay ~20%, and retired persons pay ~10%). Individuals aged <18 and those with very low income are exempted from copayments.

A2.3: Financing

Health services are financed by a social security scheme covering the majority of the population – the General Health Insurance Scheme (GHIS (Genel Saglık Sigortasi).[3] The total health spending was 6.1% of GDP (2008, latest year available), which was far below the 9.5% OECD average. The financing system is a mix of public and private not-for-profit and profit-making players. However, public funding accounts for 73% of total expenditure.

A2.4: Organization of care delivery

A2.4.1: Primary care

Primary care is provided by PCPs. Registration with a PCP is not required to access care.

A2.4.2: Specialist care

Specialist care services are provided in public hospitals. Referral is not required to access specialist care.

A3: Physician compensation

PCPs services and outpatient specialist services are reimbursed by FFS/salary.

A4: NCD policy and strategy

The NCD strategy is based on the WHO action plan for the prevention and control of NCDs for 2013–2020. There are specific policies/programs for CVD, cancer, diabetes, tobacco and alcohol. A department in the federal health ministry has specific responsibility for NCDs.

A5: CKD-specific policies, guidelines and/or service frameworks

A5.1: Specific policies

There is no specific CKD policy.

A5.2: Guidelines

There is no national or regional guideline for CKD management.

A5.3: Structures/systems for monitoring uptake of guidelines

This is not applicable as a national guideline does not exist. There is no procedure for assessing adherence to quality standards in CKD patients. A national dialysis surveillance system for follow-up of ESRD patients has been established since 2012, but quality standards have not been determined.

A5.4: CKD as a healthcare priority

No level of government recognizes CKD as a healthcare priority.

A5.5: CKD care advocacy

There is no advocacy group to raise the profile of CKD at any level of government.

B. Organization and structure of CKD care

No organized structures are available for early CKD care. CKD care is overseen by individual hospitals, PCPs and other specialists. RRT delivery is overseen by regional (provincial) authorities.[5]

B1: Role of care providers

B1.1: PCPs and other specialists

Early CKD care is provided mainly by PCPs and other specialists (cardiologists, endocrinologists, etc) until stage 5 CKD and RRT, when nephrologists take over. Some PCPs remain involved in the care of their patients after nephrology referral.

B1.2: Nephrologists

Nephrologists care mostly for patients with stage 5 CKD and RRT. There is no incentive for PCP to increase referral of CKD patients to nephrologists.

B2: CKD care structures

B2.1: RRT care

There are well-established programs for dialysis and transplantation with care delivered by 200 renal divisions comprising 871 dialysis units: 432 in state hospitals, 385 in private hospitals, 54 in universities. There are 61 transplant centres.

B2.2: CKD care (non-RRT)

No organized clinical care pathway or program is in place for CKD patients.

B2.3: Regional variation in structures and practice patterns for CKD care

There are gaps in care provision for rural/remote communities; some areas (especially the Eastern and Black Sea regions) are unable to provide specialist services because of lack of providers.

C. Access and quality of care

C1: Availability and access to care

In general, patients on RRT receive free medications and transportation to access specialized care. Medications are not publicly funded by government for CKD patients, as they have to make copayments unless exempted (see Section A2.2). Of note, the Social Security System applies restrictions to medications commonly used to treat CKD and other NCDs. For instance, only a certified cardiologist can make or change a statin medication, and a PCP is not allowed to prescribe an ARB/ACEi.

C2: Referral criteria

There are no national published standards for referral of patients with CKD to a nephrologist.

C3: Quality management programs

Quality management programs are available for patients with ESRD on RRT, only through the national RRT registry.

C4: CKD registry

There is no CKD registry for patients who do not require RRT, although the Turkish Society of Nephrology has initiated a discussion about a registry for patients with stage 3–5 CKD.

D. Capacity, workforce and access to multidisciplinary teams

D1: Physician workforce

There are 350 adult and 150 pediatric nephrologists in Turkey (2012). PCPs, internists and nurses are substantially involved in CKD care and RRT provision (Table 2-39).

D2: Multidisciplinary teams and other professionals

There are no multidisciplinary teams of nurses, dieticians, psychologists, social workers, nephrologists, vascular access and transplant coordinators for early CKD care.

D3: Workforce limitations

There are reported deficiencies in the number of nephrologists, vascular access coordinators, and dieticians (Table 2-39).

Table 2-39

Workforce	*Availability*
Physicians per 1000 population	1.7
Nephrologists per 1000 ESRD patients	7
Nephrologists per 1000 CKD patients	0.04
Nurses per 1000 population	1.6
Presence of multidisciplinary teams for CKD	No
Disciplines with most pronounced lack of capacity for CKD care, in the opinion of survey respondents	Nephrologists, Dieticians, Vascular access coordinators

E. Barriers to optimal CKD care

E1: Top five barriers to optimal CKD care (in descending importance)

1. Organizational factors
2. Economic factors
3. Political factors
4. Care providers' and policymakers' awareness of early detection and prevention of CKD
5. Patients' awareness of early detection and prevention of CKD

Organizational factors

- There are perceived shortages in the number of nephrologists. Thus, many patients who are perceived to potentially benefit from nephrology referral are managed by PCPs or other specialists.
- Accepted standards for management and referral are lacking.
- There are gaps in infrastructure needed to deliver high quality care, particularly in remote or rural regions of the country.

Economic factors

- The reimbursement policy by the Social Security Institution has limited access to appropriate medications for patients with CKD (see Section C1).
- Recurrent conflicts between the Ministry of Health and Social Security Institution about who should fund certain medications and services limit effective care for CKD patients

Political factors

Policy for renal care in the country is perceived not to be coherent, and it is perceived that political inertia prevents an increase in funding for NCD management and prevention (including CKD).

CKD awareness

Overall, awareness of the importance of CKD is low among care providers, policymakers, patients and the general population.

F. CKD burden and risk factors

F1: Epidemiology of ESRD

In 2010, the number of adult patients starting RRT was 15,509 equating to an incidence rate of 252 pmp. As of December 31, 2010, there were 52,111 adult patients receiving RRT. The prevalence of RRT was 847.4 pmp, an increase of 2.4% from 2009. From 2009 to 2010 the prevalence of HD patients increased by 3.4%, the prevalence of PD fell by 1.3%, and the prevalence of patients with a functioning transplant increased by 1.7%. Transplantation is the second most common treatment modality (12.4%), HD was used in 79.2% and PD 8.4% of RRT patients. The prevalence of patients with a functioning transplant at the end of 2010 was 104.4 pmp.[6, 7]

F2: Epidemiology of CKD

A nationally representative study, CREDIT, estimated the prevalence of CKD at 15.7% in the general population.[8]

F3: CKD cost data

ESRD care is funded exclusively by the public sector. About 5% of total healthcare expenditures are spent on ESRD care. There are no data on CKD care costs.

F4: CKD risk factors

A high burden of risk factors is associated with CKD at the population level including diabetes, hypertension, smoking, and obesity (Table 2-40).

Table 2-40

Risk factors	*Prevalence (year)*
Age >65 years	7.6% (2009)
Diabetes	7.4% (2011)
Hypertension	32.8% (2011)
Smoking	27.0% (2009)
Alcohol use	1.5 L* (2009)
Obesity	15.2% (2009)

*Mean annual consumption per capita.

G. Perceptions of care (providers, patients and policymakers)

G1: Efficiency in CKD care delivery

Efficiency was rated as average by most respondents to the KH4L survey, on the grounds of a perceived shortage in the number of nephrologists; limited infrastructure, and lack of multidisciplinary teams.

G2: Patient education

There are available educational materials for patients treated with RRT; these are chiefly funded by industry. There are no widely available materials for people with CKD.

G3: Patients' involvement in their care

Patients' involvement was rated as below average by the majority (52%) of respondents to the KH4L survey.

G4: Patients' perceptions of quality of care received

Perceived quality of care was rated as average by 36% respondents and as above average by 14% respondents to the KH4L survey.

H. Opportunities for and obstacles to improvement

H1: Opportunities

- An ongoing initiative by the Ministry of Health to start a national CKD program, with support from the WHO and the Turkish Society of Nephrology (TSN). This has a potential to raise CKD awareness among key stakeholders nationally, and lead to policy and guideline development. This project will be implemented in parallel with similar initiatives aimed at diabetes and CVD.
- A strong association of nephrology professionals with potential to influence policy and act as a lobby group.

H2: Obstacles

- Limited workforce – particularly the number of nephrologists.
- Lack of healthcare funding.
- Lack of coordinated system for CKD care.
- Poor communication between PCPs and nephrologists.
- Rapid growth of private sector involvement (especially in RRT care), which may be driven predominantly by potential for profit rather than for health.

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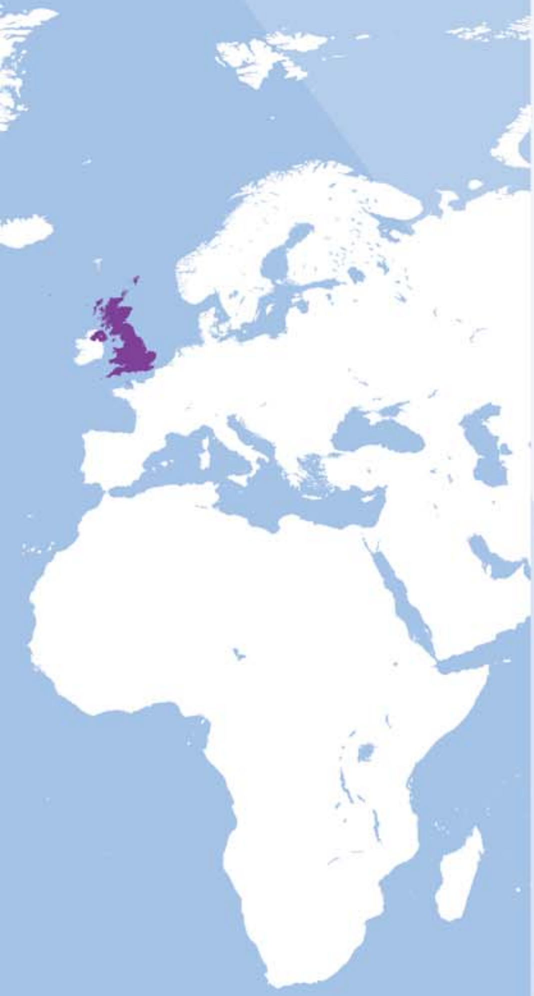
United Kingdom



COUNTRY OVERVIEW

Facts

Area	243, 610 sq km
Total population	63,047,162 (2012)

CKD care plan

National plan/strategy for NCDs	Yes
National plan/strategy: CKD-specific	Yes
Guideline/service framework	Yes
CKD (non-RRT) registry	No
Planned actions	Yes

Disease burden

ESRD data	
Incidence, pmp	106.2 (all countries)
Prevalence, pmp	820.5 (all countries)
CKD data	
Prevalence %	8.5 (overall)
Costs data	
GDP (PPP)	$2.308 trillion (2010)
Total health expenditures (% of GDP)	9.6 (2010)
CKD costs (as % total health expenditure)	Not available

Capacity and workforce

Hospital bed capacity	2.4 per 1000 population
Physician supply	2.5 per 1000 population
Nurses supply	7.7 per 1000 population
Nephrologist supply	10.3 per 1000 ESRD population
Renal units, N	75 (hubs)
Transplant centres, N	25

PPP = purchasing power parity.

A. Health systems, policies and structures

A1: Governance structure

The UK consists of Great Britain and Northern Ireland, while Great Britain includes England, Scotland and Wales. The four UK countries have separate but cooperating public healthcare systems that together form the National Health Service (NHS): (NHS England; NHS Scotland; NHS Wales; and Health and Social Care, Northern Ireland). Health services in the UK are provided chiefly by the NHS.[1-6] The planning and delivery system is hierarchical: Parliament and the Department of Health provide a policy focus and strategic direction. In England, the recently established (2012) clinical commissioning groups (CCGs) are responsible for purchasing acute care services and mental health services. Primary care and specialist commissioned services including preparation for RRT are commissioned by NHS England.

A2: Healthcare system organization

A2.1: Coverage

Healthcare coverage is universal for all types of services including physician and diagnostic (imaging and laboratory) services and medications.

A2.2: Individual copayment

In England, fixed copayments are required only for outpatient medications; the amounts are set nationally by the NHS (average about US$12 per medication). Certain people are exempt from copayments: people with diabetes, cancer, disabilities, ESRD, low income, elderly (>60 years), young (<16 or in full-time education). Of note, Wales, Northern Ireland and Scotland have recently abolished all copayments for medications.

A2.3: Financing

All NHS-funded healthcare (excluding dentistry, optometry and medications) is free at the point of delivery. The annual spending on healthcare averages 9.6% of GDP. The NHS is financed by general taxation.[7] Privately financed healthcare is a relatively small proportion of the total and mostly involves medications and private hospital care for those with private insurance.

A2.4: Organization of care delivery

A2.4.1: Primary care

Primary care is delivered by PCPs, predominantly in publicly funded private group practices as well as a few salaried PCP positions. The number of solo practices has decreased significantly over the last decade. PCPs are the first point of contact with healthcare. To access primary care, registration with a PCP is required. All PCP groups are members of their local CCG and elect the clinical chair.

A2.4.2: Specialist care

Specialist care is accessed predominantly via the NHS hospitals. Referrals are required for access; PCPs serve as the gatekeepers.

A3: Physician compensation

Most PCPs are private contractors paid using a mix of capitation, salary, contract payment for specific services and performance-related payments. A few private providers offer services through a fee-for-service system. Specialists are predominantly salaried employees of NHS hospital trusts.

A4: NCD policy and strategy

The UK NCD strategy is based in part on the WHO action plan for the prevention and control of NCDs for 2013–2020. There are specific policies/programs for CVD, cancer, diabetes, tobacco and alcohol. The Department of Health in England (and now Public Health, England) has led the UK government on the NCD strategy; the English Department of Health has coordinated and led the four health ministries. Also, National Service Frameworks (NSFs) manage chronic diseases with funding for treatment, prevention, surveillance, monitoring and evaluation. There is also the the Quality and Outcomes Framework (QoF) for primary care, a pay-for-performance system for chronic disease management that includes CKD stages 3–5. QoF awards financial incentives to PCPs for establishing and maintaining a registry of patients with certain chronic diseases, and managing these diseases according to quality markers established by the Department of Health (Table 2-41).

Table 2-41 UK Quality and Outcomes Framework indicators[11, 12]

Indicator	*Achievable points*	*Achievement thresholds*	*Underlying achievement so far in 2010/2011 (%)***
Records CKD 001. The contractor establishes and maintains a register of patients aged 18 years or over with CKD (ie, stages 3 to 5 CKD according to US National Kidney Foundation criteria)	6	No defined threshold	Not measured
Ongoing management CKD 002. The percentage of patients on the CKD register in whom the last BP reading, measured in the preceding 12 months, is ≤140/85 mmHg	11	41–81%	74.2
CKD 003. The percentage of patients on the CKD registers with hypertension and proteinuria who are currently treated with an ACEi or ARB.	9	45–80%	90.5
CKD 004. The percentage of patients on the CKD register whose notes have a record of a urine ACR or PCR test in the preceding 12 months.	6	45–80%	82.2

Source: Quality and Outcomes Framework guidance for GMS contract, 2013/14.

** Stevens et al. Engaging primary care in CKD initiatives: the UK experience. Nephrol Dial Transplant, 2012;:27 (Suppl 3):5–11.

The UK Quality and Outcomes Framework indicators are a set of measurable indicators for achievement used to reward contractors (mainly PCPs) for provision of guideline-concordant clinical care to patients with CKD. This program was introduced by the government for all PCPs in the UK on April 1, 2004, and has undergone several revisions over the years. Point indicators pertinent to CKD are now worth a total of 32 points (out of an achievable 1000 for 100 indicators across 22 clinical conditions, and 11 organisational and other service domains). Each point was worth ~US$200. (Source: http://www.nice.org.uk/aboutnice/qof/).

ACR = Albumin:creatinine ratio, ACEi = Angiotensin converting enzyme inhibitor, ARB = Angiotensin-receptor blocker, CKD = chronic kidney disease, PCR = protein:creatinine ratio

A5: CKD-specific policies, guidelines and/or service frameworks

A5.1: Specific policies

The NSFs include a policy document for renal services, which establishes standards for kidney care and good clinical practice. This document is in two parts; the first (2004) related to dialysis and transplantation, and the second (2005) to CKD and AKI – including early detection and prevention; management; and palliation at the end of life.

There are some minor national differences in how CKD care is organized in the UK. In England, a Renal Policy team within the Department of Health is headed by a national director. The Renal, Heart and Stroke team and Diabetes team form the Vascular Branch at the Department of Health. In Northern Ireland, a Planning Group oversees implementation of recommendations from the Department of Health for renal services and also influences regional commissioning policy. In Scotland, healthcare is managed by the Scottish Government Health Department, and there is no formal policy document on CKD. In Wales, a Welsh Renal NSF programme similar to the English Renal NSF is administered by the Community Primary Care and Health Services Policy Division in the Department of Health and Social Services. The All-Wales Renal Advisory Group oversees the implementation of the NSF.

A5.2: Guidelines

A national guideline for CKD management was developed by the Royal College of Physicians and UK Renal Association (updated with NICE guidance in September 2008, and NICE quality standards for CKD, 2011), and it covers:

- Identification of patients with CKD.

- Assessment of kidney function and proteinuria.
- Management and referral of CKD.
- Criteria for RRT initiation.
- Conservative management.

A5.3: Structures/systems for monitoring uptake of guidelines

The UK Renal Registry monitors implementation of the RRT component of the NSF, and the Department of Health closely monitors the QoF for early CKD. In addition, the Healthcare Quality Improvement Partnership (HQIP), which is a consortium of the Academy of Medical Royal Colleges, has recently funded a national CKD audit and a QI programme that has started in 2013.

A5.4: CKD as a healthcare priority

The national government in England recognizes CKD as a healthcare priority, as reflected by the establishment of the National Clinical Director for Kidney Care in the Department of Health. This position is responsible for the monitoring of CKD care in England.

The majority of respondents (85%; n = 23) thought that CKD was recognized as a health priority by the government in UK.

A5.5: CKD care advocacy

There was an advocacy group (Parliamentary Kidney Alliance Group) whose function was to raise the profile of CKD with government. However, this group focused chiefly on patients with ESRD and has now dissolved (2013).

B. Organization and structure of CKD care

CKD care is delivered mostly in primary care, but there is also substantial commissioning of structures to provide secondary care such as RRT for kidney failure and preparation for RRT in those with advanced CKD.[8, 9]

B1: Role of care providers

B1.1: PCPs and other specialists

Early CKD care is provided mainly by PCPs and other specialists (cardiologists, endocrinologists, etc) until stage 4 or 5 CKD, when nephrologists take over.

B1.2: Nephrologists

Nephrologists care mostly for patients with advanced stages of CKD (stage 4–5 CKD) and RRT.

B2: CKD care structures

B2.1: RRT care

As with most healthcare in the UK, nephrology services are delivered chiefly by the NHS rather than by privately funded organizations.[10] About 75 “hub” renal units in the UK have on-site consultant nephrologists and inpatient beds for renal patients. Hub units in the UK are on average much larger than in most other countries. Almost all have several or many associated “satellite” units, in which routine hemodialysis treatment of patients who live in the community is carried out by nursing staff with remote supervision by nephrologists. These units are located on NHS sites that include other services, including district general hospitals or other hospital sites. Some satellite units are provided and staffed by the private sector, although medical care remains under the supervision of consultants from hub units. Transplantation is delivered by about 25 units in the UK countries.

B2.2: CKD care (non-RRT)

The UK CKD management guideline supports the management of CKD in the community and guides referral to specialist nephrology care as required. The QoF component of the General Practice contract supports the identification and appropriate management of stage 3+ CKD (see A4).

B2.3: Regional variation in structures and practice patterns for CKD care

The major source of practice variation and access to care in the UK is within countries (ie, between units) rather than between countries. Such between-unit differences appear most pronounced for shared decision-making, pre-emptive transplantation, fistula placement and home dialysis. Similarly, reduced access to care is observed chiefly in remote or socially deprived areas of the UK rather than in any particular UK country.

In the survey, 74% (n = 20) of the responders from the UK did not report any variation in CKD care organization or delivery across the different UK countries.

C. Access and quality of care

C1: Availability and access to care

CKD care and delivery including all forms of RRT is wholly covered by the NHS and accessible to all UK residents. This includes all aspects of ambulatory or hospital care inclusive of physician and diagnostic (laboratory and imaging) services. However, not all medication costs are publicly funded (Section A2.2). In general, patients on RRT receive free medications and transportation to access specialized care. Kidney transplantation is free, and immunosuppressive medications are wholly covered by the NHS.

For all medications except erythropoietin and parenteral iron (which are dispensed by the dialysis units in hospital), CKD medications are generally obtained in private pharmacies in the community.

C2: Referral criteria

National published standards for referral of patients with CKD to a nephrologist are as follows:

- Stage 4 and 5 CKD
- Significant proteinuria (PCR ≥ 100 mg/mmol, ACR ≥ 70 mg/mmol)
- Rapid progression based on clinical evaluation
- Refractory hypertension
- Presence of proteinuria and hematuria

C3: Quality management programs

Quality management programs are available for patients with ESRD through the UK Renal Registry, and for patients with CKD through the establishment of NSF and QoF.

C4: CKD registry

There is no registry for early CKD patients. A national CKD registry using electronic data is planned to emulate the national diabetes audit. The challenge is a lack of unique patient identifiers to track quality of care and outcomes. Interviewees believed that the new registry should be led by the PCPs and coordinated by the Renal Association. The QoF is an important facilitator for a national CKD registry, since the QoF provides incentives for the establishment of registers in primary care for multiple chronic diseases including CKD and its major risk factors.

A second facilitator is that every UK resident registered with the NHS has a unique identifier, and most PCP practices are now computerised with the use of electronic medical records. The main limiting factor is the lack of integration between hospital and PCP records.

D. Capacity, workforce and access to multidisciplinary teams

D1: Physician workforce

Early CKD care is provided by PCPs. As of February 2010, there were 519 renal consultants (of which 110 were women), equating to 398 full-time equivalents (FTEs) covering 75 hub units and their satellites (http://www.rcplondon.ac.uk/sites/default/files/renal-medicine-census-2010.pdf). In practice, however, the number of FTEs devoted to renal care is substantially lower since many nephrologists have commitments to general internal medicine, academic positions or administrative roles (Table 2-42).

D2: Multidisciplinary teams and other professionals

Advanced renal care is carried out by multidisciplinary teams, supervised by consultant nephrologists. The multidisciplinary teams include nurses, dieticians, psychologists, social workers, nephrologists, and vascular access and transplant coordinators. Any patient with advanced stage 4 CKD (eGFR < 20 ml/min/1.73m2) generally receives MDT service within 1 year of diagnosis.

D3: Workforce limitations

There are reported deficiencies in the number of dieticians, counsellors/psychologists, social workers and nephrologists (Table 2-42). The number of nephrologists is below the Royal College of Physicians recommendation of 570 FTE consultants in renal medicine for the UK to cover requirements in research, education and clinical service.

Table 2-42

Workforce	*Availability*
Physicians per 1000 population	2.5
Nephrologists per 1000 ESRD patients	10.3
Nephrologists per 1000 CKD patients	0.08
Nurses per 1000 population	7.7
Presence of multidisciplinary teams for CKD	yes
Disciplines with most pronounced lack of capacity for CKD care, in the opinion of survey respondents	Dieticians, Counselors/psychologists, Renal social workers, Nephrologists

E. Barriers to optimal CKD care

E1: Top five barriers to optimal CKD care (in descending importance)

1. Political factors
2. Economic factors
3. Organizational factors
4. Care providers' and policymakers' awareness of early detection and prevention of CKD
5. General population's and patients' awareness of early detection and prevention of CKD

Political factors

CKD is not recognised as a politically important topic in the same way as diabetes, dementia, cancer or vascular disease. In contrast to these other conditions, few questions are asked in parliament about CKD care or access to it.

Economic factors

The 2008 global financial crisis led to reduced funding for most public services, which is perceived to have affected CKD care.

Organizational factors

- Primary care is represented by heterogeneous groups across the UK despite a standard centralised NHS system. There are 8500 to 8600 primary care practices in England and 10,000 to 11,000 in the UK as a whole.
- There is a perceived lack of coordination in primary and secondary care, and often a lack of good relationships among providers who are jointly responsible for CKD care.
- Although progress has been made in educating primary care providers about the importance of CKD, case finding for CKD among people at risk continues to be variable. The major barriers are thought to be lack of education and failure to appreciate the significance of CKD. Focusing on survivors of acute kidney injury is considered an important potential way to address this barrier.

CKD awareness

Overall, awareness of the importance of CKD is low among care providers, policymakers, patients and the general population. Lack of media attention is felt to be an important but potentially reversible barrier.

F. CKD burden and risk factors

F1: Epidemiology of ESRD

In 2010, the number of adult patients starting RRT in the UK was 6,610, equating to an incidence rate of 106.2 pmp. Diabetes and glomerulonephritis are the leading causes of ESRD. The incidence rate has been stable over the last decade. As of December 31, 2010, there were 51,087 adult patients receiving RRT in the UK. The prevalence of RRT was 820.5 pmp in 2010, an increase of 0.37% from 2009. From 2009 to 2010 the prevalence of HD patients decreased by 2.1%, the prevalence of PD fell by 11%, and the prevalence of patients with a functioning transplant increased by 7.2%. The number of patients receiving home HD increased by 5.9%, although the absolute increase in the number of patients was small (609 to 645 patients). Transplantation and HD were the most common prevalent RRT modalities (47% and 45% of RRT patients, respectively) and PD was used in 8%. The prevalence of patients with a functioning transplant at the end of 2010 was 373.2 pmp.[13-15]

F2: Epidemiology of CKD

Nationally representative data suggest that the prevalence of CKD is 10.6% and 5.6% in females and males respectively (~8.5% overall).[16] These data are supplemented by reports from QoF Register, Health Survey of England and Quality Improvement in CKD (QICKD) (Table 2-43).[17]

F3: Data on costs of CKD

ESRD care is funded exclusively by the public sector (NHS). About 1–2% of total healthcare expenditures across the UK countries are spent on ESRD care. The NHS in England spent an estimated £1.45 billion on CKD in 2009–10, equivalent to £1 of every £77 of NHS expenditure.[18] This estimate includes the costs of treatment directly associated with CKD (renal care and prescribing to prevent disease progression), and also costs of treatment for excess non-renal problems such as strokes, heart attacks and infections in people with CKD. In the case of non-renal problems, costs are estimated only for excess events, over and above the expected number for people of the same age and sex who do not have CKD. There were no comparable data from other countries to confirm these published data, which therefore should be interpreted with caution.

Table 2-43 Estimated CKD prevalence, stages 3–5 CKD (non-RRT)

Source	*Coverage*	*Population*	*Male*	*Female*	*All*	*Estimated burden of CKD stages 3–5*
Quality and Outcomes Framework (QoF) register 2011–2012	National	General (≥18 years)			11.7%	5.1 million
Health Survey for England (HSE) 2010	National	General (≥16 years)	6%	7%	6.5%	2.71 million
New Opportunities for Early Renal Intervention by Computerised Assessment (NEOERICA) project	Primary care at Kent, Manchester, Surrey (130,226 adults)	General (≥18 years)	5.8%	10.6%	8.5%	3.64 million
Quality Improvement in CKD (QICKD) study	129 general practices in England (930,997 patients)	All adults	3.5%	7.3%	5.4%	2.81 million (97% at stage 3)

F4: CKD risk factors

A high burden of risk factors is associated with CKD at the population level, including increasing age, diabetes, hypertension, smoking and obesity (Table 2-44).

Table 2-44

Risk factors	*Prevalence (year)*
Age >65 years	15.8% (2009)
Diabetes	6.8% (2011)
Hypertension	43.5% (2011)
Smoking	21.5% (2009)
Alcohol use	10.2 L* (2009)
Obesity	15.2% (2008)

*Mean annual consumption per capita.

G. Perceptions of care (providers, patients and policymakers)

G1: Efficiency of CKD care delivery

Efficiency of CKD care delivery was rated as above average by 67% of respondents to the KH4L survey and as average by 27%. Strengths of the existing system are felt to be a strong network of advocates for CKD care within the UK renal community, the universal healthcare system, the QOF pay-for-performance framework for CKD management and a health system that allows CKD to be treated as a policy priority even though it is not a political priority. The existence of the National Clinical Director position is felt to enable the centralized and coordinated care strategies that enhance CKD care delivery across the UK.

G2: Patient education

Primary care providers are not felt to have sufficient time to educate patients about CKD. Although renal charities and foundations are felt to be effective potential allies, these organizations have traditionally focused on ESRD (dialysis and transplantation). According to the CEAPIR European Kidney Patients' Federation 2011 survey, about 70% patients say they have never received education to help them manage in their CKD.[19] Educational materials are available for all severities of CKD but patients on RRT appear to be much more engaged in educational activities.

G3: Patients' involvement in their care

Patients' involvement was rated as average in the KH4L survey. According to the CEAPIR European Kidney Patients' Federation 2011 survey results, about 50% of CKD patients feel they were very involved in making decisions about their treatment.[19]

G4: Patients' perceptions of quality of care received

Quality of care was rated as above average in the KH4L survey. According to the CEAPIR European Kidney Patients' Federation 2011 survey results, about 50% of patients are very satisfied with care for their kidney disease, and another 15% are somewhat satisfied.[19]

H. Opportunities for and obstacles to improvement

H1: Opportunities

- Universal healthcare system and well-developed infrastructures.
- National director for kidney care in the Department of Health, with responsibility for care coordination and quality assurance nationally.
- Renal association and community working in partnerships with other groups such as the diabetes association across the various UK countries.
- Greater public involvement and awareness in CKD care.
- Information technology for CKD data surveillance.
- Improvement in the coordination of CKD care since the publication of the NSF and QoF.
- Integrated care model with major NCDs at the Department of Health (though there is concern that CKD could be more prominent).
- Pan-vascular prevention policy: Health Check program conducted every 5 years (2009) aims to help prevent heart disease, stroke, diabetes and CKD in those aged 40–74 years.
- High level policymaker involvement in devising CKD care strategies.
- Early detection strategies: for the 2009 and 2010 Health Surveys, NHS Kidney Care funded the inclusion of measures of kidney function, providing an opportunity for population-based studies on CKD in the survey group.

H2: Obstacles

- Limited funding and economic factors with ever-increasing competing priorities.
- Low political awareness and involvement. CKD is not seen as a politically important topic compared to cancer, CVD and dementia.
- Complex nature of CKD with frequent presence of multiple comorbidities.

- Limited contact time between patients and primary care providers. Even the QoF fails to identify many CKD patients because the demands of the QoF with regard to other chronic diseases (eg, diabetes, CVD, hypertension) leave insufficient time for the renal care indicators.
- Limited media involvement in CKD.
- Heterogeneous organizational system with different funding mechanisms for primary and secondary care between the various UK countries.
- Poor coordination between primary and secondary care.
- Low awareness of CKD among patients, policymakers and primary care practitioners.
- Funding bodies and charities focused only on ESRD.
- Rapid changes in high-level policy direction, which have led to major changes to the way that healthcare is delivered, with consequent impact on CKD care.

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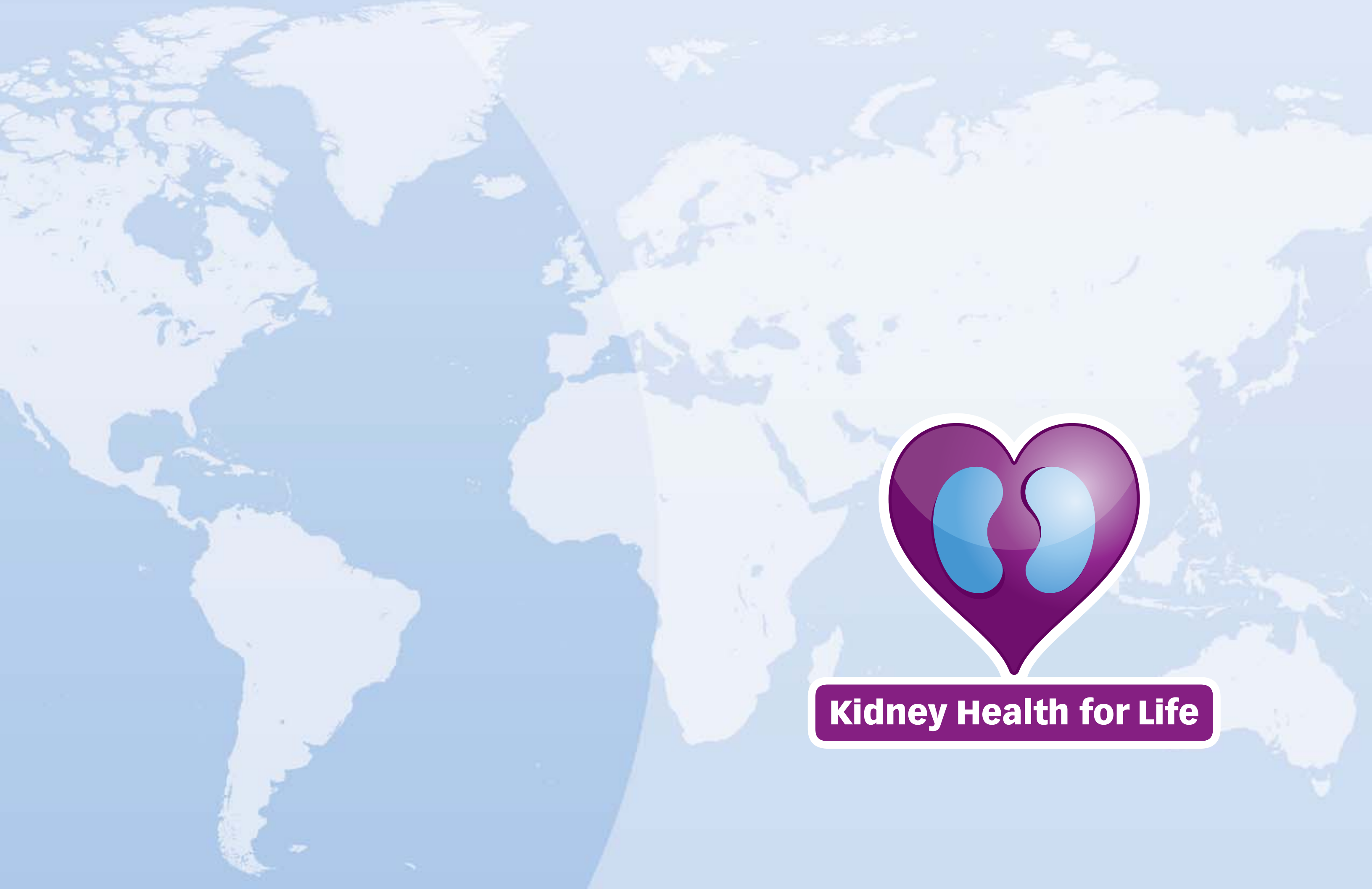
Kidney Health for Life (KH4L)

Chronic Kidney Disease
Multinational Inventory

Section 3

Summary of Findings



A. Health systems, policies and structures

Clearly defined governance structure, policies (vision and direction) and strategies (plans for implementation) are essential elements of an efficient healthcare delivery system in all nations. These elements listed below are covered in this section, which summarizes key findings from the individual country chapters.

Definitions of terms:

A1. The governance structure:

The organization of government and the specific roles of each tier of government (central, regional, local) on policy, strategy and delivery of healthcare in a country.

A2. Healthcare system organization:

The structures in place (institutions, people and resources) for healthcare delivery. These structures encompass level of coverage (universal or not), care provision (primary, secondary/tertiary), copayments and financing, roles of physicians and other personnel, and interrelationships between providers (referral and gatekeeping system).

A3. Physician compensation:

This refers to the predominant method of provider (physician) remuneration for healthcare services delivered in a country. There are three main types of physician compensation:[1, 2]

- Fee-for-service (FFS): an agreed upon value is associated with each service provided.
- Salary: providers are paid a negotiated amount of money for a fixed period of time, in return for which they provide specified services. The number of patients seen, services provided and the cost of services do not affect the payment made to a care provider.
- Capitation: providers are paid in return for providing a set of specified services to patients for a defined period of time.

A4. NCD policy:

This refers to a country having at least one policy plan in place to address NCDs and associated risk factors, irrespective of whether the policy or strategy is operational.[3]

A5. CKD-specific policies, guidelines or service frameworks:

These entail a specific official decision or set of decisions aimed at executing a government-endorsed course of action, including goals, priorities and next steps. Guidelines refer to a recommended (ideally evidence-based) course of action for providers. Service frameworks are defined pathways for clinical care implementation. Policy documents may include a strategy to implement the policy or framework, and may use guidelines (and associated dissemination strategies) to help implementation. We have naturally focused on policies, frameworks and guidelines that address the early detection and management of CKD.

A1. Governance structure

The 19 countries included in the inventory are all democracies with well-defined systems of government: generally as three-tier structures with central, regional (state, canton or provincial) and local (municipal) levels. The only exception was the United Kingdom, which uses a two-tier structure of a national and local (municipal) government (Figure 3.1).

A2. Healthcare system organization

Healthcare coverage

The healthcare systems in all included countries are predominantly publicly funded and provide universal coverage at least at a basic level for all types of essential services – including physician and diagnostic (imaging and laboratory) services and medications. However, the precise scope of coverage varies by services across countries (Figure 3.2).

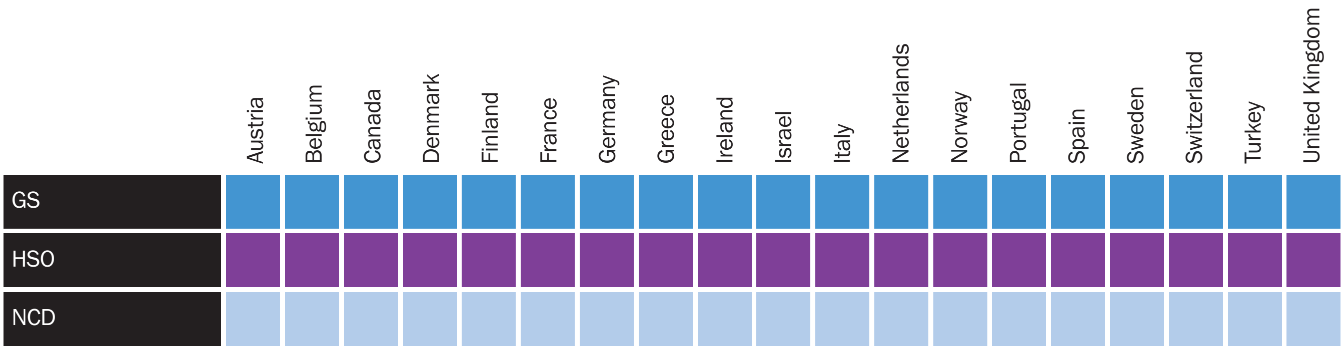
Copayments

Copayments are in place for all countries, mainly for pharmaceuticals and services (clinic attendance/consultations) (Figure 3.2). However, all countries have a safety net to reduce or eliminate copayments for those of limited means (eg, low-income persons, the elderly population, and persons with chronic debilitating diseases).

Healthcare financing

The included countries have different healthcare financing systems which can be broadly grouped into national health insurance (NHI) and social health insurance (social security) schemes (Table 3-1).

Figure 3.1 Health systems, policies and structures



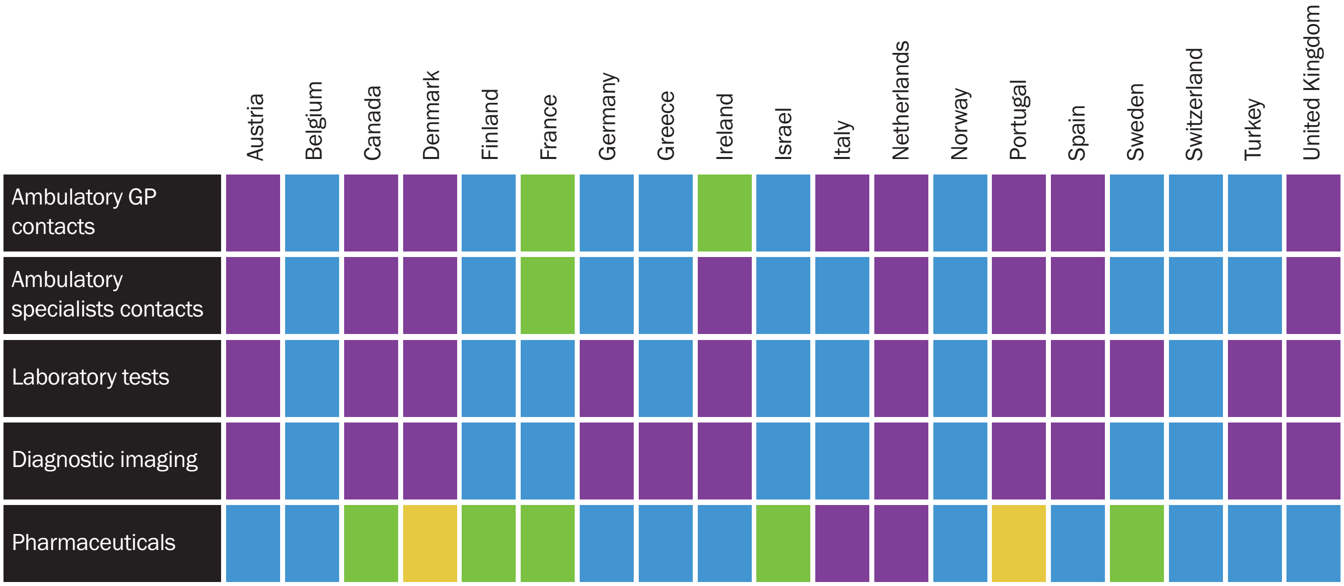
	Austria	Belgium	Canada	Denmark	Finland	France	Germany	Greece	Ireland	Israel	Italy	Netherlands	Norway	Portugal	Spain	Sweden	Switzerland	Turkey	United Kingdom
GS	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦
HSO	🟪	🟪	🟪	🟪	🟪	🟪	🟪	🟪	🟪	🟪	🟪	🟪	🟪	🟪	🟪	🟪	🟪	🟪	🟪
NCD	⬜	⬜	⬜	⬜	⬜	⬜	⬜	⬜	⬜	⬜	⬜	⬜	⬜	⬜	⬜	⬜	⬜	⬜	⬜

🟦 GS = Governance structure – responsibility for policy and strategy rests with the central government

🟪 HSO = Health system organization – Universal coverage and predominantly funded

⬜ NCD = Non-communicable diseases (NCDs) strategy in place

Figure 3.2 Spectrum of general health care coverage across countries (not specific to CKD)



	Austria	Belgium	Canada	Denmark	Finland	France	Germany	Greece	Ireland	Israel	Italy	Netherlands	Norway	Portugal	Spain	Sweden	Switzerland	Turkey	United Kingdom
Ambulatory GP contacts	🟪	🟦	🟪	🟪	🟦	🟩	🟦	🟦	🟩	🟦	🟪	🟪	🟦	🟪	🟪	🟦	🟦	🟦	🟪
Ambulatory specialists contacts	🟪	🟦	🟪	🟪	🟦	🟩	🟦	🟦	🟪	🟦	🟦	🟪	🟦	🟪	🟪	🟦	🟦	🟦	🟪
Laboratory tests	🟪	🟦	🟪	🟪	🟦	🟦	🟪	🟦	🟪	🟦	🟦	🟪	🟦	🟪	🟪	🟪	🟦	🟪	🟪
Diagnostic imaging	🟪	🟦	🟪	🟪	🟦	🟦	🟪	🟪	🟪	🟦	🟦	🟪	🟦	🟪	🟪	🟦	🟦	🟪	🟪
Pharmaceuticals	🟦	🟦	🟩	🟨	🟩	🟩	🟦	🟦	🟦	🟩	🟪	🟪	🟦	🟨	🟦	🟩	🟦	🟦	🟦

🟪 100% Coverage

🟦 76 – 99% Coverage

🟩 51 – 75% Coverage

🟨 1 – 50% Coverage

Table 3-1 Organization of health systems based on funding mechanism

National Health Service (Beveridge) system	*Social Health Insurance (Bismarck) system*
Canada	Austria
Denmark	Belgium
Finland	France
Ireland	Germany
Italy	Greece
Israel	Netherlands
Norway	Switzerland
Portugal	Turkey*
Spain	
Sweden	
UK	

* Approximately 20–30% of the population is not covered by the scheme and is thus uninsured (OECD, 2010).

Table 3-2 Ranked total healthcare spending as a percentage of GDP

Ranking	*Country*	*Healthcare spending (% of GDP)*
1	Netherlands	12.0
2	France	11.6
3	Germany	11.6
4	Canada	11.4
5	Switzerland	11.4
6	Denmark	11.1
7	Austria	11.0
8	Portugal	10.7
9	Belgium	10.5
10	Greece	10.2
11	UK	9.6
12	Spain	9.6 *
13	Sweden	9.6
	OECD average	9.5
14	Norway	9.4
15	Italy	9.3
16	Ireland	9.2
17	Finland	9.0
18	Israel	7.4
19	Turkey	6.7 (2009)

Source: OECD (2010).
* Source: OECD (2009).
GDP = Gross domestic product.

Eleven of the countries have an NHS (the so-called Beveridge system), where healthcare is predominantly financed from taxation, and the remaining eight countries use a social health insurance (the Bismarck system), which is based on income-related social contributions from citizens, often supplemented by government tax-financed revenues.

According to the OECD Health Data (2010) a significant share of the economy in all of the inventory countries is devoted to health: 13 of the countries spend above the OECD average of 9.5%, and the remainder spend less than average; Israel and Turkey spend the least (Table 3-2). Spending by the general government (public sector) accounted for the largest share of expenditures on health in all inventory countries (Figure 3.3).

Organization of care delivery

In general, health services in the included countries are structured into the standard categories of primary, secondary and tertiary healthcare. Primary care is usually the first point of contact with healthcare and is typically provided by PCPs, for which different countries use different terminologies: general practitioners [GPs], family doctors, family physicians, basic doctors, etc. Secondary healthcare is generally provided by specialists accessible in a hospital or an ambulatory care facility, and is usually accessed by referral from a PCP. Tertiary healthcare encompasses specialized consultative services, often provided in academic/university hospitals. Since tertiary care may overlap with secondary care in some countries, these two categories are considered together in the current inventory and referred to as “specialist” care. The models for delivery of primary and specialist care vary substantially across countries by locations of where care is being delivered (Figures 3.4, 3.5). To access treatment in a primary care facility in most countries (with the exception of Austria, Canada, Finland, Greece, Ireland, Sweden and Turkey), registration with a PCP is required (Figure 3.6). Similarly, in order to access specialist care in all countries (except Austria, Greece, Sweden and Turkey), referral from a PCP is essential (Figure 3.6).

A3: Physician compensation

There is substantial variation across countries in the modalities used to compensate PCPs and specialists. Primary care providers are most commonly paid through a combination of capitation, FFS and salary. Specialists are most commonly paid by salary in the NHS tax-funded systems, while social insurance systems most commonly

Figure 3.3 ***Expenditure on health by type of financing***

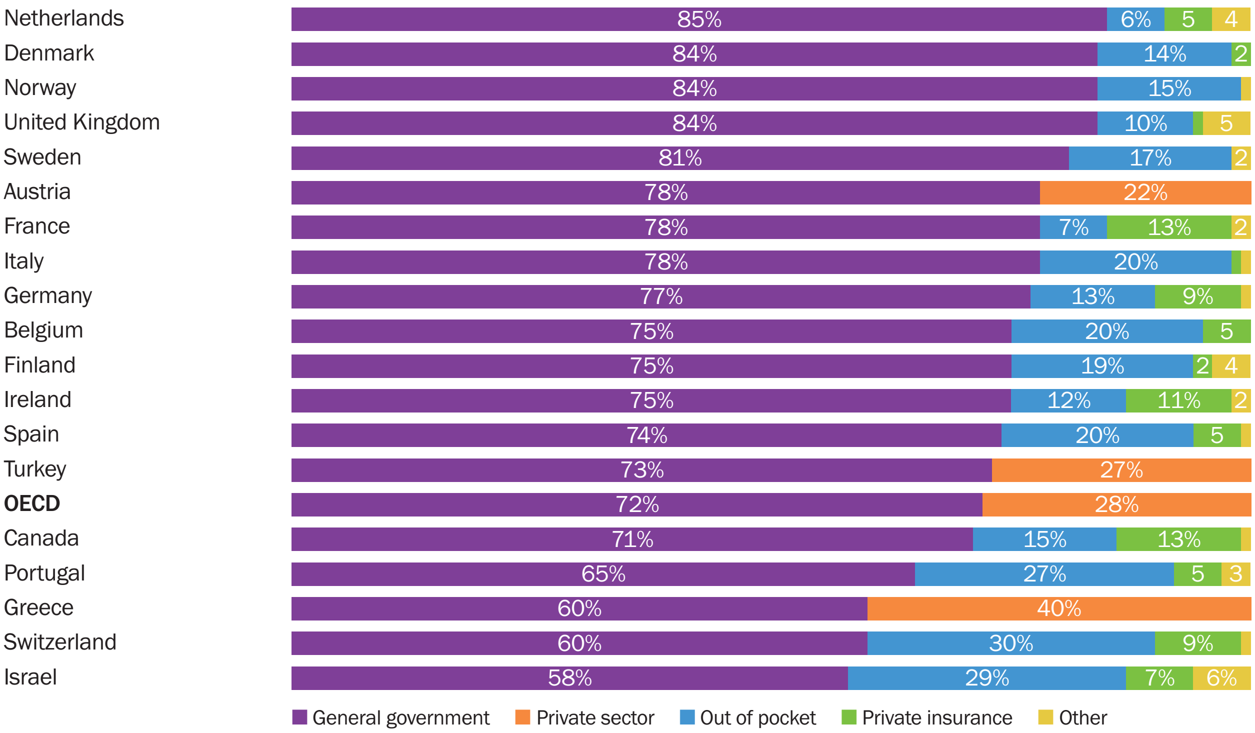


Figure 3.4 ***Predominant mode of provision of primary care services (not specific to CKD)***

Private Group Practices	Private Solo Practices	Public Centres
Canada	Austria	Finland
Denmark	Belgium	Israel
Netherlands	France	Italy
United Kingdom	Germany	Portugal
	Greece	Spain
	Ireland	Sweden
	Norway	Turkey
	Switzerland	

Figure 3.5 ***Predominant mode of provision of specialists care services (not specific to CKD)***

Private Group Practices	Private Solo Practices	Public Centres
Netherlands	Austria	Canada
	Belgium	Finland
	Denmark	Ireland
	France	Israel
	Germany	Italy
	Greece	Portugal
	Norway	Spain
	Switzerland	Sweden
		Turkey
		United Kingdom

Figure 3.6 Gatekeeping for access to specialist care across countries (not specific to CKD)

	Austria	Belgium	Canada	Denmark	Finland	France	Germany	Greece	Ireland	Israel	Italy	Netherlands	Norway	Portugal	Spain	Sweden	Switzerland	Turkey	United Kingdom
Registration with a primary care physician	🟦	🟪	🟦	🟪	🟦	🟪	🟪	🟦	🟦	🟪	🟪	🟪	🟪	🟪	🟪	🟦	🟪	🟦	🟪
Referral to access secondary care	🟦	🟪	🟪	🟪	🟪	🟪	🟪	🟦	🟪	🟪	🟪	🟪	🟪	🟪	🟪	🟦	🟪	🟦	🟪

🟪 Required 🟦 No obligation

Figure 3.7 Predominant mode of payment for primary care physician services (not specific to CKD)

FFS	Cap	Salary	FFS/ Cap	FFS/Salary	Salary/Cap	FFS/ Salary/Cap
Belgium	Italy	Greece	Austria	Turkey	Spain	Finland
Canada		Portugal	Denmark			United Kingdom
France		Sweden	Netherlands			
Germany		Israel	Norway			
Ireland						
Switzerland						

Figure 3.8 Predominant mode of payment for outpatient specialist services (not specific to CKD)

FFS	Cap	Salary	FFS/ Cap	FFS/Salary	Salary/Cap	FFS/ Salary/Cap
Austria		Denmark		Greece		
Belgium		Finland		Norway		
Canada		Ireland		Israel		
France		Italy		Netherlands		
Germany		Portugal		Turkey		
Switzerland		Spain				
		Sweden				
		United Kingdom				

Cap = Capitation, FFS = Fee for service

use FFS. However, these patterns are not universal, since, for example, Canada (which has an NHS) pays both PCPs and specialists predominantly by FFS (Figures 3.7, 3.8). Finally, certain countries (the UK and Sweden) include performance-based reimbursement (incentives) for PCPs.

A4: NCD policy

All included countries are signatories to the World Health Assembly adopted resolution (WHA64.11), a WHO action plan for the prevention and control of NCDs for 2013–2020, building on lessons learned from the 2008–2013 action plans. This policy document consists of a specific agenda for reducing the harm associated with CVD, cancer, diabetes, tobacco and alcohol. Each signatory country must establish a department in its MOH that is responsible for NCD control, and which leads programs for NDC treatment, prevention/health promotion, surveillance, monitoring and evaluation (WHO, Non-communicable Diseases Country Profiles, 2011). This resolution includes a defined action plan and an agreed set of voluntary targets to be implemented by all signatory countries, with an overarching principle of according NCDs the right recognition they deserved as obstacles to socio-economic development. The essential elements of achieving these targets are a universal and equitable access to healthcare, life-course approach to chronic disease, and management based on evidence and full engagement of people and communities. Therefore, to some extent all countries that are included in the current inventory can be said to have a national NCD policy.

A5: CKD-specific policies, guidelines and/or service frameworks

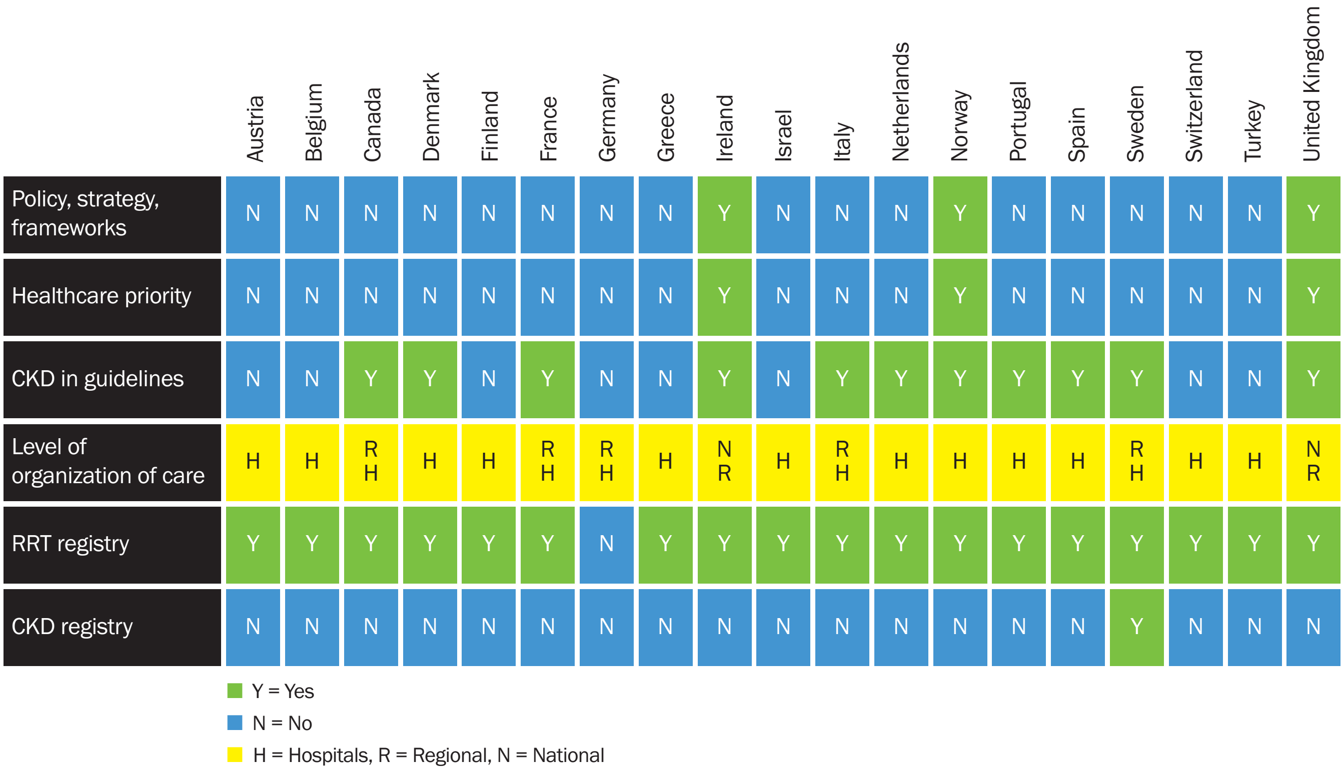
CKD-specific policies and/or service frameworks

Only three inventory countries (Ireland, Norway and the UK) have a national specific policy or a service framework for CKD (Figure 3.9). (See relevant specific country section: A5.1).

CKD as a healthcare priority

Our survey suggests that governments generally do not consider CKD a health priority. In only three inventory countries (UK, Ireland and Norway) did the majority of respondents (>75%) believe that CKD was recognized as a health priority by the national (federal) government (Figure 3.9).

Figure 3.9 Organization and structure of CKD care



	Austria	Belgium	Canada	Denmark	Finland	France	Germany	Greece	Ireland	Israel	Italy	Netherlands	Norway	Portugal	Spain	Sweden	Switzerland	Turkey	United Kingdom
Policy, strategy, frameworks	N	N	N	N	N	N	N	N	Y	N	N	N	Y	N	N	N	N	N	Y
Healthcare priority	N	N	N	N	N	N	N	N	Y	N	N	N	Y	N	N	N	N	N	Y
CKD in guidelines	N	N	Y	Y	N	Y	N	N	Y	N	Y	Y	Y	Y	Y	Y	N	N	Y
Level of organization of care	H	H	R H	H	H	R H	R H	H	N R	H	R H	H	H	H	H	R H	H	H	N R
RRT registry	Y	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
CKD registry	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	Y	N	N	N

🟩 Y = Yes
🟦 N = No
🟨 H = Hospitals, R = Regional, N = National

Table 3-3 CKD guidelines, by country

Country	Presence of national guidelines (Y/N)	Notes
Austria	No	National guidelines are available for diabetic nephropathy only. In some centres, nephrologists use the international KDIGO guidelines.
Belgium	No	There are no national or regional guidelines for CKD management. In some centres, nephrologists use the international KDIGO guidelines.
Canada	Yes	There are national guidelines, with variable implementation across the provinces.
Denmark	Yes	There are national guidelines for CKD management.
Finland	No	There are no national guidelines for CKD management. Some regional guidelines exist (there are differences between regions) but are not widely implemented. Diabetes and CVD guidelines recommend checking for serum creatinine as part of patients' assessment.
France	Yes	There are national guidelines for CKD management but they are not widely implemented.
Germany	No	There are no national or regional guidelines for referral and management of CKD. Screening for CKD is integrated in diabetes guidelines (Versorgungsleitlinie), but is not well implemented nationally. The KDIGO guidelines (CKD, transplantation, AKI) have been translated into German and approved by the German Guidelines Institute but are not widely implemented.
Greece	No	There are no national or regional guidelines for CKD management. However, the KDIGO or European Best Practice guidelines are used in everyday clinical practice and are popular in the Greek nephrology community. Moreover, the Hellenic Nephrology Society has already endorsed these guidelines, translated them and included them on its website.
Ireland	Yes	There are national guidelines for referral and management of CKD. These are currently established by the Irish Nephrology Society; National Renal Office Guidelines in 2014.
Israel	No	There are no existing national or regional guidelines for CKD management. But these are being developed by the Israeli Society of Nephrology (under revision at the Ministry of Health).
Italy	Yes	From the National Institute of Health (Istituto Superiore di Sanità, ISS), guidelines have been issued (January 2012) jointly by the Italian Society of Nephrology and several other societies (laboratory medicine, diabetology, hypertension, cardiology, endocrinology). These guidelines are updates of the UK NICE guidelines and are not widely implemented. A few regions (Lombardy, Campania and Sicily) have local CKD guidelines with variable rates of implementation.
Netherlands	Yes	There are national guidelines for referral and management of CKD, but with limited implementation across care providers.
Norway	Yes	There are national guidelines for management of CKD, but with limited implementation across care providers.
Portugal	Yes	There are national guidelines for referral and management of CKD.
Spain	Yes	There are national guidelines for referral and management of CKD.
Sweden	Yes	There are national guidelines for referral and management of CKD.
Switzerland	No	There are no national or regional guidelines for CKD management.
Turkey	No	There are no national or regional guidelines for CKD management.
United Kingdom	Yes	National guidelines for CKD management were developed initially by the UK Renal Association in March 2005 (and updated with NICE guidelines in September 2008).

CKD = Chronic kidney disease, KDIGO = Kidney Disease: Improving Global Outcomes, NICE = National Institute for Health and Care Excellence.

CKD in guidelines

Eleven countries have national CKD management guidelines, developed either by government-funded agencies (eg, NICE in the UK) or professional associations (eg, Canadian Society of Nephrology in Canada) (Figure 3.9; Table 3-3). These guidelines generally include recommendations on:

- Identification of patients with CKD
- Assessment of kidney function and proteinuria
- Management and referral of CKD
- Criteria for RRT initiation
- Conservative management (no RRT).

Structures/systems for monitoring uptake of guidelines

None of the included countries have established schemes to monitor adherence to national CKD guidelines. The UK QoF rewards performance for achieving certain thresholds in quality of care parameters (See Section 2: UK B2.2).

CKD care advocacy

Of the inventory countries only the Netherlands has a specific advocacy group at any level of government aimed at increasing awareness of early CKD. The few kidney-related advocacy organizations in other countries are mainly kidney foundations that generally focus on patients on RRT and advanced CKD (Table 3-4).

Table 3-4 Early CKD care advocacy across countries

Country	Presence (Y/N)	Notes
Austria	No	The patients' association, an advocacy group that focuses mainly on patients with ESRD.
Belgium	No	
Canada	No	The Kidney Foundation of Canada
Denmark	No	Advocacy for ESRD patients only
Finland	No	
France	No	The Kidney Foundation of France, an advocacy group that focuses mainly on patients with ESRD.
Germany	No	
Greece	No	
Ireland	No	The Irish Kidney Association, an advocacy group at the patient level, focused on the ESRD population.
Israel	No	Advocacy group with focus on ESRD only.
Italy	No	
Netherlands	Yes	The Dutch Kidney Foundation (together with the Heart & Diabetes association), constitutes an advocacy group promoting a CKD agenda to the government, and focusing not only on ESRD but on early CKD as well.
Norway	No	
Portugal	No	
Spain	No	
Sweden	No	
Switzerland	No	
Turkey	No	
United Kingdom	No	The Parliamentary Kidney Alliance Group, an advocacy group whose function is to raise the profile of CKD with government, focusing, however, on ESRD patients only.

B. Structure and organization of CKD care

This section explores the structure and organization of CKD care, including the roles and responsibilities of care providers (PCPs, nephrologists and other specialists). Structure here refers to the existence of appropriately staffed and equipped facilities for provision of CKD care. Organization refers to a deliberate arrangement by government to arrange the structures to deliver effective CKD care. This section also highlights variations between and within countries in the structure and organization of CKD care.

Oversight of CKD care is the responsibility of individual hospitals and/or regional authorities in all countries – with the exception of the UK and Ireland, each of which has a national directorate to coordinate renal care (Figure 3.9).

B1: Role of care providers

In general, PCPs are responsible for early CKD care although other specialists such as diabetologists / endocrinologists, cardiologists and internists may be involved. There is little consistency across countries regarding the relative roles of PCPs versus nephrologists and other specialists in early CKD care (Figure 3.10). However, in most countries, CKD patients are identified by PCPs and then referred to specialist nephrology care. Nephrology referral most commonly occurs once CKD is advanced (stages 3b–5), and nephrologists are responsible mainly for advanced CKD and/or RRT care (Figure 3.10).

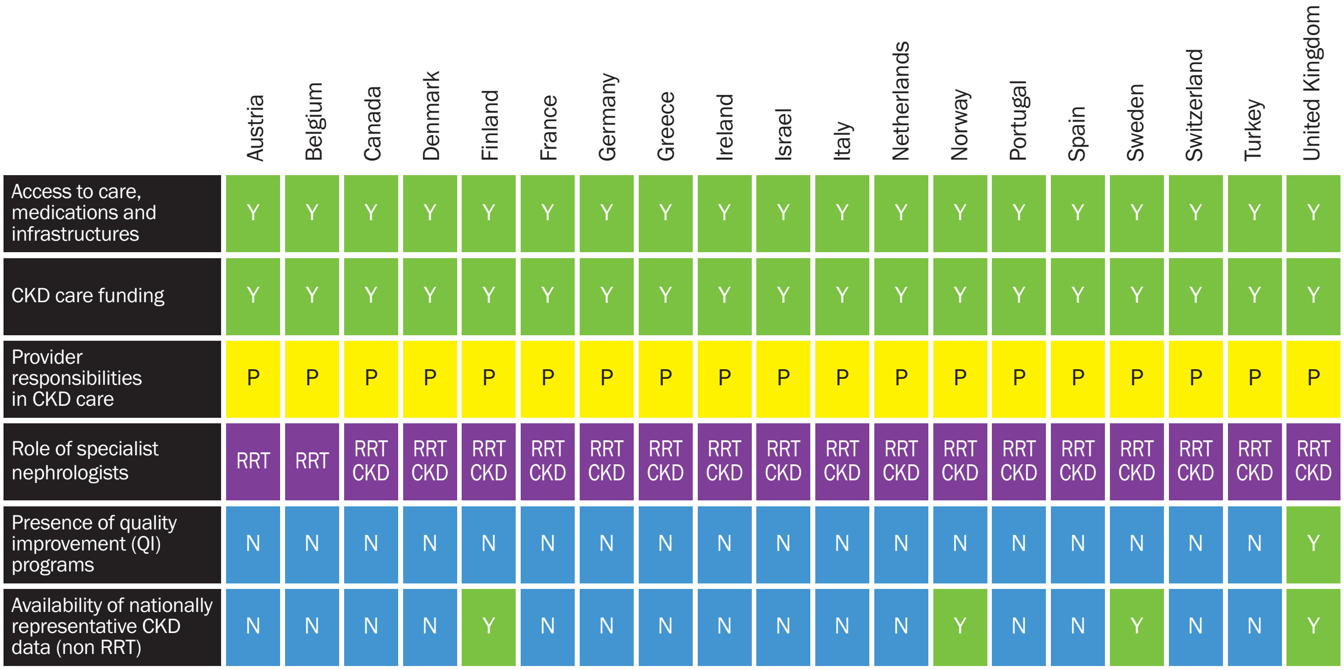
B2: CKD care structures

All countries have highly organized systems in place to provide RRT care. However, no organized systems or care pathways are in place for early CKD care except in the UK (See Section 2, UK chapter: A4).

Regional variation in structures and practice patterns for CKD care

How CKD care is organized varies considerably between and within countries (Table 3-5).

Figure 3.10 Access and quality of care for CKD



	Austria	Belgium	Canada	Denmark	Finland	France	Germany	Greece	Ireland	Israel	Italy	Netherlands	Norway	Portugal	Spain	Sweden	Switzerland	Turkey	United Kingdom
Access to care, medications and infrastructures	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
CKD care funding	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Provider responsibilities in CKD care	P	P	P	P	P	P	P	P	P	P	P	P	P	P	P	P	P	P	P
Role of specialist nephrologists	RRT	RRT	RRT CKD	RRT CKD	RRT CKD	RRT CKD	RRT CKD	RRT CKD	RRT CKD	RRT CKD	RRT CKD	RRT CKD	RRT CKD	RRT CKD	RRT CKD	RRT CKD	RRT CKD	RRT CKD	RRT CKD
Presence of quality improvement (QI) programs	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	Y
Availability of nationally representative CKD data (non RRT)	N	N	N	N	Y	N	N	N	N	N	N	N	Y	N	N	Y	N	N	Y

🟩 Y = Yes
🟦 N = No
🟨 P = Primary care

Table 3-5 Regional variation in structures and practice patterns for CKD care across countries

Country	Presence (Y/N)	Notes
Austria	No	Reported differences in chronic disease management priorities (for instance, some Länders have well-developed diabetes management program, and some others have none).
Belgium	No	No major variation in CKD care in North, South or the German parts of Belgium. Cultural differences are noticeable in patients' attitudes toward their care. But these differences did not generally translate into structural differences in chronic disease care delivery.
Canada	No	Different structures and care policies across provinces and territories. No national standards but because of the universal nature of healthcare, no major differences in the way care is organized or delivered.
Denmark	No	No major practice variations across regions or municipalities.
Finland	No	
France	Yes	Some variations across regions and hospitals in the organization and delivery of CKD care.
Germany	No	No variation in terms of structures, workforce and patient characteristics.
Greece	No	No variations across states or municipalities.
Ireland	Yes	Renal practices in the country are organized into four clinical regions, between which there are certain variations particularly in human resources (staffing ratios for nephrologists and nursing staff), infrastructural supports (eg, some units have dedicated inpatient facilities for kidney patients, while others do not), service provision (some offer facilities for home therapies, while others do not) and clinical information systems (some places have no electronic care facilities).
Israel	No	No major practice variations across the administrative regions (districts).
Italy	Yes	Substantial inequalities in levels of service provision in renal care in the Northern and Southern parts of Italy. These might be linked with relevant economic disparities among regions: some regions have enormous resources (eg, Lombardy has a GDP like that of Germany), while others are limited in resources (eg, Calabria has a GDP like that of Greece). These disparities translate also into major organizational and managerial differences.
Netherlands	No	No regional variations in structures, organization and care delivery systems.
Norway	Yes	Geography plays a significant role in differences in practice patterns across northern and southern Norway. Recruitment of health personnel, particularly doctors and specialized nurses, is difficult in rural areas, particularly in the north.
Portugal	Yes	Some remote/rural regions have poor access to specialist care.
Spain	Yes	There are 17 regions, each of which has its own health department, so there is no uniformity in policies, structures or systems for delivery of chronic disease care (including CKD).
Sweden	Yes	Substantial variation in the organization and delivery of primary care among the 21 county councils with different policy focus according to unique needs and circumstances. It is not clear how this directly affects CKD care as no data on quality of care and related outcomes are available.
Switzerland	Yes	The healthcare system is not centrally coordinated, and each canton has its own delivery system and priorities, which could affect how CKD care is organized across the various administrative regions.
Turkey	Yes	Gaps in care provision are due to geographical imbalances (rural/remote communities). Some areas, particularly in the Eastern and Black Sea regions of the country, are unable to provide certain specialist services because personnel or facilities are not available.
United Kingdom	Yes	The major source of variation and access to care in the UK predominantly reflects individual renal units' differences in practice pattern rather than major structural differences between countries. Such between-unit differences appear most pronounced for shared decision-making in CKD care, pre-emptive transplantation, fistula placement, and home dialysis. Similarly, reduced access to care is chiefly observed in remote or socially deprived areas of the UK rather than in any particular UK country.

C. Access and quality of care

This section covers access to care; quality of care delivery (structures, processes and outcomes); and availability of quality management programs and disease surveillance systems.

Access to care refers to the ease with which health services are used. This term encompasses diverse components, in that barriers to access can take many different forms such as physical barriers (geography, travel distance), financial barriers (out-of-pocket payments or copayments for healthcare) or psychological/social barriers. Further, ensuring access requires that appropriate health services be available for use.[4]

Quality of care refers to the extent to which health services improve desired health outcomes. The care should be based on the strongest clinical evidence and provided in a technically and culturally competent manner with good communication and shared decision-making.[5]

C1: Availability and access to care

All included countries have a universal healthcare system that strives for equitable access to health care, and/or that facilitates access based on need rather than ability to pay. Despite this, access to care is at least partly contingent upon financial factors, such as the degree of copayment for medications or services.[6] In all included countries, basic health care services are free at the point of delivery, and mechanisms exist to reduce the financial burden associated with copayments. Thus, we did not identify access to facilities, services, or medications as major barriers to good CKD care for any country overall (Figure 3.10). However, this overall judgment does not consider individual-level factors that likely do influence access to care (such as race, social status, educational attainment, mobility status), or regional differences in specialist availability, travel time, etc, that may influence access to care within particular countries.

C2: Referral criteria

Only seven of the inventory countries have national published standards for appropriate referral of patients with CKD to a nephrologist (Table 3-6).

Table 3-6 Nationally published standards for referral of patients with CKD to a nephrologist, by country

Country	Presence (Y/N)	Notes
Austria	No	National criteria under development.
Belgium	No	
Canada	Yes	
Denmark	Yes	
Finland	No	Only regional guidelines but not widely used.
France	Yes	Not widely implemented.
Germany	No	
Greece	No	65–70% of referred CKD patients in Greece visit a nephrologist for the first time at an advanced stage of CKD.
Ireland	Yes	
Israel	No	
Italy	No	
Netherlands	Yes	
Norway	No	In development. Currently multiple county-level or hospital-level guidelines are available in some regions.
Portugal	No	
Spain	No	There are defined criteria for nephrology referrals with variation across regions. National criteria are under development.
Sweden	Yes	
Switzerland	No	
Turkey	No	
United Kingdom	Yes	

C3: Quality improvement programs

Quality improvement (QI) strategies constitute an integrative process of continuous monitoring of structures, process of care and outcomes to ensure optimal healthcare delivery).[7] For most countries, ESRD care is the sole focus of kidney-related QI activities, which are often administered in conjunction with a national registry. The exception is the UK, which includes a QI initiative specifically targeted to earlier stages of CKD (See sections A5.3 and B2.2, UK chapter; Table 3-7).

C4: National CKD registry

A national CKD registry ideally would include data on burden of disease, risk factors, progression, process of care and outcomes for patients with CKD before the onset of RRT. Of the countries included in the inventory, only Sweden has established a national CKD registry, which is limited by certain logistical issues (see Section 2, Sweden chapter: C4). There are also ongoing initiatives in Italy, Netherlands, Turkey and the UK to establish a registry for the CKD population not yet on RRT. In the UK, one of the quality parameters under the QoF is for PCPs to keep a register of patients with CKD, and the data are being used to monitor trends and process of care but have not been organized into a national register outside the NSF (see sections C4: Italy, Netherlands, Turkey, UK chapters).

Of note, Ireland, Switzerland and Germany (since 2006) do not have a comprehensive RRT registry and do not contribute to the regional ERA-EDTA registry.

Table 3-7 National CKD quality improvement programs, by country

Country	Presence (Y/N)	Notes (patients covered)
Austria	Yes	ESRD on RRT by the national registry
Belgium	Yes	ESRD on RRT by the national registry
Canada	Yes	ESRD on RRT by the national registry
Denmark	Yes	ESRD on RRT by the national registry
Finland	Yes	ESRD on RRT by the national registry
France	Yes	ESRD on RRT by the national registry
Germany	Yes	There are only local initiatives for RRT. Since the RRT registry closed in 2006 nationally defined quality management programs have been available only for dialysis adequacy and anemia management of patients on RRT in some units, not for the whole spectrum of CKD patients.
Greece	Yes	ESRD on RRT by the national registry
Ireland	Yes	ESRD on RRT by the national registry The registry is not comprehensive and does not contribute data to the regional ERA-EDTA registry. Efforts are ongoing to develop a national kidney disease surveillance system
Israel	Yes	ESRD on RRT by the national registry
Italy	Yes	ESRD on RRT by the national registry
Netherlands	Yes	ESRD on RRT by the national registry
Norway	Yes	ESRD on RRT by the national registry The Norwegian Directorate for Health is responsible for ensuring quality improvement in the health system. It focuses on chronic diseases. However, there are no specific elements on CKD.
Portugal	Yes	ESRD on RRT by the national registry
Spain	Yes	ESRD on RRT by the national registry
Sweden	Yes	ESRD on RRT by the national registry
Switzerland	Yes	ESRD on RRT by the national registry The registry is not comprehensive and does not contribute data to the regional ERA-EDTA registry.
Turkey	Yes	ESRD on RRT by the national registry
United Kingdom	Yes	ESRD on RRT by the UK national registry, and non-dialysis-dependent CKD through the National Service Framework and QoF

CKD = Chronic kidney disease, ESRD = End stage renal disease, QoF = Quality and Outcomes Framework, RRT = Renal replacement therapy.

D. Capacity, workforce and access to multidisciplinary teams

D1: Physician workforce

As noted in the previous section (Section C.1 Availability and access to care), ensuring timely and appropriate access to physicians is an important quality parameter. In all countries non-nephrologist physicians play an important role in CKD care (B.1 Role of care providers).

This section focuses on the overall distribution of physicians across countries, and specifically the adequacy of the nephrology workforce.

There is a substantial variation in the supply of physicians (per 1000 population) across the various countries. The country with the highest supply of physicians was Greece with 5.4 physicians per 1000 population (above the OECD average of 3.1). All other countries were above the OECD average with the exception of UK, Belgium, Canada and Turkey (Figure 3.11).

Figure 3.11 Workforce: physicians supply, by country (per 1000 population)

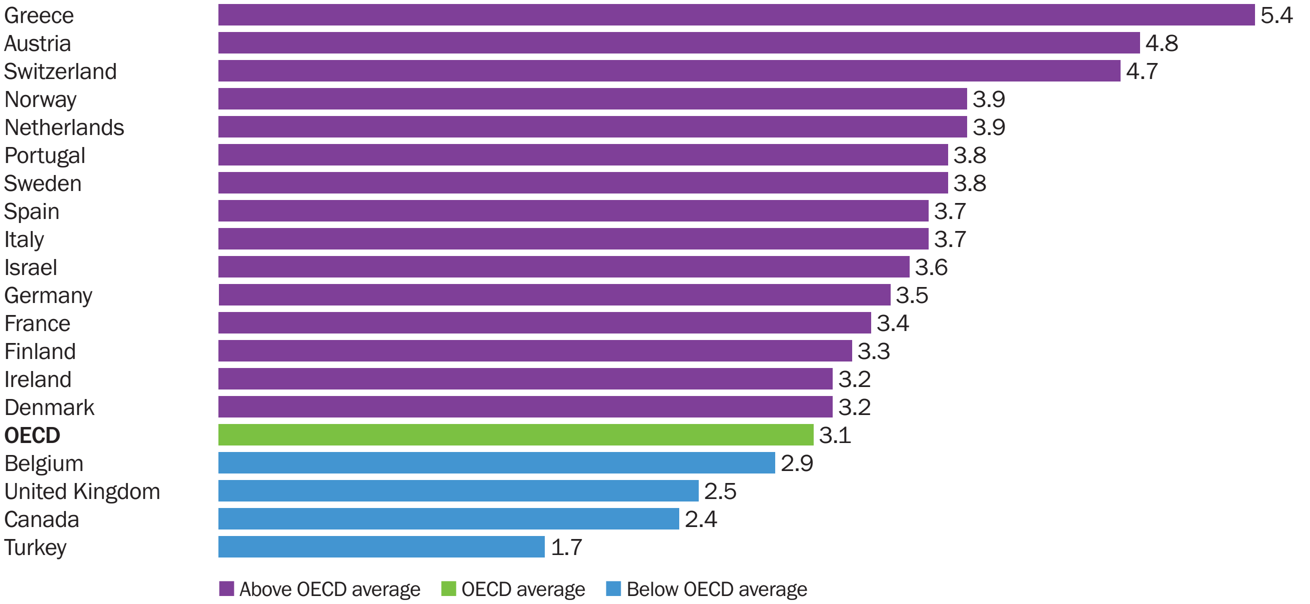
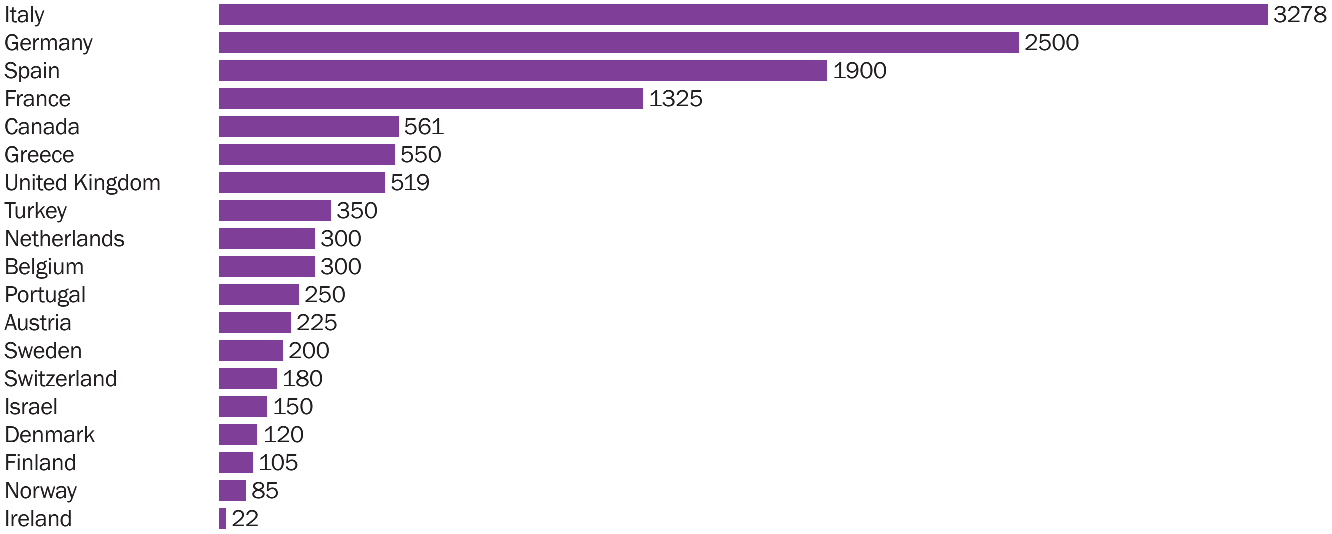


Figure 3.12 Workforce: nephrologists supply, by country N



The nephrology workforce across countries is detailed in Figures 3.12–3.14. Italy has the highest number of nephrologists per capita, and Ireland the least. All countries except Portugal, Canada, UK, Turkey and Ireland had at least one nephrologist per 50 ESRD patients (Figures 3.12–3.14). There are obvious limitations to these data. First, these figures do not reflect the broader network of support from other physician professional groups (PCPs, internists, staff grade physicians, physician assistants, hospitalists, etc) that contribute to the ESRD patients' care in renal units across countries. Second, no assumptions were made about the relative FTE contributions by the nephrologists specifically for renal care. Some nephrologists may have additional responsibilities for research, education and administration. Third, the specific time commitment to renal care varied significantly within and across countries. Fourth, expressing per capita workforce in terms of the general population assumes that demand for CKD care is equal across countries. Finally, the contributions of trainee nephrologists (fellows, registrars, residents) are not included in these statistics, as the data were not

Figure 3.13 Workforce: nephrologists supply, by country (per 1000 ESRD population)

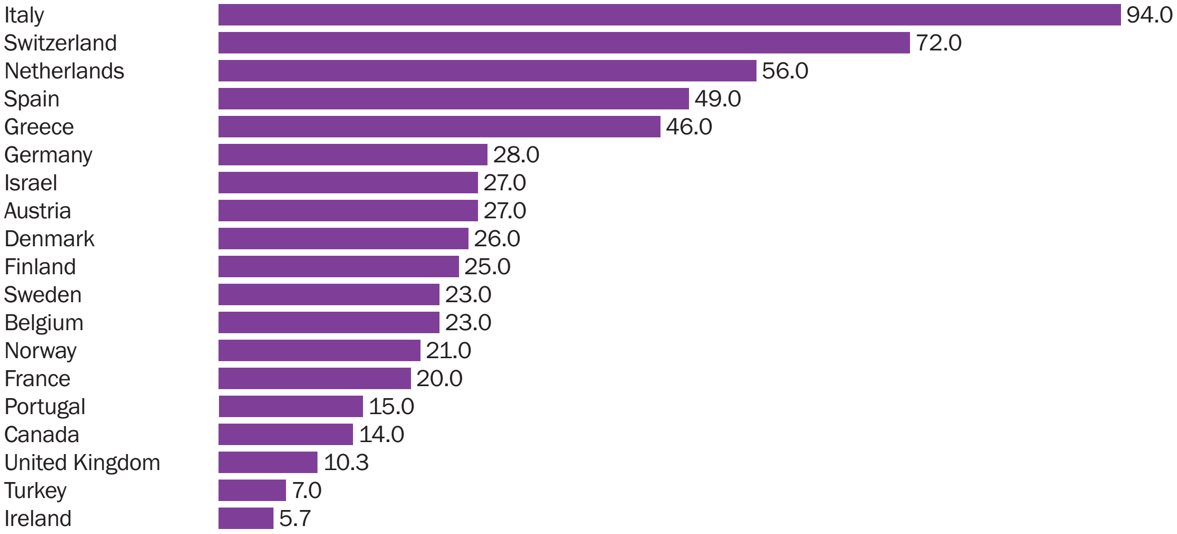
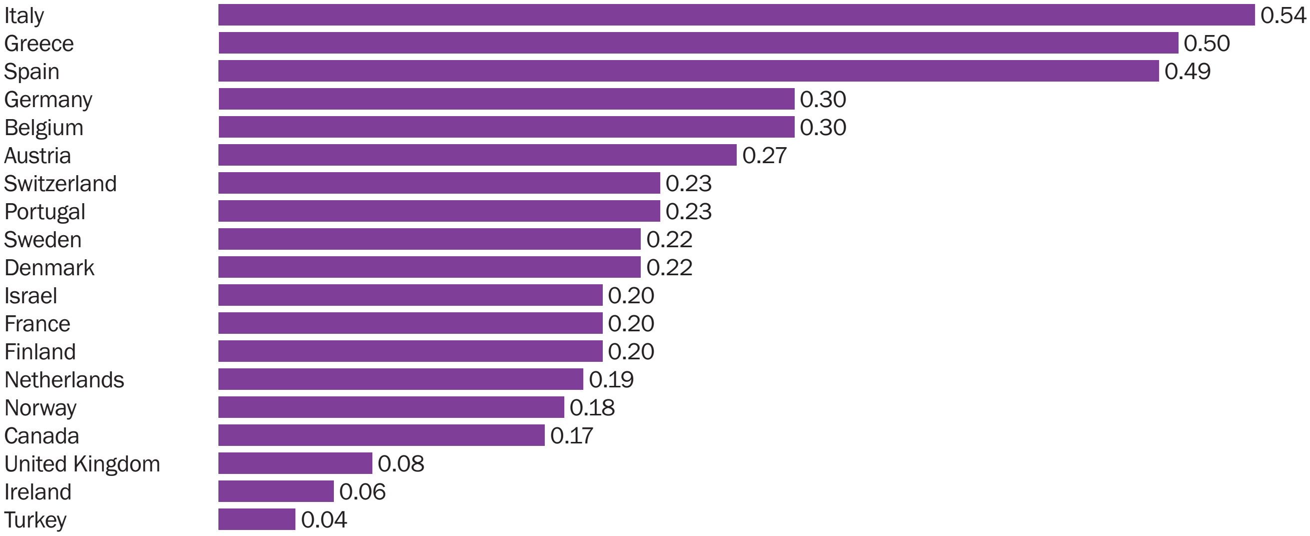


Figure 3.14 Workforce: nephrologists supply, by country (per 1000 CKD population)



available. However, the workforce data as presented here are similar to the perceptions of the survey respondents and those who participated in the inventory interviews.

D2: Multidisciplinary teams and other professionals

The “multidisciplinary team” refers here to a group of healthcare professionals representing the different disciplines needed for comprehensive CKD care.[8] The exact mix of disciplines needed likely varies across settings but could potentially include nephrologists, other physicians, nurses, nutritionists (dieticians), counselors/psychologists, pharmacists, vascular access coordinators, social workers and pastoral care workers.

Apart from specialist physicians, survey respondents felt that nurses played the most prominent role in CKD care. No workforce data on the availability of renal nurses were available. However, OECD data on general nursing workforces across countries suggest that Switzerland has the highest nursing workforce per capita with 15.2 per 1000 population (above the OECD average of 8.4 per 1000 population). All countries were above the OECD average except the Netherlands, France, Austria, Italy, Portugal, Spain, Israel, Greece and Turkey (Figure 3.15).

Only nine countries had organized multidisciplinary teams for CKD care (Table 3-8).

D3: Workforce limitations

Respondents from most countries reported that lack of availability of certain types of practitioner limited their ability to provide optimal CKD care (Table). Limited numbers of dieticians, social workers/psychologists/counselors; vascular access coordinators and renal pharmacists were most frequently described as problematic (Table 3-9).

Table 3-8 Presence of multidisciplinary teams for CKD care, by country

Country	Presence of MDT (Y/N)	Notes	Presence of renal pharmacists (Y/N)
Austria	No		No
Belgium	Yes	Variable across centres. Some centres have MDT of dieticians, psychologists, nursing, and social workers, while others do not.	No
Canada	Yes	Nephrologists work with support of MDT comprising vascular access practitioners, dieticians, pharmacists, social workers, etc.	Yes
Denmark	Yes	MDT of nurses, dieticians, psychologists, and social workers.	No
Finland	No		No
France	No		No
Germany	No		No
Greece	No		
Ireland	Yes	MDT of nurses, dieticians, psychologists, social workers, nephrologists, vascular access and transplant coordinators.	Yes
Israel	No		No
Italy	Yes		No
Netherlands	Yes		Yes
Norway	No		No
Portugal	Yes		No
Spain	No		No
Sweden	Yes	Different mix in different places. There are “uremia coordinators” for pre-dialysis patients mainly to organize ESRD care (access, anemia, MBD, nutrition management.	No
Switzerland	No		No
Turkey	No		No
United Kingdom	Yes	Any patient with advanced CKD stage 4 (eGFR < 20 ml/min/1.73m2) generally receives MDT care within 1 year of diagnosis.	Yes

Figure 3.15 Workforce: nurses supply (per 1000 population)

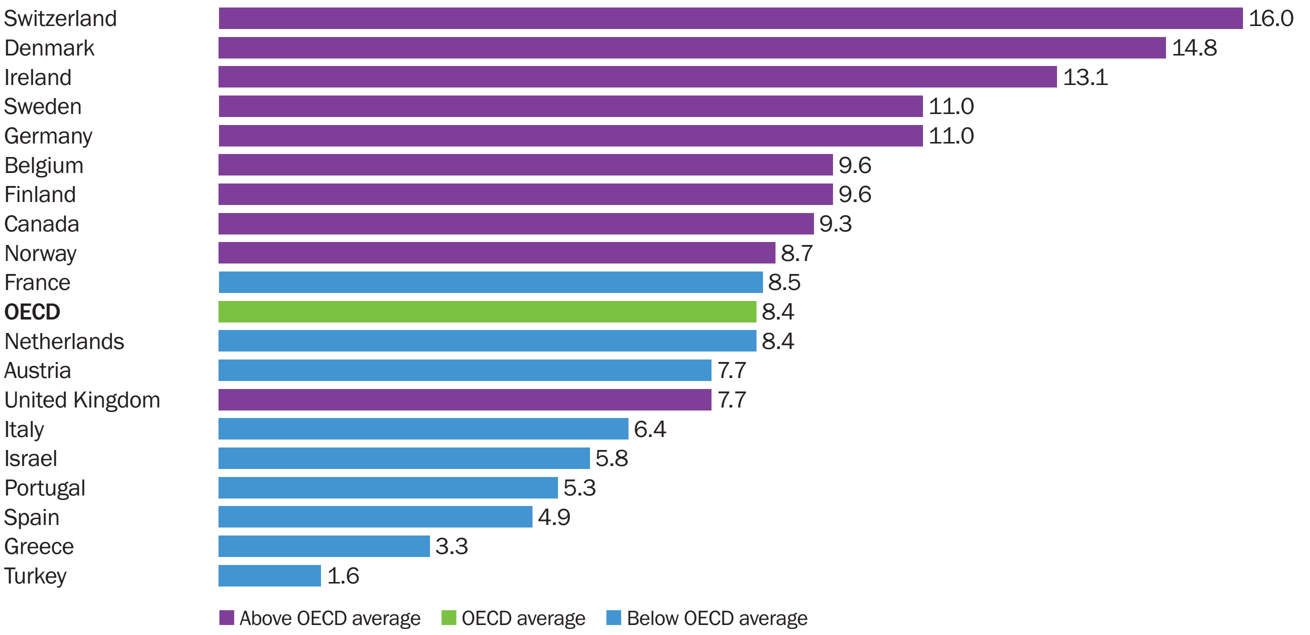


Table 3-9 Limitations of workforce team for CKD care, by country

Country	Disciplines with most pronounced lack of capacity for CKD care, in the opinion of survey respondents
Austria	Nephrologists, renal pharmacists and social workers.
Belgium	Vascular access coordinators, nurse practitioners and counselors/psychologists.
Canada	Vascular access coordinators, PCPs and renal pharmacists.
Denmark	Vascular access coordinators, counselors/psychologists, renal social workers, dieticians and nephrologists.
Finland	Dieticians, vascular access coordinators and nurses.
France	Nephrologists, dieticians, and nurses.
Germany	Vascular access coordinators, nurse practitioners and counsellors. In fact, only nurses, dieticians and doctors are available.
Greece	Renal nurses, dieticians and psychologists.
Ireland	Nephrologists, dieticians, and access coordinators across regions.
Israel	Nephrologists, vascular access coordinators, and dialysis nurses.
Italy	Vascular access coordinators, counselors/psychologists and dieticians.
Netherlands	Nurse practitioners, dialysis nurses and renal pharmacists.
Norway	Dieticians, psychologists, and social workers.
Portugal	Nurse practitioners, dialysis nurses and renal pharmacists.
Spain	Dieticians, social workers and psychologists.
Sweden	Nephrologists, dieticians, dialysis nurses and renal pharmacists.
Switzerland	Vascular access coordinators, nurse practitioners and PCPs.
Turkey	Nephrologists, vascular access coordinators, and dieticians.
UK	Dieticians, counselors/psychologists, social workers and nephrologists.

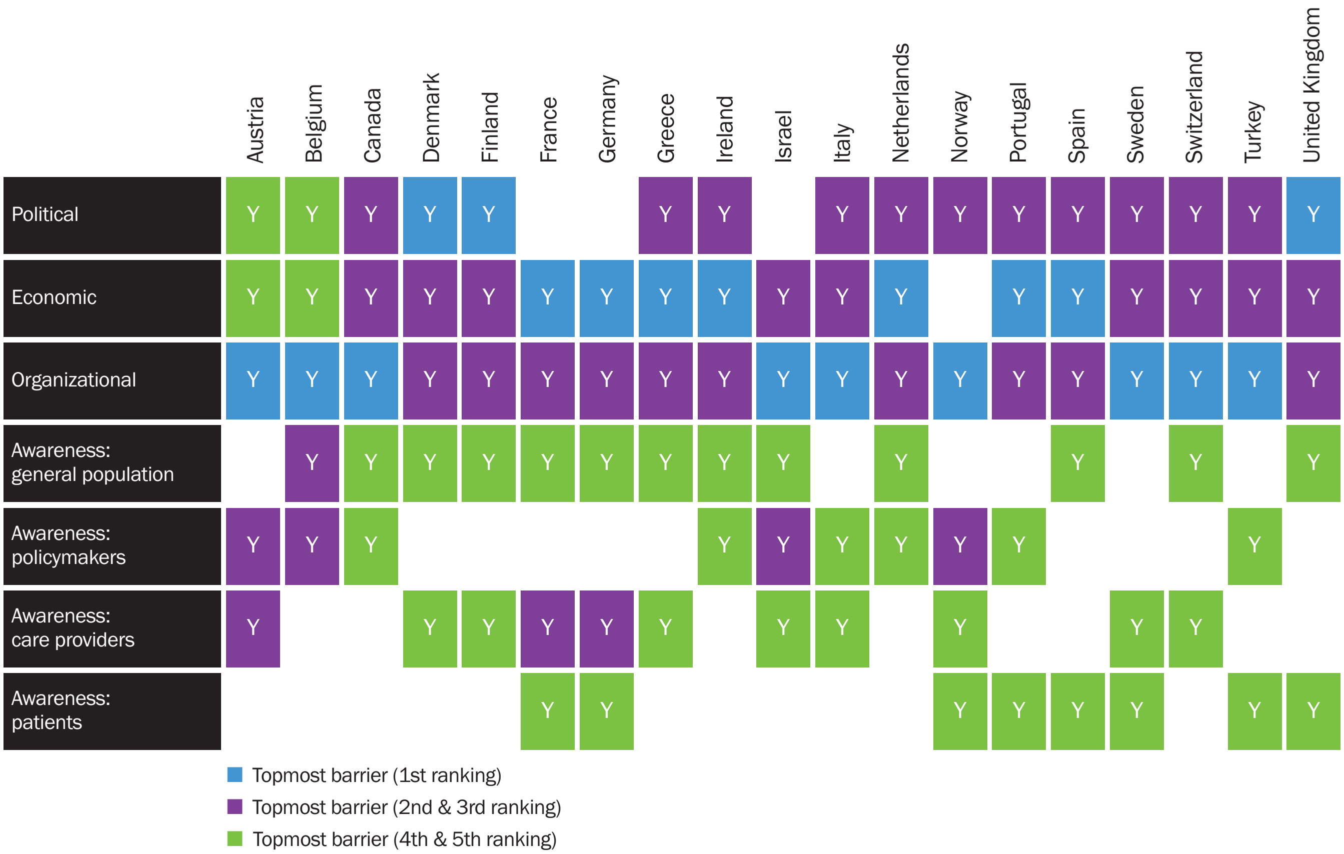
*All countries reported some limitations with workforce. PCPs = Primary care practitioners.

E. Barriers to optimal CKD care

Our survey of providers and policymakers assessed perceptions about barriers to optimal CKD care (Figure 3.16; Figure 3.17). Political, economic and organizational factors and low awareness of CKD on the part of care providers, policymakers, patients were the key barriers reported by respondents. The operational definitions of these parameters as used in the survey are as follows:

- Political: factors originating from individuals, groups or organizations connected to a government or multi-governmental organizations such as their own Government, EU, WHO or UN.
- Economic: lack of adequate financial resources to achieve desired goals.
- Organizational: lack of coordination of active organizations, lack of an organization responsible for chronic disease care, etc.
- Media: no consistent systematic promotion/debate/information on chronic disease care and prevention in the various outlets (TV/newspapers/radio/Internet).
- General population's awareness of CKD: refers to lack of sufficient knowledge among the general population about how and why to prevent CKD.
- Policymakers' awareness of CKD: refers to lack of sufficient knowledge among policymakers about how and why to prevent CKD.
- Care providers' awareness of CKD (doctors, nurses, other): refers to lack of sufficient knowledge among providers about how and why to prevent CKD.

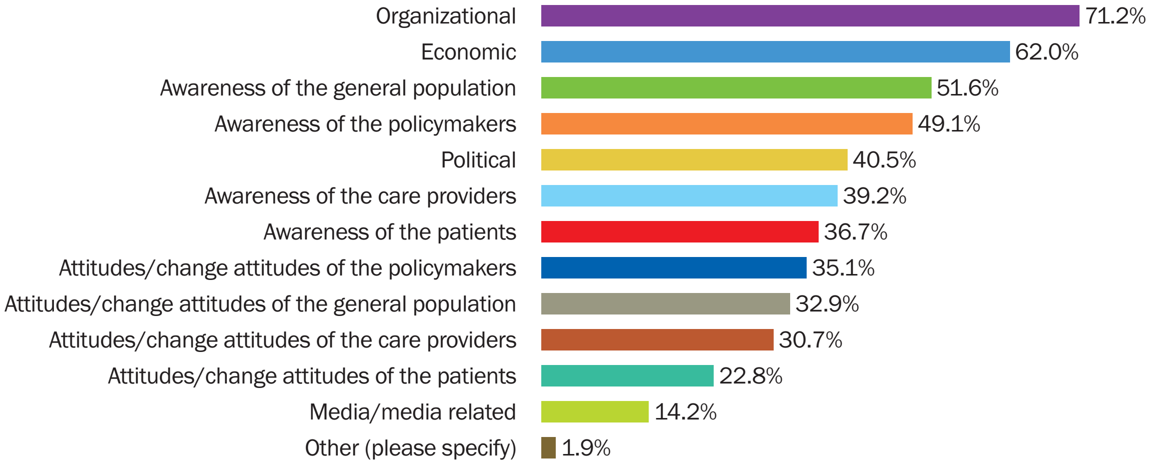
Figure 3.16 Major barriers to optimal care for CKD, country-specific responses



	Austria	Belgium	Canada	Denmark	Finland	France	Germany	Greece	Ireland	Israel	Italy	Netherlands	Norway	Portugal	Spain	Sweden	Switzerland	Turkey	United Kingdom
Political	🟩 Y	🟩 Y	🟪 Y	🟦 Y	🟦 Y			🟪 Y	🟪 Y		🟪 Y	🟪 Y	🟪 Y	🟪 Y	🟪 Y	🟪 Y	🟪 Y	🟪 Y	🟦 Y
Economic	🟩 Y	🟩 Y	🟪 Y	🟪 Y	🟪 Y	🟦 Y	🟦 Y	🟦 Y	🟦 Y	🟪 Y	🟪 Y	🟦 Y		🟦 Y	🟦 Y	🟪 Y	🟪 Y	🟪 Y	🟪 Y
Organizational	🟦 Y	🟦 Y	🟦 Y	🟪 Y	🟪 Y	🟪 Y	🟪 Y	🟪 Y	🟪 Y	🟦 Y	🟦 Y	🟪 Y	🟦 Y	🟪 Y	🟪 Y	🟦 Y	🟦 Y	🟦 Y	🟪 Y
Awareness: general population		🟪 Y	🟩 Y	🟩 Y	🟩 Y	🟩 Y	🟩 Y	🟩 Y	🟩 Y	🟩 Y		🟩 Y			🟩 Y		🟩 Y		🟩 Y
Awareness: policymakers	🟪 Y	🟪 Y	🟩 Y						🟩 Y	🟪 Y	🟩 Y	🟩 Y	🟪 Y	🟩 Y				🟩 Y	
Awareness: care providers	🟪 Y			🟩 Y	🟩 Y	🟪 Y	🟪 Y	🟩 Y		🟩 Y	🟩 Y		🟩 Y			🟩 Y	🟩 Y		
Awareness: patients						🟩 Y	🟩 Y						🟩 Y	🟩 Y	🟩 Y	🟩 Y		🟩 Y	🟩 Y

🟦 Topmost barrier (1st ranking)
🟪 Topmost barrier (2nd & 3rd ranking)
🟩 Topmost barrier (4th & 5th ranking)

Figure 3.17 Care providers: "In your opinion, what are the key barriers to achieving optimal chronic disease care in your country?"



- Patients' awareness of CKD: refers to lack of sufficient knowledge among CKD patients about how and why to prevent CKD.
- Attitudes of the general population: refers to the will to act on information that might improve one's own health (or the health of a family member or friend with CKD), among members of the general population.
- Attitudes of the policymakers: refers to the will to act on information that might improve the health of the public or a defined subset, among policymakers.
- Attitudes of providers (doctors, nurses, other): the will to act on information that might improve the health of one's patients, among providers.
- Attitudes of the patients: the will to act on information that might improve one's own health, among CKD patients.
- Other: none of the above.

F. CKD burden and risk factors

F1: Epidemiology of ESRD

This section presents trends on the incidence and prevalence of RRT for ESRD across countries – focusing on overall RRT burden and use of the different ESRD treatment modalities.

Incidence of RRT for ESRD

Figure 3.18 shows the incidence of ESRD (pmp) in 2010 across countries and secular trends in incidence over the last decade (Table 3-10). The highest incidence (>150 pmp) was reported by Belgium, Canada, Germany, Greece, Israel, Italy, Portugal and Turkey, and the lowest incidence (<120 pmp) was reported by Finland, Ireland, the Netherlands, Norway and the UK.

Prevalence of RRT for ESRD

Data on the prevalence of treated ESRD are shown in Figure 3.19 as well as secular trends in the prevalence over the last decade (Table 3-11). Portugal and

Figure 3.18 Incidence of ESRD (pmp), 2010

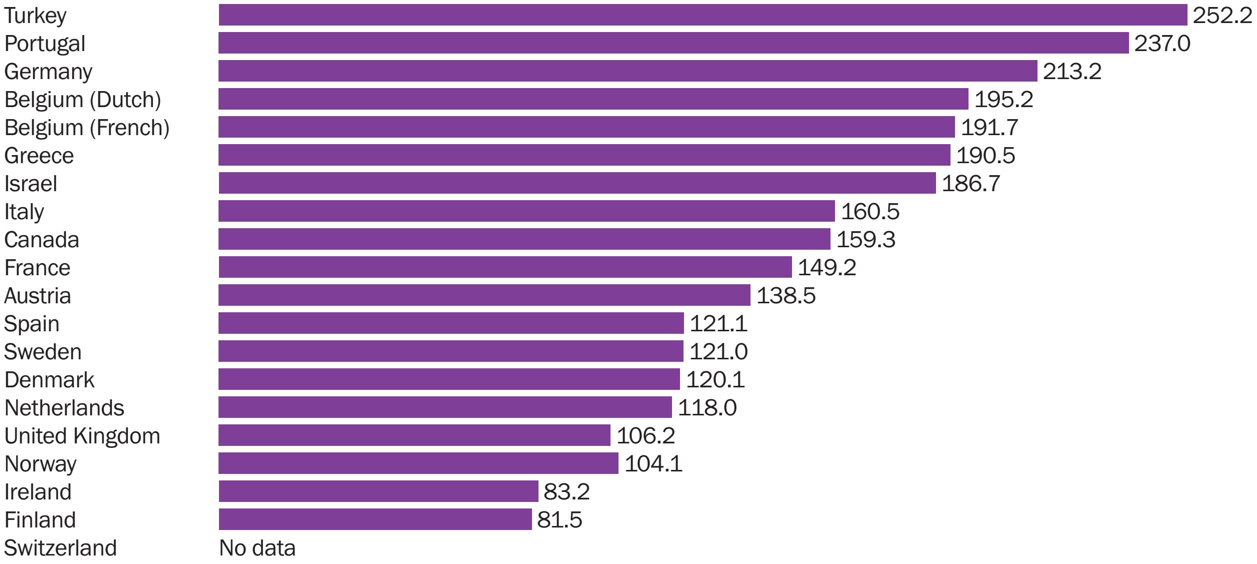
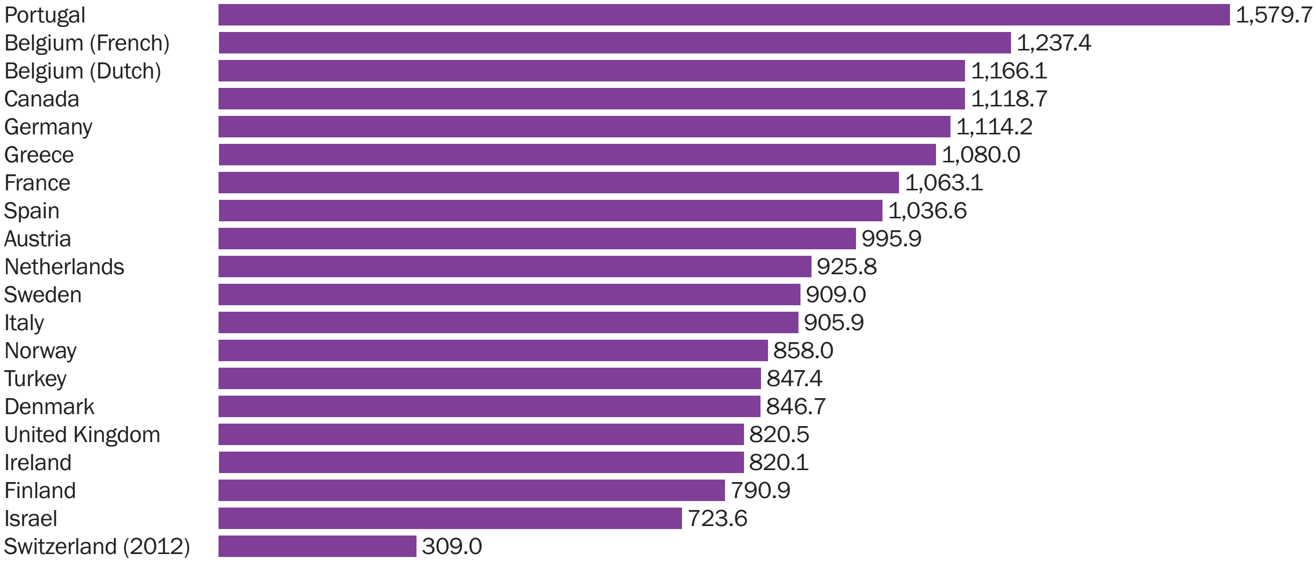


Figure 3.19 Prevalence of ESRD (pmp), 2010



NB: Endstage renal disease (ESRD) refers to the number of patients receiving different forms of renal replacement therapy (RRT)– dialysis and transplantation.

Table 3-10 Trend in the overall incidence of RRT for ESRD from 2000 to 2010 (N [pmp])

			2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010
Austria		N	1038	1097	1060	1128	1290	1234	1306	1261	1224	1232	1162
		pmp	**128.6**	**136.0**	**131.4**	**139.9**	**159.2**	**151.8**	**158**	**152.3**	**146.9**	**147.5**	**138.5**
Belgium	(Dutch)	N	854	951	1016	1034	1060	1085	1169	1143	1162	1250	1226
		pmp	**143.8**	**159.8**	**169.8**	**172.2**	**175.8**	**179.0**	**191.7**	**186.2**	**188.6**	**200.6**	**195.2**
	(French)	N	—	733	—	—	811	775	826	830	855	896	885
		pmp	**—**	**170.0**	**—**	**—**	**184.7**	**175.4**	**185.6**	**185.0**	**189.8**	**196.2**	**191.7**
Canada		N	4755	5013	5043	5128	5226	5300	5418	5527	5490	5375	5646
		pmp	**154.9**	**161.6**	**160.8**	**162.0**	**163.6**	**164.2**	**166.1**	**167.8**	**164.8**	**159.3**	**165.5**
Denmark		N	—	740	692	701	717	652	640	770	694	698	673
		pmp	**—**	**138.2**	**128.7**	**130.1**	**132.7**	**120.3**	**117.7**	**141.0**	**126.3**	**125.1**	**120.1**
Finland		N	—	458	476	486	490	495	441	485	504	443	437
		pmp	**—**	**88.2**	**91.6**	**93.0**	**93.7**	**94.4**	**83.7**	**91.7**	**94.9**	**83.0**	**81.5**
France*		N	—	—	—	2072	3470	4706	5128	7196	8033	8560	9439
		pmp	**—**	**—**	**—**	**122.9**	**138.7**	**139.1**	**142.2**	**138.8**	**146.9**	**148.8**	**149.2**
Germany		N	14370	15148	14358	15360	16027	16766	17548	—	—	—	—
		pmp	**175.0**	**184.0**	**174.0**	**186.1**	**194.3**	**203.4**	**213.2**	**—**	**—**	**—**	**—**
Greece		N	1635	1793	1820	1962	2157	2139	2185	2126	2239	2307	2154
		pmp	**154.2**	**163.5**	**165.4**	**178.1**	**195.0**	**192.6**	**196.0**	**189.9**	**199.3**	**204.5**	**190.5**
Ireland		N	—	—	—	—	—	—	—	—	446	486	372
		pmp	**—**	**—**	**—**	**—**	**—**	**—**	**—**	**—**	**99.4**	**107.2**	**81.7**
Israel**		N	—	—	—	—	—	1281	1436	1388	1383	1450	1423
		pmp	**—**	**—**	**—**	**—**	**—**	**184.8**	**203.6**	**193.3**	**189.2**	**193.7**	**186.7**
Italy***		N	—	—	—	7831	9312	7134	5857	5263	6676	5600	6167
		pmp	**—**	**—**	**—**	**150.3**	**173.0**	**161.9**	**146.3**	**144.6**	**150.9**	**156.5**	**160.5**
Netherlands		N	1502	1600	1619	1629	1703	1698	1828	1925	1988	2025	1960
		pmp	**94.3**	**100.1**	**100.3**	**100.4**	**104.6**	**104.0**	**111.8**	**117.5**	**120.9**	**122.5**	**118.0**
Norway		N	400	427	420	436	459	459	464	530	533	560	509
		pmp	**89.1**	**94.4**	**92.5**	**95.5**	**100.0**	**99.3**	**99.6**	**112.5**	**111.8**	**116.0**	**104.1**
Portugal		N	—	—	2084	2133	2268	2162	—	2413	2467	2548	2519
		pmp	**—**	**—**	**200.2**	**203.6**	**215.4**	**204.6**	**—**	**227.3**	**232.1**	**239.8**	**237.0**
Spain****		N	—	—	—	3468	2836	4116	4628	4577	5673	4937	5518
		pmp	**—**	**—**	**—**	**131.9**	**123.8**	**126.0**	**131.5**	**126.3**	**128.0**	**128.5**	**121.1**
Sweden		N	—	1107	1117	1087	1099	1079	1156	1180	1126	1176	1135
		pmp	**—**	**124.3**	**125.2**	**121.3**	**122.2**	**119.5**	**127.3**	**129.0**	**122.1**	**126.5**	**121.0**
Switzerland		N	—	—	—	—	—	—	—	—	—	—	—
		pmp	**—**	**—**	**—**	**—**	**—**	**—**	**—**	**—**	**—**	**—**	**—**
Turkey		N	—	—	—	—	—	12758	12979	16154	18672	18627	15509
		pmp	**—**	**—**	**—**	**—**	**—**	**186.9**	**184.1**	**231.2**	**263.7**	**259.3**	**252.2**
United Kingdom		N	—	—	—	—	—	5841	6294	6746	6596	6655	6610
		pmp	**—**	**—**	**—**	**—**	**—**	**105.9**	**112.5**	**110.6**	**107.5**	**107.7**	**106.2**

ESRD = End stage renal disease, N = Number, pmp = Per million population, — = No data.

* Number of reporting regions varied in different years for France: 7 [in 2003], 9 [in 2004], 13 [in 2005], 15 [in 2006], 18 [in 2007] out of 24 regions and 20 [in 2008 and 2009] and 23 [in 2010] out of 26 regions.

** Data include dialysis patients only.

*** Number of reporting regions varied in different years for Italy: 17 [in 2005], 13 [in 2006], 14 [in 2007], 16 [in 2008], 14 [in 2009] and 14 [in 2010] out of 20 regions.

**** Number of reporting regions varied in different years for Spain: 14 [in 2003], 11 [in 2004], 16 [in 2005], 17 [in 2006 and 2007], 18 [in 2008], 17 [in 2009] and 18 [in 2010] out of 19 regions.

Table 3-11 Trend in the overall prevalence of RRT for ESRD from 2000 to 2010 (N [pmp])

			2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010
Austria		N	5769	6053	6300	6570	6951	7242	7544	7738	7920	8177	8355
		pmp	714.5	750.5	781.2	814.8	857.6	890.6	912.4	934.4	950.6	978.7	995.9
Belgium	(Dutch)	N	4790	5088	5279	5488	5721	6040	6325	6586	6871	7110	7322
		pmp	806.4	854.8	882.2	913.8	948.8	996.6	1037.2	1072.7	1115.1	1141.2	1166.1
	(French)	N	—	3459	—	—	4419	4448	4774	4975	5194	5448	5712
		pmp	—	802.4	—	—	1006.3	1006.8	1072.8	1109.0	1152.9	1193.2	1237.4
Canada		N	24915	26575	28071	29541	31046	32453	33847	35202	36429	37744	39352
		pmp	811.9	856.7	894.8	933.1	971.8	1005.7	1037.5	1068.9	1093.1	1118.7	1153.7
Denmark		N	—	3636	3820	3984	4148	4243	4307	4511	4683	4677	4745
		pmp	—	679.0	710.7	739.4	768.0	782.9	792.1	826.0	852.4	838.3	846.7
Finland		N	—	3167	3302	3441	3582	2724	3807	3943	4081	4166	4242
		pmp	—	609.6	635.6	658.2	685.1	709.9	722.9	745.5	768.1	780.3	790.9
France*		N	—	—	—	15148	23630	31566	34932	52448	57874	62739	67270
		pmp	—	—	—	898.2	944.7	933.2	968.5	1011.5	1058.6	1090.8	1063.1
Germany		N	71513	75672	75777	78281	82305	87151	91718	—	—	—	—
		pmp	870.0	919.0	918.1	948.5	997.6	1057.2	1114.2	—	—	—	—
Greece		N	8456	8902	9253	9697	10200	10648	10968	11298	11607	12018	12212
		pmp	797.6	811.9	840.9	880.1	922.1	958.9	983.8	1009.4	1032.9	1065.2	1080.0
Ireland#		N	—	—	—	—	—	—	—	3143	3329	3487	3651
		pmp	—	—	—	—	—	—	—	718.3	742.2	769.2	801.6
Israel**		N	—	—	—	—	—	4418	4631	4818	5032	5287	5516
		pmp	—	—	—	—	—	637.5	656.5	671.0	688.5	706.3	723.6
Italy**,***		N	—	—	—	51861	59184	44388	37695	29747	37144	36007	34809
		pmp	—	—	—	995.4	1099.3	1007.4	941.6	817.0	839.4	1006.0	905.9
Netherlands		N	9929	10224	10618	10994	11461	12023	12617	13163	13895	14794	15383
		pmp	623.5	639.5	657.5	677.6	703.9	736.7	771.9	803.5	844.9	895.0	925.8
Norway		N	2591	2740	2911	3037	3251	3384	3508	3692	3890	4066	4195
		pmp	576.9	605.6	641.4	665.3	708.0	731.9	752.7	784.0	815.8	842.0	858.0
Portugal		N	—	—	11419	11818	—	13227	—	14567	14965	16010	16788
		pmp	—	—	1097.2	1128.2	1197.4	1251.7	—	1371.1	1408.2	1506.5	1579.7
Spain****		N	—	—	—	24208	20362	29382	34598	34025	44067	39708	47230
		pmp	—	—	—	920.8	888.7	899.5	982.8	939.0	994.1	1033.4	1036.6
Sweden		N	—	6551	6777	6954	7204	7385	7677	7969	8044	8277	8525
		pmp	—	735.3	759.3	776.3	801.0	817.9	845.4	871.1	872.5	890.1	909.0
Switzerland		N	—	—	—	—	—	—	—	—	—	—	—
		pmp	—	—	—	—	—	—	—	—	—	—	—
Turkey		N	—	24492	26199	29250	33504	35983	42196	50221	53859	59443	52111
		pmp	—	361.0	386.4	433.5	475.0	527.1	598.6	718.7	760.7	827.5	847.4
United Kingdom		N	—	33556	37039	37388	37848	37426	39744	46153	48242	50513	51087
		pmp	—	566.0	626.0	632.0	638.0	678.4	710.1	756.9	785.9	817.5	820.5

ESRD = End stage renal disease, N = Number, pmp = Per million population, — = No data.

* Number of reporting regions varied in different years for France: 7 [in 2003], 9 [in 2004], 13 [in 2005], 15 [in 2006], 18 [in 2007] out of 24 regions and 20 [in 2008 and 2009] and 23 [in 2010] out of 26 regions.

** Data include dialysis patients only.

*** Number of reporting regions varied in different years for Italy: 17 [in 2005], 13 [in 2006], 14 [in 2007], 16 [in 2008], 14 [in 2009] and 16 [in 2010] out of 20 regions.

**** Number of reporting regions varied in different years for Spain: 14 [in 2003], 11 [in 2004], 16 [in 2005], 17 [in 2006 and 2007], 18 [in 2008], 17 [in 2009] and 18 [in 2010] out of 19 regions.

Data based on 2012 report.

Switzerland reported the highest and lowest prevalence of treated ESRD, respectively.

Prevalence of kidney transplantation (people living with a functioning kidney transplant)

The countries with the highest prevalence of kidney transplantation (>500 pmp) are Belgium (French), Netherlands, Norway, Portugal, Spain and Sweden (Figure 3.20) (Table 3-12). The lowest prevalence of transplantation (<300 pmp) were reported in Greece and Turkey (Figure 3.20). The distribution of different RRT modalities (HD, PD, transplantation) is shown in Figure 3.21.

Figure 3:20 Prevalence of kidney transplant [people living with a functioning transplant] (pmp), 2010

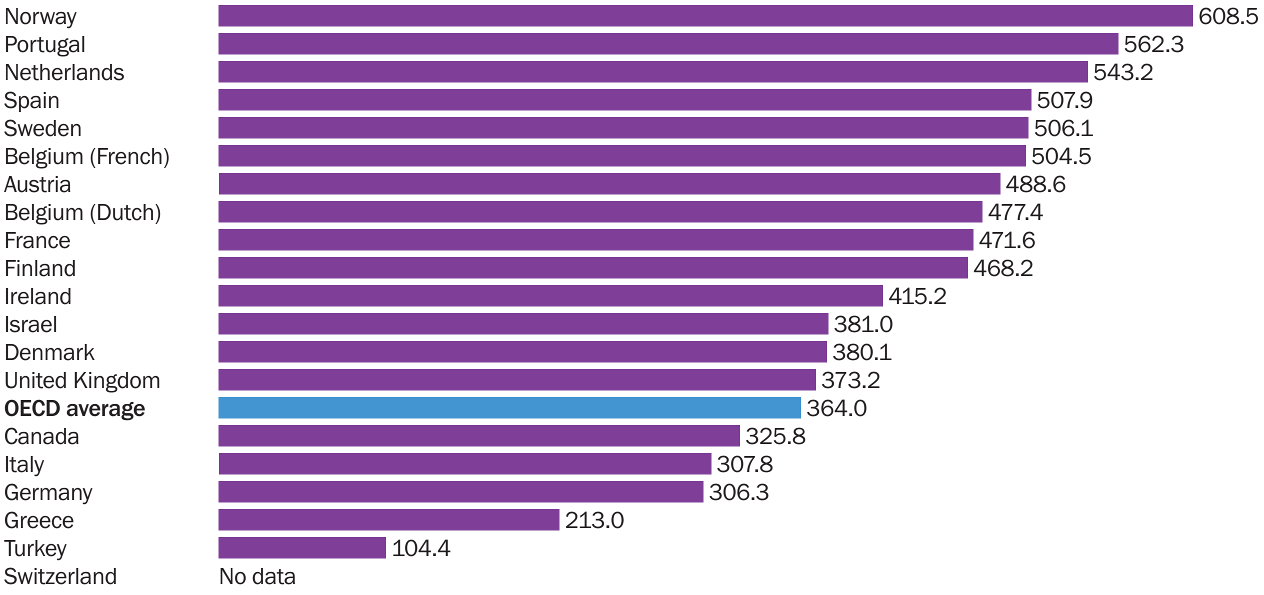


Figure 3.21 Distribution of RRT modalities, by country, 2010

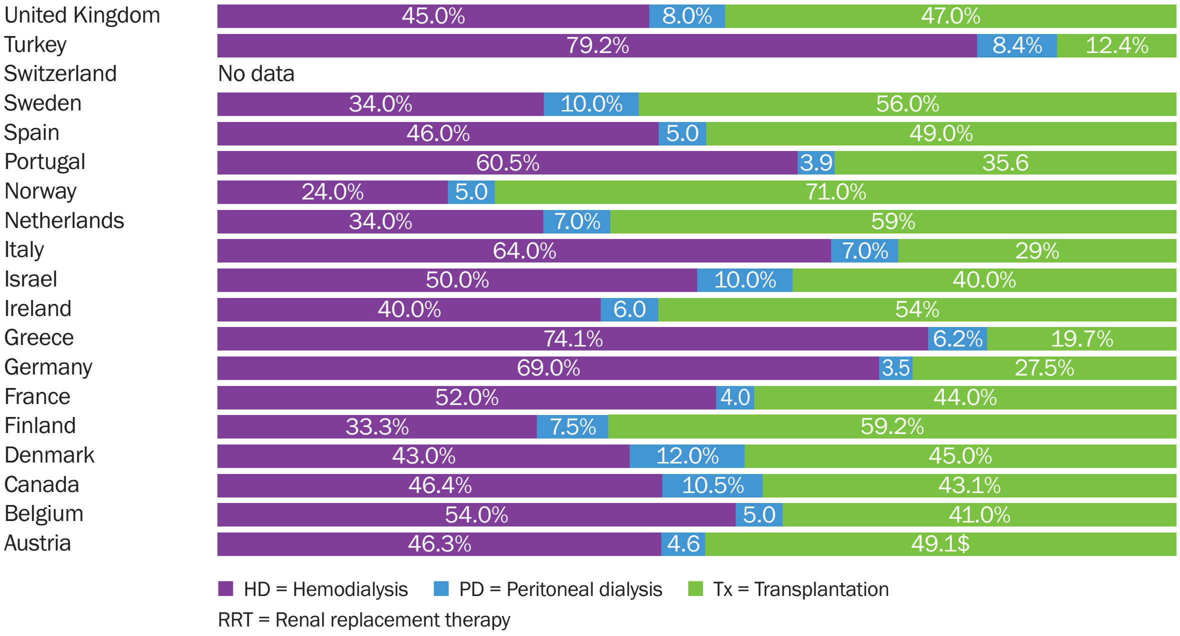


Table 3-12 Trend in the prevalence of kidney transplantation from 2000 to 2010 (N [pmp])

			2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010
Austria		N	2784	2963	3152	3253	3379	3500	3663	3791	3875	3979	4099
		pmp	**344.8**	**367.4**	**390.8**	**403.4**	**416.9**	**430.4**	**443.0**	**457.8**	**465.1**	**476.2**	**488.6**
Belgium	(Dutch)	N	2130	2234	2268	2328	2385	2445	2595	2715	2831	2902	2998
		pmp	**358.6**	**375.3**	**379.0**	**387.6**	**395.5**	**403.4**	**425.5**	**442.2**	**459.5**	**465.8**	**477.4**
	(French)	N	—	1388	—	—	1655	1746	1892	2017	2094	2211	2329
		pmp	—	**322.0**	—	—	**376.9**	**395.2**	**425.2**	**449.6**	**464.8**	**484.2**	**504.5**
Canada		N	9998	10567	11093	11642	12164	12669	13306	14045	14694	15434	9998
		pmp	**325.8**	**340.6**	**353.6**	**367.7**	**380.8**	**392.6**	**407.9**	**426.5**	**440.9**	**457.4**	**325.8**
Denmark		N	—	1381	1463	1551	1632	1699	1765	1827	1936	2028	2130
		pmp		**257.9**	**272.2**	**287.9**	**302.2**	**313.5**	**324.6**	**334.5**	**352.4**	**363.5**	**380.1**
Finland		N	—	1914	1975	2038	2142	2189	2289	2362	2390	2456	2511
		pmp	—	**268.4**	**380.2**	**389.8**	**409.7**	**417.3**	**434.7**	**446.6**	**449.8**	**460**	**468.2**
France*		N	—	—	—	7294	9895	13299	14787	23992	26439	29181	29841
		pmp	—	—	—	**432.5**	**395.6**	**393.1**	**410.0**	**462.7**	**483.6**	**507.3**	**471.6**
Germany		N	18917	18484	18896	19702	21313	23724	25210	—	—	—	—
		pmp	**230.0**	**224.0**	**228.9**	**238.7**	**258.3**	**287.8**	**306.3**	—	—	—	—
Greece		N	1438	1514	1609	1743	1854	2012	2119	2235	2379	2429	2409
		pmp	**135.6**	**138.1**	**146.2**	**158.2**	**167.6**	**181.2**	**190.1**	**199.7**	**211.7**	**215.3**	**213.0**
Ireland		N	—	—	—	—	—	—	—	1623	1728	1824	1891
		pmp	—	—	—	—	—	—	—	**370.9**	**385.3**	**402.3**	**415.2**
Israel		N	—	—	—	—	—	—	—	—	—	—	—
		pmp	—	—	—	—	—	—	—	—	—	—	—
Italy**		N	—	—	—	10735	15200	11493	7493	—	—	—	—
		pmp	—	—	—	**206.1**	**282.3**	**260.8**	**187.2**	—	—	—	—
Netherlands		N	5042	5239	5533	5829	6167	6571	6858	7324	7865	8401	9025
		pmp	**316.6**	**327.7**	**342.6**	**359.3**	**378.8**	**402.6**	**419.5**	**447.1**	**478.2**	**508.2**	**543.2**
Norway		N	1951	2021	2114	2205	2336	2406	2501	2597	2729	2852	2975
		pmp	**434.4**	**446.7**	**465.8**	**483.0**	**508.7**	**520.4**	**536.6**	**551.5**	**572.3**	**590.6**	**608.5**
Portugal		N	—	—	3673	3861	—	4408	—	5013	5151	5793	5976
		pmp	—	—	**352.9**	**368.6**	—	**417.1**	—	**472.1**	**484.7**	**545.1**	**562.3**
Spain***		N	—	—	—	10717	9150	13636	16916	16028	21131	19031	23140
		pmp	—	—	—	**407.7**	**399.4**	**417.4**	**480.5**	**442.3**	**476.7**	**495.3**	**507.9**
Sweden		N	—	3437	3543	3678	3822	3965	4117	4324	4461	4621	4446
		pmp	—	**385.8**	**397.0**	**410.6**	**425.0**	**439.1**	**453.4**	**472.7**	**483.9**	**497.0**	**506.1**
Switzerland		N	—	—	—	—	—	—	—	—	—	—	—
		pmp	—	—	—	—	—	—	—	—	—	—	—
Turkey		N	—	3403	2570	3667	5648	4095	4143	5647	7821	7375	6422
		pmp	—	**50.2**	**37.9**	**54.3**	**80.1**	**60.0**	**58.8**	**80.8**	**110.5**	**102.7**	**104.4**
UK		N	—	—	17135	13363	—	16314	15922	19107	20192	21509	23235
		pmp	—	—	—	—	—	**295.7**	**284.5**	**313.4**	**328.9**	**348.1**	**373.2**

ESRD = End stage renal disease, N = Number, pmp = Per million population, — = No data.

* Number of reporting regions varied in different years for France: 7 [in 2003], 9 [in 2004], 13 [in 2005], 15 [in 2006], 18 [in 2007] out of 24 regions and 20 [in 2008 and 2009] and 23 [in 2010] out of 26 regions.

** Number of reporting regions varied in different years for Italy: 17 [in 2005], 13 [in 2006] out of 20 regions.

*** Number of reporting regions varied in different years for Spain: 14 [in 2003], 11 [in 2004], 16 [in 2005], 17 [in 2006 and 2007], 18 [in 2008], 17 [in 2009] and 18 [in 2010] out of 19 regions.

F2: Epidemiology of CKD

This section describes the epidemiology of non-dialysis-dependent CKD across countries. Data used in this section were obtained from a comprehensive search of published literature on population-based studies of CKD. This was carried out with a literature search on PubMed, Google Scholar, CINAHL®, Embase, and Cochrane databases from January 1, 1990 to March 31, 2013. Several keywords were used in the search including "population-based" "community" "screening" "chronic kidney disease" "CKD" "chronic kidney failure" "CKF" "end stage renal disease" "ESRD" "early detection" "prevention" "management" "risk factors" "epidemiology" "albuminuria" "microalbuminuria" and "proteinuria".

Only studies that examined CKD and/or albuminuria in a community setting and published in English were retrieved. In situations where multiple studies have been published based on the same population base, the first original publication and/or the most recent (as appropriate) was selected for review.

Studies were included if they were peer-reviewed and met the following criteria:

1. Having a measure of prevalence for CKD and/or albuminuria in a general population.
2. Enrolled adults aged 18 years and above.
3. Recruited subjects from a community-based population sample.
4. Presented detailed methodology and results.
5. Provided evidence of ethics review.
6. Were population-based studies from the included countries.

These studies were highly variable in terms of size, targeted population, design and findings (Table 3-13). Many of these studies were designed in response to the initial observation by the NHANES III study that possibly up to 11% of the US population may have CKD. Most assessed the epidemiology of CKD as identified in the general population; some specifically targeted individuals at high risk of CKD. Most studies relied on urinalysis (with or without albumin:creatinine ratio), and/or prediction equations based on serum creatinine to estimate GFR. The prevalence of CKD ranged 5.5–15.7%, elevated albuminuria was 3–10.3%, and for eGFR<60mls/min was 3.1–17.2%. We did not identify population-based data from Austria, Greece and Sweden (Table 3-13). Data from large regions (but not national data) were available from Belgium, France, Germany, Italy, Netherlands and Switzerland.

Table 3-13 Population-based studies on CKD, by country

Country	Reference	Study	Design	N	Target	CKD (%)	Alb/Prot (%)	GFR < 60, ml/min/1.73m2 (%)	Coverage
Austria									
Belgium	Delanaye et al, 2009	Liege	CS	754 45–75 yrs)	GP (age		—	17.2	Regional
Canada	Garg et al, 2004	Elderly in LTCF	CS	9,931	HR			35.7 (Overall), 27.1 (M), 38.8 (F)	Regional
Canada	Gao et al, 2007			658,664 (GP) 14,989 (FN)		HR/GP		67.5/1000 pop (GP) 59.5/1000 pop (First Nations)	Regional
Canada	Arora et al, 2013	CHMS	CS	3689		12.5 (3M Canadian adults)	10.3	3.1	National
Denmark	Jensen et al, 1993	Copenhagen City Heart Study	CS	1011	GP	—	MA = 3	—	Regional
Finland	Juutilainen et al, 2012	FINRISK	CS	11277		—		4.5	National
France	Stengel et al, 2011	Villejuif	CS	8705	HR (age > 65yrs)			13.7	Regional
France	Assogba et al, 2012	ENTRED	CS	3894	HR (DM)	29		—	—

continued

Table 3-13 Population-based studies on CKD, by country (continued)

Country	Reference	Study	Design	N	Target	CKD (%)	Alb/Prot (%)	GFR < 60, ml/min /1.73m2 (%)	Coverage
Germany	Schottker et al, 2012	ESTHER	CS/L	9953	HR (DM)	—	—	14.6	Regional
Germany	Liese et al, 2001	MONICA/ AUSBURG	CS	2136	GP		MA = 8 (M), 7.5 (F)		
Greece									
Ireland	Browne et al,2012	SLÁN	CS	1098	GP/HR		Alb = 10.1	11.6	National
Israel									
Italy	Cirillo et al, 2006*	Gubbio	CS/L	4574	GP	10		6.6 (M), 6.2 (F)	Regional
Italy	Gambaro et al, 2010	INCIPE	CS	6200	GP	13.2			Regional
Netherlands	De Zeeuw et al, 2005 & Hillege et al, 2002	PREVEND	CS/L	48,000	GP	10.4	7.0	5.3	Regional
Norway	Romundstad et al, 2002	HUNT	GS	65258	GP/HR		MA = DM: 27.8 HT: 19.3 Non-DM/HT: 5.2	9.3%	National
Portugal	Vinhas et al, 2011	PREVADIAB	CS	5167	GP			6.1	National
Spain	Otero et al, 2005	EPIRCE	CS	237	GP		MA = 7.6	5.1 (Overall)	National
Sweden									
Switzerland	Nitsch et al, 2006	SAPALDIA	CS	6317	GP			13 (M); 36 (F)	Regional
Turkey	Suleymanlar et al, 2011	CREDIT	CS	10748	GP	15.7			National
United Kingdom		Quality and Outcomes Framework (QOF) register 2011–2012	CS		GP	11.7			National
United Kingdom		Health Survey for England (HSE) 2010	CS		GP	6 (M), 7(F)			National
United Kingdom	Stevens et al, 2006	New Opportunities for Early Renal Intervention by Computerised Assessment (NEOERICA) project	CS		GP			5.4	National
United Kingdom		Quality Improvement in CKD (QICKD) study	CS		GP	5.5			National
United Kingdom	Kearns et al, 2013		CS	743,935	GP	6.7			

Alb = Albuminuria, CHMS = Canadian Health Measures Survey, CKD = Chronic kidney disease, CS = Cross-sectional, DM = Diabetes mellitus, EPIRCE = Estudio Epidemiológico de la Insuficiencia Renal en España. F = Female, FN = First Nations. GP = General population, GFR = Glomerular filtration rate, HR = High risk, LTCF = Long term care facility, L = Longitudinal, M = Male, MA = Microalbuminuria, N = Number, PREVEND = Prevention of End stage Renal and Vascular Disease, Prot = Proteinuria, SAPALDIA = The Swiss Cohort Study on Air Pollution and Lung Diseases in Adults, SLÁN = Survey of Lifestyle, Attitudes and Nutrition, — = No data.

* personal communication -Dr Eliezer Golan (Ref in Hebrew language)

F3: Data on costs of CKD care

Nationally representative data on non-dialysis CKD costs were available only from the UK (see Section F3: UK chapter), based on preliminary estimates reported in 2012. The costs of RRT care in OECD countries are estimated to constitute approximately 1–2% of the total healthcare budget.[9] Although the per capita costs associated with RRT are much higher than those associated with non-dialysis-dependent CKD, the latter patients are much more prevalent than the former (people with ESRD represent less than 0.5% of the CKD population). Estimating the costs of CKD care is complex, because there is no agreement as to how to handle the costs associated with CKD-related comorbidity such as hypertension or vascular disease.

F4: CKD risk factors

Definition of risk factor

A risk factor is an attribute that is associated with increased risk of an outcome. In principle, the relationship between the risk factor and the outcome may be either causal or non-causal. Causal risk factors are determinants of the outcome, and successful intervention to reduce exposure to them would improve outcomes. Non-causal risk factors may be associated with the outcome through confounding or reverse causation. Interventions to reduce exposure to non-causal risk factors would not necessarily improve outcomes.[10] A large body of epidemiological and clinical evidence has demonstrated a link between a number of these factors and the initiation as well as progression of CKD. These can be classified into two distinct categories based on presence or absence of established causation; factors that have been proven to be causal (risk factors) and those that are associated with CKD in the absence of an established causal relationship (risk markers).[11]

Risk factors for development of CKD include susceptibility factors and initiation factors. Susceptibility factors increase susceptibility to CKD, eg, older age, male sex and familial/genetic predisposition. While initiation factors directly initiate kidney damage, these include clinical factors such as diabetes, hypertension, chronic infections, drugs and toxins. The progression factors are risk factors associated with worsening of already established kidney damage, such as high levels of proteinuria, hypertension, poor glycemic control in diabetes, obesity and smoking. A large number of potential risk factors for CKD have been reported in the literature. The aim of identifying susceptibility and initiation factors for CKD is to define individuals at high risk of developing CKD.[11]

The profile of the various risk factors (age, diabetes, hypertension, obesity, smoking, alcohol use) associated with increased risk of development and progression of CKD across countries is depicted in Figures 3.22–3.26.

Figure 3.22 Age as a risk factor for CKD: prevalent elderly population (>65 years), by country relative to OECD average, 2009

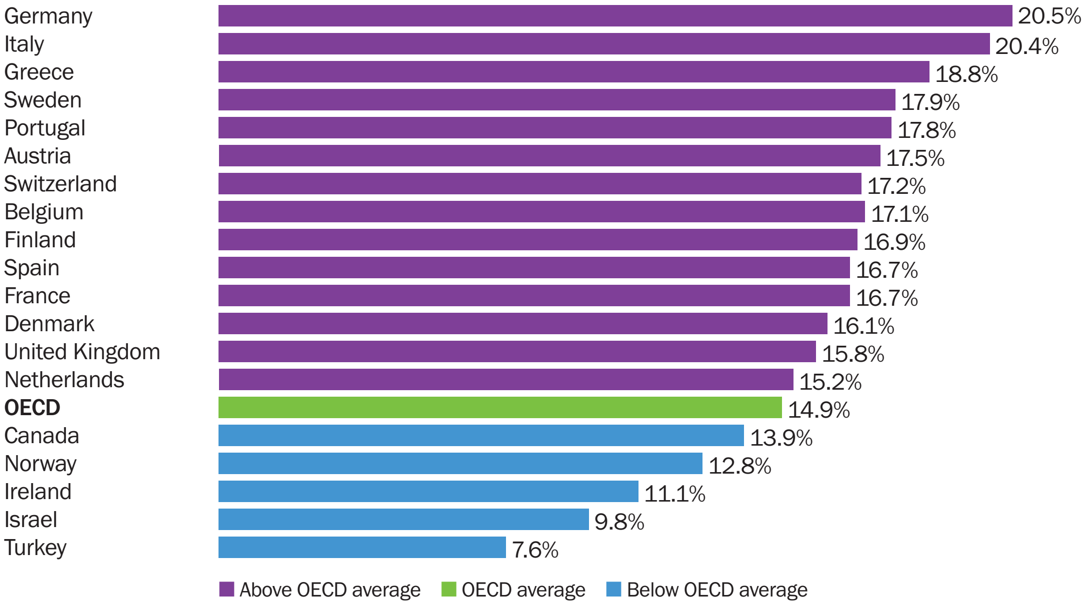


Figure 3.23 Diabetes as a risk factor for CKD: prevalence of diabetes, by country relative to OECD average, 2011

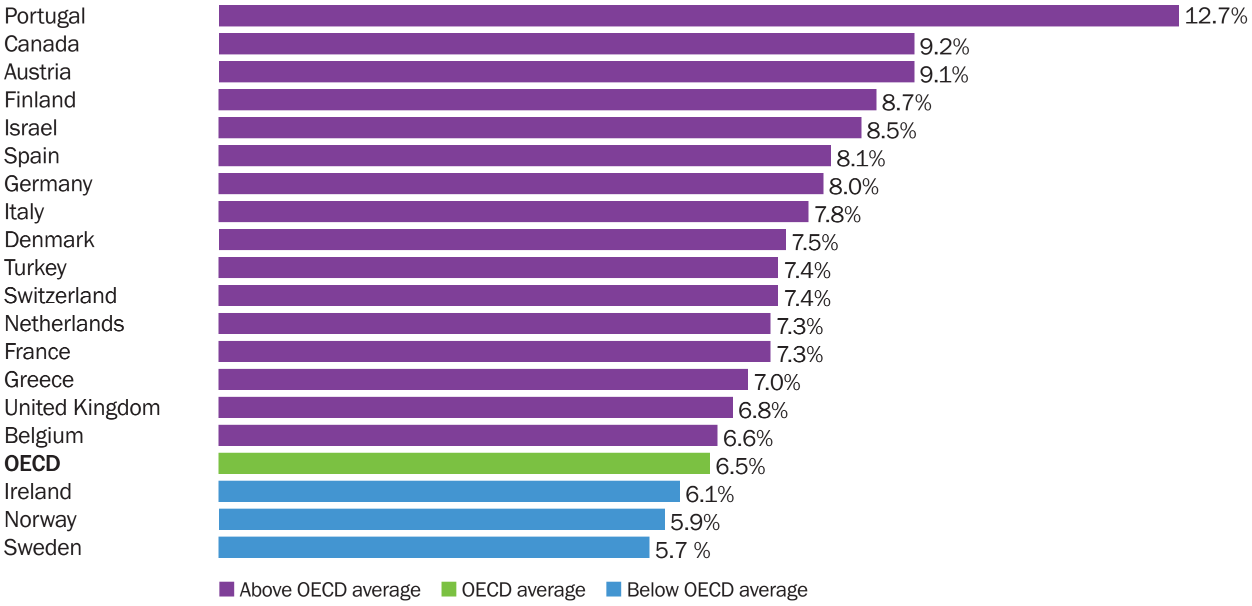
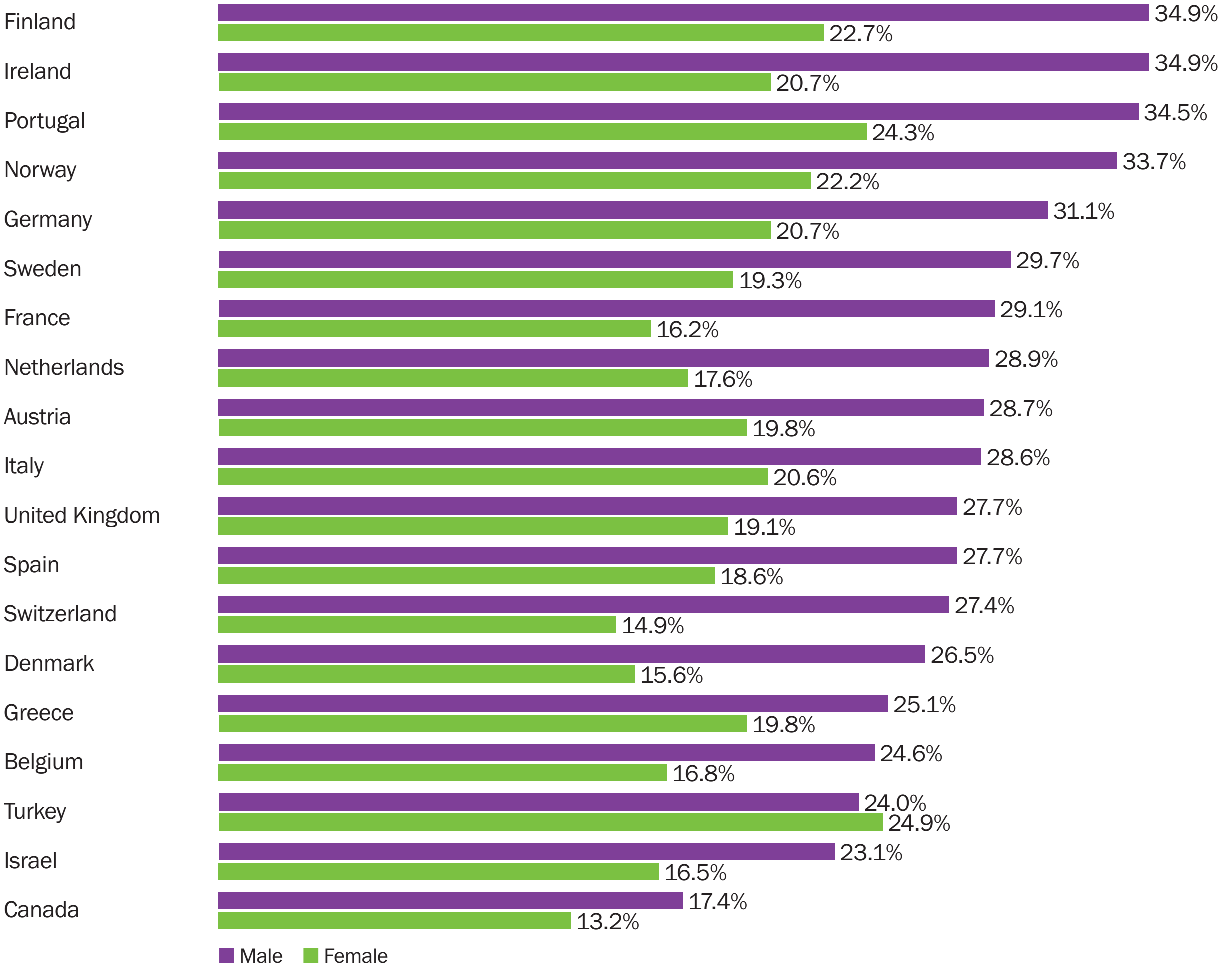


Figure 3.24 Prevalence of raised blood pressure among adults aged ≥25 years, by country, 2010



All the countries with the exception of Canada, Norway, Ireland, Israel and Turkey have a high burden of an aging population – the prevalence of elderly citizens is well above the OECD average (Figure 3.22). The prevalence of diabetes was also higher than the OECD average for most countries (Figure 3.23). The prevalence of hypertension ranges from 17–35% for males, and 13–23% for females across countries (Figure3.24). Canada, UK, Ireland, Finland, and Greece topped the OECD average for obesity (Figure 3.25). Eight of the countries topped the OECD average for smoking rates (Figure 3.26).

Figure 3.25 Obesity as a risk factor for CKD: prevalence of obesity, by country relative to OECD average, 2009

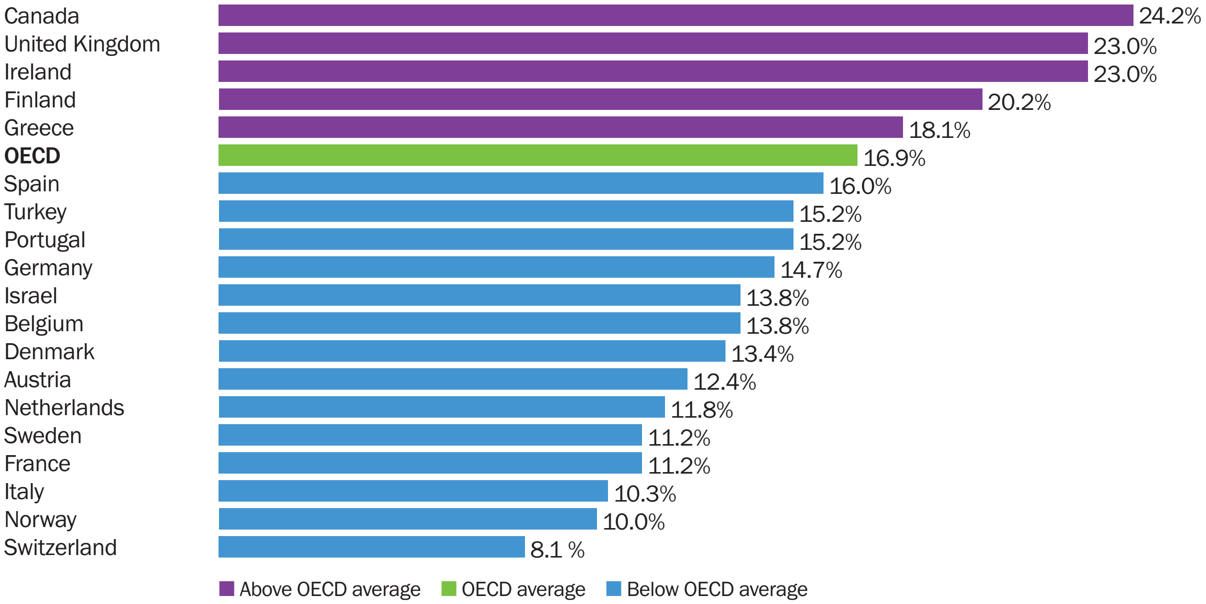
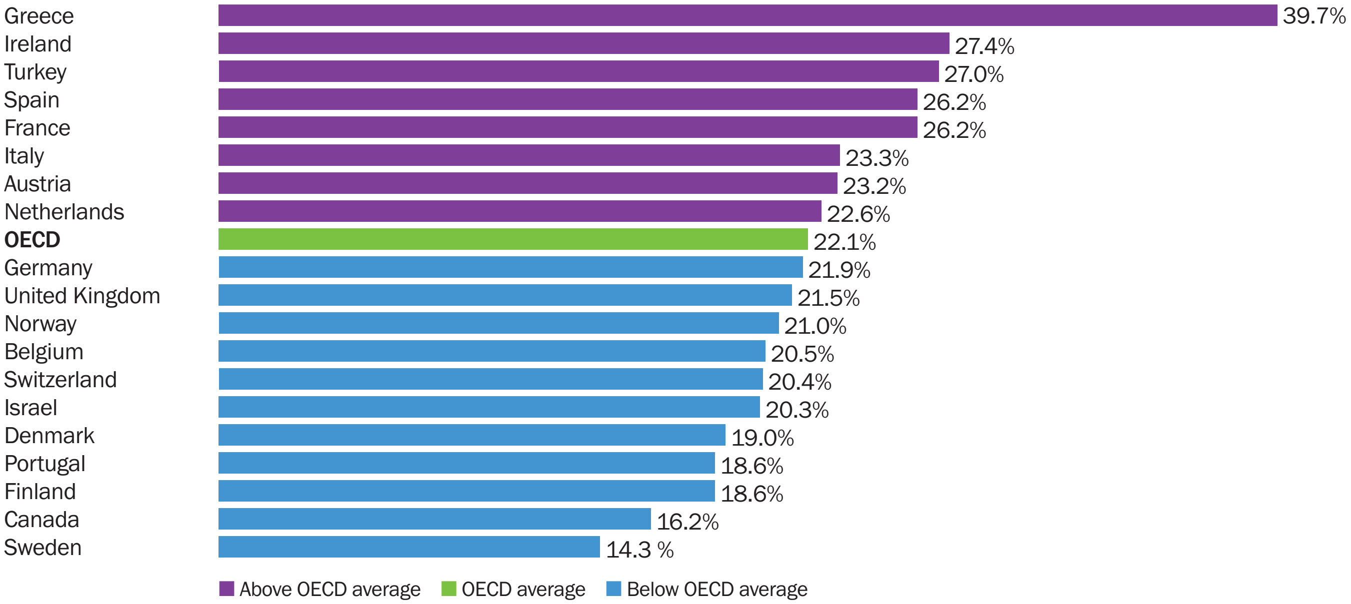


Figure 3.26 Smoking as a risk factor for CKD: prevalence of smoking, by country relative to OECD average, 2009



G. Perceptions of care (providers, patients and policymakers)

This section describes the perceptions of the various stakeholders (care providers, patients and policymakers) about CKD care in their own countries. Providers were asked primarily about the delivery of CKD care (organization, efficiency and quality). All respondents were asked about their perceptions regarding patients' participation in their own care; their level of education regarding CKD; and the availability and adequacy of relevant educational materials about CKD.

A total of 1,245 individuals completed the questionnaire survey across the study population sub-groups) (Table 3-14). A total of 37 individuals were interviewed across countries (Table 3-14).

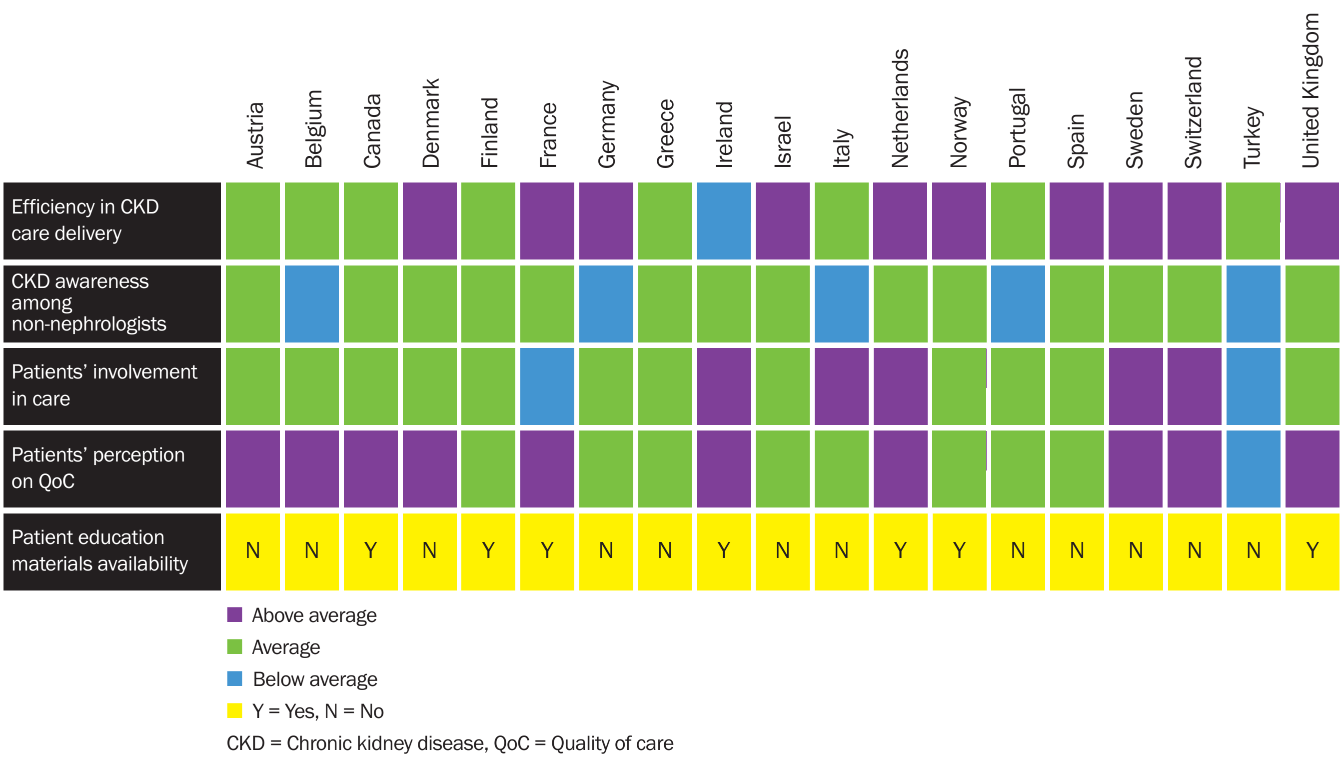
Perceptions of care providers

The responses of the care providers (nephrologists) across countries are shown in Figure 3.27. When asked "in general, how would you rate the involvement/participation of CKD patients not yet on RRT in their care?" the majority (47%) responded with a rating of "average" (3 on a scale of 5 with 5 as excellent, and 1 as extremely poor) (Figure 3.28); a similar pattern was observed concerning RRT patients (Figure 3.29), and concerning perceptions about the quality of care received by patients (Figures 3.30, 3.31). Only 37% of provider respondents believed that there were nationally available educational resources suitable for educating CKD patients.

Table 3-14 Responders across the study population subgroups

Category	N
Nephrologists	728
Other physicians (PCPs, specialists)	29
Policymakers	32
Patients	421 *CKD = 99, Dialysis = 116, Tx = 62* *Patient leaders/others = 36* *Skipped = 108*
Interviewees	37

Figure 3.27 Perceptions of care (Responses of care providers)



	Austria	Belgium	Canada	Denmark	Finland	France	Germany	Greece	Ireland	Israel	Italy	Netherlands	Norway	Portugal	Spain	Sweden	Switzerland	Turkey	United Kingdom
Efficiency in CKD care delivery	🟩	🟩	🟩	🟪	🟩	🟪	🟪	🟩	🟦	🟪	🟩	🟪	🟪	🟩	🟪	🟪	🟪	🟩	🟪
CKD awareness among non-nephrologists	🟩	🟦	🟩	🟩	🟩	🟩	🟦	🟩	🟩	🟩	🟦	🟩	🟩	🟦	🟩	🟩	🟩	🟦	🟩
Patients' involvement in care	🟩	🟩	🟩	🟩	🟩	🟦	🟩	🟩	🟪	🟩	🟪	🟪	🟩	🟩	🟩	🟪	🟪	🟦	🟩
Patients' perception on QoC	🟪	🟪	🟪	🟪	🟩	🟪	🟩	🟩	🟪	🟩	🟩	🟪	🟩	🟩	🟩	🟪	🟪	🟦	🟪
Patient education materials availability	N	N	Y	N	Y	Y	N	N	Y	N	N	Y	Y	N	N	N	N	N	Y

🟪 Above average
🟩 Average
🟦 Below average
🟨 Y = Yes, N = No

CKD = Chronic kidney disease, QoC = Quality of care

Figure 3.28 Care providers: "In general, how would you rate the involvement/participation of CKD patients not yet on RRT in their care?"

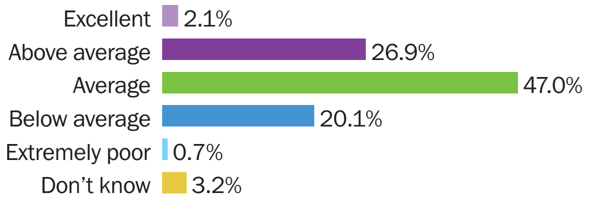


Figure 3.29 Care providers: "In general, how would you rate the involvement/participation of CKD patients on RRT in their care?"

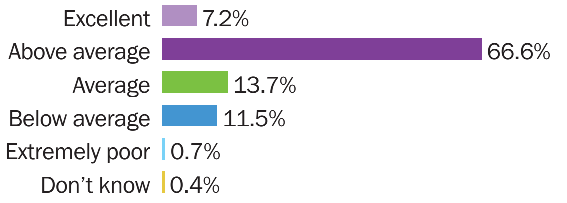


Figure 3.30 Care providers: "In your opinion, how do CKD patients not yet on RRT perceive the care being provided to them?"

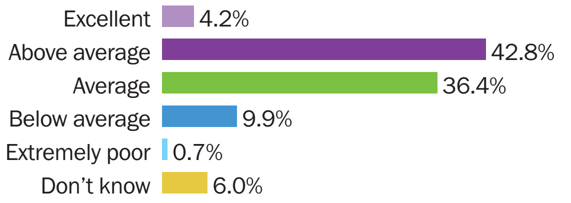
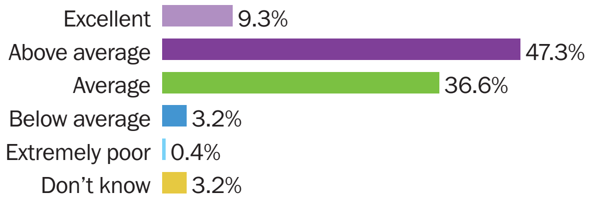


Figure 3.31 Care providers: "In your opinion, how do CKD patients on RRT perceive the care being provided to them?"



Perceptions of patients

The majority of patients (~63%) rated their involvement in decision-making about their care as above average to excellent (Figure 3.32). About 66% of patient respondents did not perceive that they received adequate support in managing their CKD; where present, such support was received primarily from family members and friends (Figure 3.33). Respondents indicated that defects in the structure and organization of health systems and government constituted the major barriers to optimal CKD care, followed by their own level of knowledge about and involvement in their own care (Figure 3.34). Many respondents indicated that patients' lack of knowledge and lack of involvement in care should be targeted to improve the quality of CKD care (Figure 3.35). Most patients (71%) reported having previously participated in kidney research, and the majority (>70%) believed that kidney research is very important or extremely important (Figure 3.36). Patients identified research on symptoms of CKD (poor sleep, itchiness, pain) and methods for increasing kidney donation as key future priorities (Figure 3.37). Most (>70%) of patients reported having been diagnosed with CKD as an incidental or clinical finding, rather than one made in the course of screening for CKDs (Figure 3.38). Copayments for medications were reported in the range predicted by the literature review (0–20%), with no reported copayment exceeding 20% of the total

Figure 3.32 Patients: "Please grade your involvement in the overall decision-making processes related to your care."

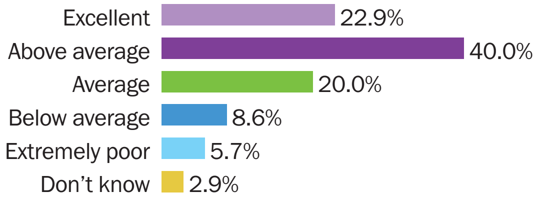


Figure 3.33 Patients: "If yes, please grade from the following list where you received the most support" (1 = Most support, 5 = Least support)

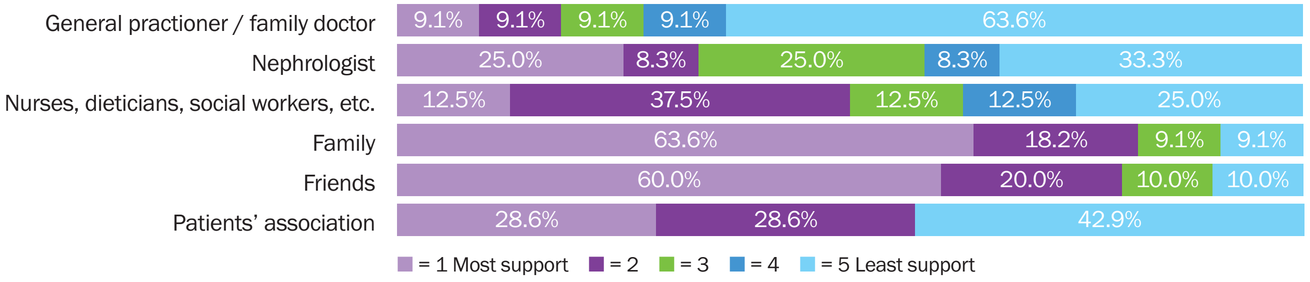


Figure 3.34 Patients: "At which levels are the main barriers to the provision of high quality chronic kidney disease care in your country?"

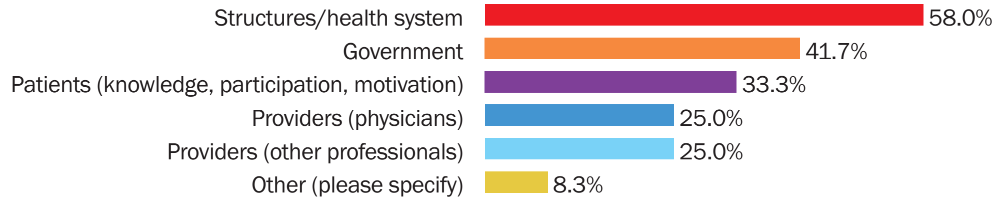


Figure 3.35 Patients: "In your opinion, who should be targeted to improve the quality of chronic kidney disease care delivery?"

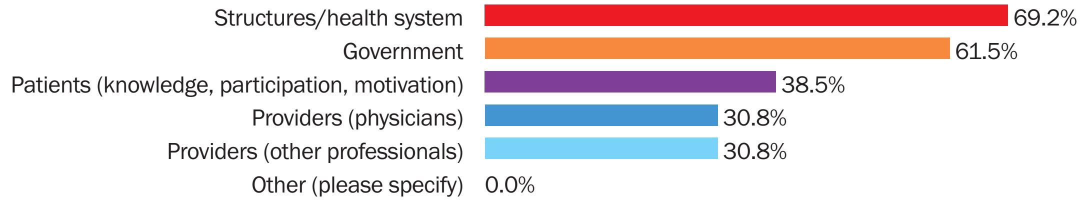


Figure 3.36 Patients: "How do you perceive the importance of kidney disease research for patients living with kidney disease?"

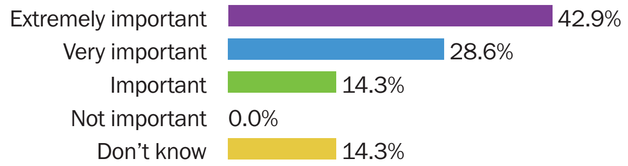


Figure 3:37 Patients: "In your opinion, which area of kidney disease research is most important for patients?"

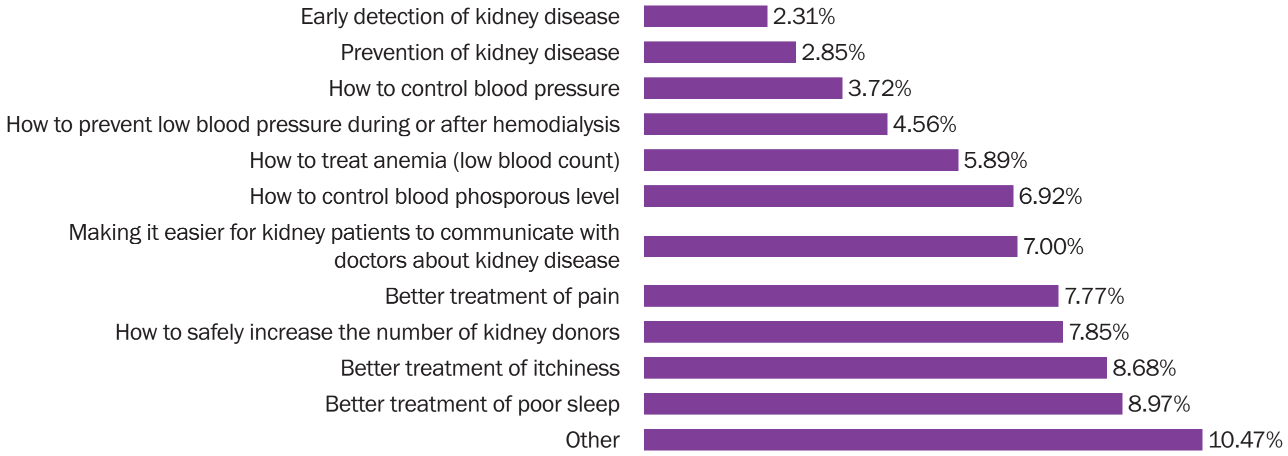
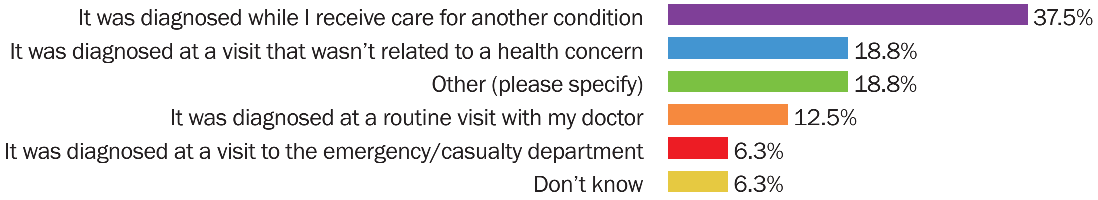


Figure 3.38 Patients: Over 70% of cases of CKD diagnosed incidentally



cost as 57% of the respondents reported paying <10%, and the rest paid between 10-20%. Patients' perceptions about their access to MDT availability are shown in Figure 3.39; lack of access to counselors/psychologists, dieticians and nurses was most commonly reported.

Perceptions of policymakers

Most policymakers surveyed were affiliated with academic institutions (Figures 3.40). Respondents indicated that CKD care was typically organized by individual hospitals/organizations rather than regional or national authorities (Figure 3.41). Despite this, most policymakers (74%) reported little perceived variation in the structure or organization of CKD care across different regions of their country. The key barriers to optimal CKD care were believed to be issues related to organization of care (referring to lack of standard clinical pathways for patients' management across the spectrum of CKD), low awareness of CKD (among patients, providers and the general public), and political and economic factors (Figure 3.42).

Figure 3.39 ***Patients: "In your opinion, is there a shortage of the following providers in your country?"***

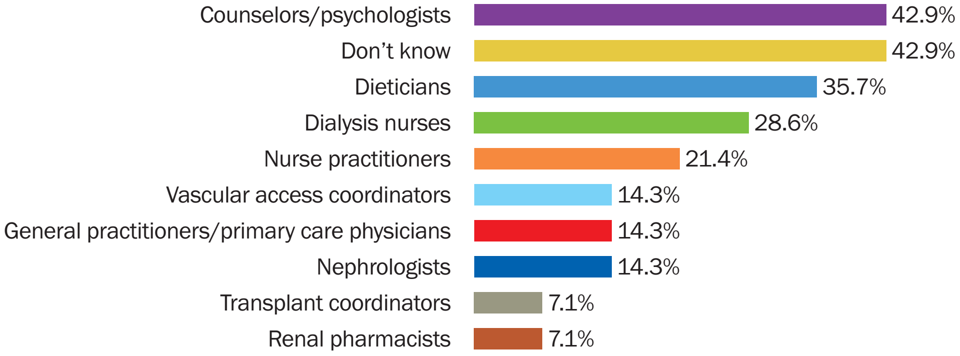


Figure 3.40 ***Policymakers: "What best describes your organization?"***

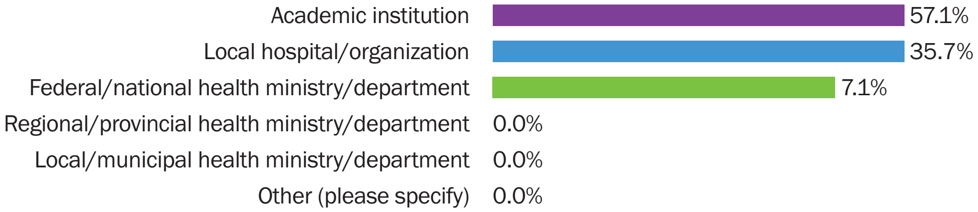


Figure 3.41 ***Policymakers: "What system best describes the oversight/direction of CKD care for patients not yet on dialysis or transplant in your country?"***

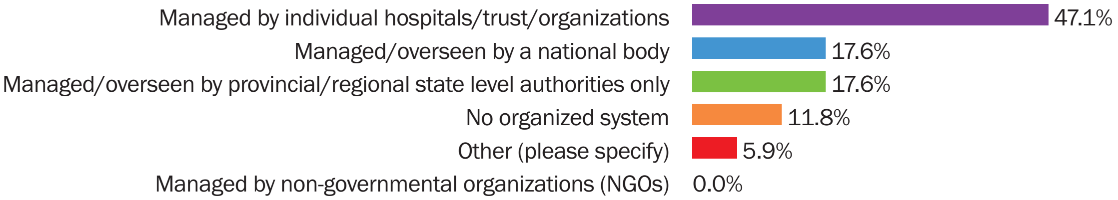
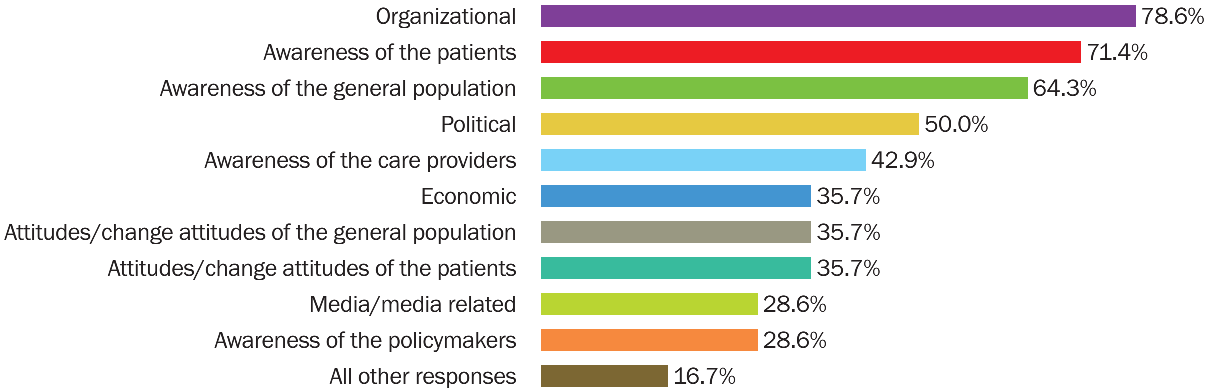


Figure 3.42 Policymakers: "In your opinion what are the key barriers to achieving optimal chronic disease care in your country?"



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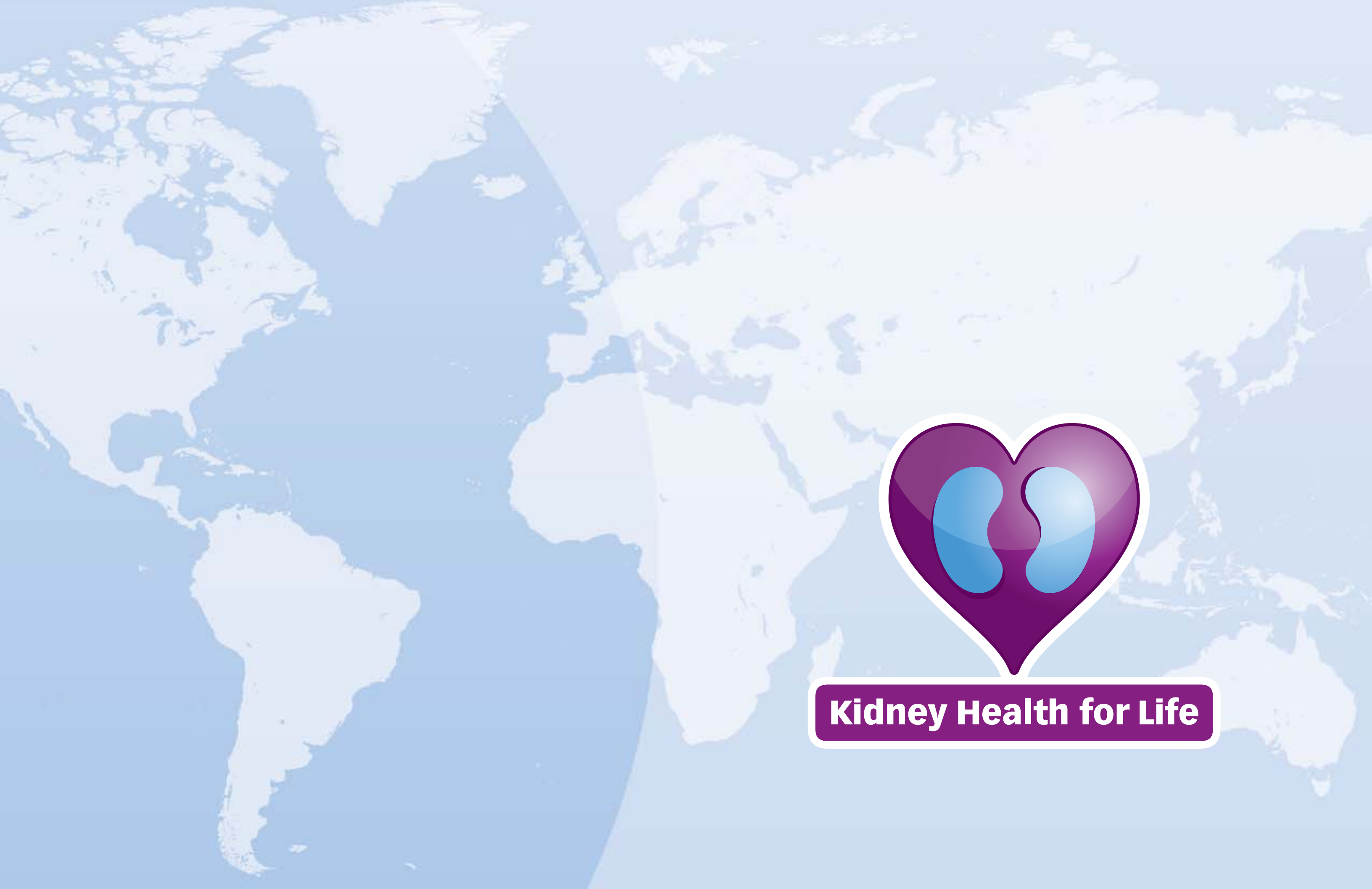
Kidney Health for Life (KH4L)

Chronic Kidney Disease
Multinational Inventory

Section 4

Key Findings, Synthesis and Recommendations



Kidney Health for Life

Chronic kidney disease is an important public health issue because of its high associated costs and poor health outcomes. Renal replacement therapy (RRT) is a costly healthcare intervention that consumes 1-2% of total healthcare budgets worldwide.[1-3] This does not include upstream costs related to management of CKD and its complications. However, it is now clear that the costs and morbidity of kidney failure represent only one component of the total impact of CKD, which is also mediated through accelerated cardiovascular disease and much other comorbidity such as frailty, poor nutritional status and excess risk of infection.[4-7]

Although the burden associated with CKD is already considerable, its health impact has increased substantially over the last two decades[5-7] and is expected to increase further in parallel with the rising global prevalence of diabetes, hypertension, obesity and vascular diseases, all of which are major risk factors for CKD.[8]

Most developed countries have highly organized systems for managing patients with ESRD. Less is known about the health policies, systems and structures relevant to the management of people with earlier stages of CKD. This Inventory summarizes these characteristics for 19 different nations, focusing on aspects that are related to prevention and early detection. The overarching objective was to summarize the status quo and to identify opportunities for improving CKD care worldwide.

A. Key findings

1. Health systems, policies and structures

- All 19 countries have a robust governance structure and a highly developed health system.
- All 19 countries have developed health policies, systems and structures relevant to NCD control, although these have been implemented to varying degrees. All 19 countries are signatories to the Health Assembly adopted resolution (WHA64.11), a WHO action plan for the prevention and control of NCDs for 2013–2020. Although the WHO document focuses on control of CVD, cancer, diabetes, tobacco and alcohol, its overarching principles and objectives are potentially relevant to CKD (see Section 3:A1–A4).

2. Organization and structure of CKD care

- CKD is not perceived by decision makers to be a healthcare priority and is not included in the national NCD agenda in most countries. Only 3 of the 19 countries (Ireland, Norway and the UK) have a national policy or service framework specific to CKD.
- Eleven countries have a national CKD management guideline, developed either by national agencies (eg, NICE in the UK) or professional associations (eg, Canadian Society of Nephrology in Canada).
- In general, coordination of care for people with CKD is lacking, as are agreed quality targets for practitioners or policy makers (see Section 3:A5). This may lead to inefficiencies (eg, specialist referral of patients with uncomplicated CKD who could be managed by PCPs) and suboptimal outcomes (eg, late referral of patients with advanced CKD).
- Oversight of CKD care is the responsibility of regional authorities or individual hospitals in 17 countries. Only the UK and Ireland have national directorates that coordinate delivery of CKD care across regions and hospitals.

3. Access and quality of care

- All 19 countries provide universal health coverage, meaning that basic healthcare services are free to all citizens at the point of delivery. Many countries require copayments to access care, but most have arrangements that reduce or eliminate these payments on the basis of medical or financial need. No major structural barriers to accessing CKD care in its current form were identified for any of the 19 countries. On the other hand, defined criteria for care standards, monitoring and target parameters (quality improvement programs) are absent in most countries.

- In all 19 countries, PCPs are predominantly responsible for the care of people with early CKD (stages 1–3). Nephrologists are mainly responsible for advanced CKD and/or RRT care. In many countries the care of people with early CKD is beginning to involve nephrologists and other specialists such as diabetologists or endocrinologists, cardiologists and internists, although the nature and extent of such involvement varies across countries.

4. Workforce capacity

- Although there is some variability across countries, the supply of PCPs and nurses was generally not considered a major barrier to the delivery of optimal CKD care.
- Some countries identified inadequate supply of nephrologists as a potential barrier, although this was not a consistent finding.
- In contrast, limitations in the supply of other allied health professionals were consistently identified as a potential barrier (Section 3:D3). Most frequently cited were inadequate supply of renal dieticians, social workers, psychologists, renal pharmacists and vascular access coordinators.
- Between-country differences were identified in the scope of practice for allied health providers – especially for renal pharmacists and nurses, who are substantially more autonomous in some countries than in others.
- Given the value of multidisciplinary care for NCD control, understanding the explanations for these between-country differences and ensuring that all providers work to their full scope of practice should be high priorities for future work.

5. Barriers to optimal CKD care

- The key barriers to optimal CKD care across nations were mainly described as political, economic and organizational in nature. These three generic barriers were usually interrelated. “Political barriers” often referred to the absence of a high-level commitment to action from all levels of government. This in turn was often perceived to contribute to inadequate funding for CKD care (“economic barrier” – and in some cases, to lack of a coordinated framework for delivery of care (“organizational barrier”), although the latter was acknowledged to have multiple potential causes.
- Nearly all respondents identified low awareness of CKD among the general population and among policy makers as an important potential barrier.

6. Epidemiological data on CKD and its major risk factors

- Most countries except Germany and Switzerland have a functioning RRT registry. These data have been pooled to allow comparisons between countries, as in the ERA-EDTA registry.
- In contrast, only Sweden and the UK have national registries for patients with earlier stages of CKD. Of note, the UK registry is an element of the QoF.
- Although the UK has published some data from its CKD registry, no countries have done representative national studies of CKD epidemiology. Available regional studies consistently suggest that the prevalence of CKD is increasing. This is compatible with multiple national studies that demonstrate aging of the general population and increasing prevalence of the major risk factors for CKD.
- Data on the costs of CKD care (non-RRT) are very limited; only the UK had nationally representative data, and even these data had major limitations.
- Similarly, national data on processes of care and outcomes were not available for any country except the UK, where they are part of the QoF initiative. Early data suggest that QoF has improved the processes of care for CKD patients, although it is too early to assess whether it has improved clinically relevant outcomes.
- The striking lack of data on disease burden, costs and processes of care presents a key opportunity for action, which should be given high priority.

7. Stakeholder perceptions

- Interest in how CKD care could be better organized and delivered has continued to grow over the last decade.
- Respondents (providers, policy makers and patients) all consistently stated that care delivery for non-RRT CKD (stages 1–4) is uncoordinated and fragmented, with suboptimal communication between primary care and specialist providers.

- Providers and policy makers also indicated that many CKD patients do not take responsibility for their health – while many patients indicated that they had not been provided with adequate educational materials related to CKD.

B. Synthesis and implications

The inventory identified some consistent findings across countries: substantial limitations of available CKD data (disease burden, process of care and outcomes), a general absence of national strategies for CKD care, workforce limitations (especially for allied health professionals), low awareness of CKD, and generic barriers to quality healthcare. These barriers include political (lack of government commitment), economic (limitations in resource availability) and organizational (issues with care organization and delivery) factors.

The following section discusses key priorities based on the key findings above and suggests strategies that could to address these priorities.

1. Incorporating CKD care into global and national NCD strategies

Lack of awareness among policymakers and the general public was frequently cited as a barrier to optimal CKD care. Removing this barrier will depend on continued emphasis including World Kidney Day[9] and similar initiatives, as well as on international advocacy efforts such as the ISN-led initiative that recently led to the inclusion of CKD in the UN resolution for the control of NCDs.[1, 10] Similar advocacy efforts at the regional (EU Commission, OECD) and country levels are required to build awareness among all stakeholders about the importance of CKD. The specific message delivered by these awareness initiatives (as well as the methods used to deliver the message) will likely require some adaptation for each country.

Rather than participating in a zero-sum game (promoting one chronic disease at the expense of others), it will be critical for CKD advocacy efforts to leverage the global momentum behind NCD control agendas. This will require sustained engagement with other disease-specific organizations at the national and international level – and deliberate attempts to integrate with existing NCD control initiatives where possible.

2. Early detection and appropriate management of CKD

Given the poor health outcomes and high costs associated with CKD, as well as the anticipated increases in the burden of CKD over time, early detection and appropriate management strategies will be essential for CKD – as they are for other NDCs.[11] General population screening is not supported by evidence, but there is agreement that case-finding (searching for CKD in populations with higher-than-average prevalence) is likely to be efficacious and economically attractive. Despite this, there was substantial variability between and within countries in the approach taken to early detection of CKD. Of potential interest is the policy initiative in England by the Department of Health to systematically assess CVD risk from the age of 40 to 75 years – which includes testing for CKD and other risk factors such as diabetes, hypertension and dyslipidemia.[12] This policy is compatible with what is known about the potential benefits of early detection – but whether it will improve clinically relevant outcomes remains to be shown. There are similar initiatives across countries with varied focus and priorities (Table 4.1). These initiatives need strong policy support and direction from the government; roles and responsibilities must be clearly delineated among the various stakeholders involved in providing CKD care.

3. Population-based national CKD registries

Reliable national data systems are needed to assess the burden of CKD, processes of care and clinical outcomes. Once established, these systems could be used for routine surveillance (including secular trends), quality improvement, resource allocation (including workforce planning) and between-country comparisons. If combined with existing data sources, better data on CKD and its major causes might also facilitate efforts to integrate CKD care with care for other major NCDs.

There are potential synergies between a systematic early detection strategy and a national CKD registry, since the latter (especially if linked to an RRT registry) could be used to evaluate the clinical impact of the former. Agreement on a standard international definition and classification of CKD[13] would facilitate this objective and would allow between-country comparisons of the burden and treatment of CKD, as is currently done for treated ESRD in Europe and Canada. Ideally, each national registry should collect data on specific risk factors, burden of disease (population trends, complications, costs of care), process of care and outcomes. It should leverage existing registries for other major NCDs such as diabetes and cancer. Establishing such a comprehensive national registry would be a major undertaking for each country and would require support from nephrologists, nephrology societies, other care providers, policymakers, CKD advocacy groups and patients. Despite the obvious challenge, reliable data repositories must be developed in order to deliver and plan for optimal care.[14] These repositories could come under quality improvement programs as in the UK QoF.[15] Effective implementation would require legislation and political support for reimbursements or other incentives for providers to participate.

Table 4-1 National initiatives to improve CKD care delivery

Country	*Initiatives to improve CKD care*
Austria	There are no specific CKD care initiatives.
Belgium	"Trajectory" ("Trajectoire") established to care for CKD 3b–4–5 patients: early identification of cases, referral and improved collaboration between PCPs and specialists.
Canada	See Kidney Disease (SeeKD)[21] targeted screening program by the Kidney Foundation of Canada, the first nationally targeted screening program for CKD in high risk groups in Canada. Canadian Kidney Knowledge Translation and Generation Network (CANN-NET), which facilitates knowledge transfer and implementation of guidelines.[22]
Denmark	There are no specific CKD care initiatives.
Finland	National policy document on chronic disease including CKD (in development, to cover aspects of care guidelines, improving CKD awareness and collaboration between PCPs and nephrologists).
France	A white paper by RENALOO, a patient organization, to urge government to prioritize CKD care.
Germany	There are no specific CKD care initiatives.
Greece	There are no specific CKD care initiatives.
Ireland	National Renal Care Policy administered by the National Renal Office.
Israel	CKD guideline recommendations (in progress). Health costs study about the economic burden of CKD (planning phase).
Italy	CKD care policy document (in development by the Ministry of Health). National CKD prevalence study (in preparation in collaboration with the Ministry of Health).
Netherlands	PCP standard Prevention Consult developed in 2012, to guide management and referrals.
Norway	National action plan for CKD (in preparation, to include early CKD care and RRT).
Portugal	There are no specific CKD care initiatives.
Spain	A current initiative to adapt the KDIGO guidelines for CKD management to the Spanish setting, and target them at PCPs (in progress).
Sweden	There are no specific CKD care initiatives.
Switzerland	National study on the prevalence of CKD in the Swiss population, including its socioeconomic impact, a model of future cost trends of CKD, and a comparison of data across cantonal systems (to be completed in December 2013).
Turkey	A national study on the prevalence of CKD (the CREDIT Study) by the Turkish Society of Nephrology.
United Kingdom	Pan-vascular prevention policy: Health Check program (2009–present) to prevent heart disease, stroke, diabetes and CKD in those aged 40–74 years.[12] Done on a 5-year cycle. Quality and Outcomes Framework for CKD.[15]

CKD = Chronic kidney disease, PCPs = Primary care practitioners, RRT = Renal replacement therapy.

4. Development of coordinated systems for CKD care

All countries need a coordinated CKD care structure that addresses all stages of illness – from the identification of risk to terminal care (Panel). Many countries' lack of national guidelines for referral and management of CKD patients could be construed as a barrier towards achieving this objective but may actually constitute an opportunity to take up the high quality international guidelines published by KDIGO or ERA-EDTA and adopt them to the national context. This would require financial resources and commitment from nephrologists as well as policy makers – and would be facilitated by partnerships with professional organizations of PCPs and other specialists (endocrinologists, cardiologists and general internists). Although evidence-based guidelines should ideally be international or national, effective implementation strategies often need to be regional or even local – and care pathways adapted to each specific circumstance can help to increase uptake of evidence-based practices, especially if promoted by a clinical champion.

Panel

Pathway for optimal and coordinated CKD care

Optimal CKD care refers to best practice in management and prevention of complications in the following domains (based on a review of various CKD guidelines KDIGO, NKF, Australia, Canada and the UK):[13, 16-19]

1. Identification and early detection program: An organized system to identify people with risk factors for CKD, and evaluate them for the presence of CKD markers. Examples of risk factors include hypertension, diabetes, CVD (ischemic heart disease, heart failure, peripheral vascular disease and stroke), urological problems (structural renal tract disease, kidney stones and prostatic disorders), multisystem diseases (systemic lupus erythematosus, rheumatoid arthritis, infective endocarditis, etc) and family history of kidney disease.
2. Appropriate referral and management system: An organized system to ensure that people with CKD who may benefit from specialist care are referred for specialist assessment appropriately. The criteria would include advanced stages of CKD (stages 3b, 4 and 5), significant proteinuria or albuminuria (Protein:creatinine ratio ≥ 100 mg/mmol, Albumin:creatinine ratio ≥ 70 mg/mmol), rapid CKD progression based on clinical evaluation, difficult-to-control hypertension, hematuria and history of acute kidney injury.
3. Standard care plan: An organized system to ensure that people with CKD have a current agreed care plan appropriate to the stage and rate of progression of CKD. Those with early stages would be monitored appropriately in a primary care setting, while those in need of specialist care would have access to it.
4. Monitoring of complications, risk factor control and disease progression: An organized system to ensure that people with established CKD:
    - Are evaluated for cardiovascular risk.
    - Are evaluated for risk factor control (good blood pressure and diabetes control, and appropriate reduction of proteinuria).
    - Are continually monitored for disease progression.
    - Are assessed for and receive appropriate treatment for disease complications such as anemia, bone disease, malnutrition and psychological issues (eg, depression).
5. Preparation for RRT: An organized system to ensure for people with established CKD
    - If they are likely to progress to established kidney failure within a short time period (1–2 years), they receive information on care for established kidney failure and their options for RRT.
    - If they are likely to progress to kidney failure within a short time period (1–2 years), and are not candidates for RRT, they receive information on conservative care for advanced CKD.
    - They have access to psychosocial support.
    - If they might potentially receive a pre-emptive kidney transplant, they are given the opportunity to receive such treatment.
    - They commence RRT with a functioning arteriovenous fistula or peritoneal dialysis catheter as appropriate.
    - If they are already on long-term dialysis, they receive the best possible care, including access to home-based therapies.

5. Reducing risk of progression and improving outcomes

Given the variability between and within countries in the perceived quality of CKD care delivery, there appear to be opportunities to reduce those variations. Many of the countries included in the inventory have implemented strategies to improve the quality of CKD care (Table 4.1), although some have not. The UK QoF is a national initiative that uses financial incentives together with continuous monitoring of process-based outcomes to facilitate certain evidence-based provider behaviours (see Section 2: UK chapter, B2.2).[15] The QoF has led to considerable improvements in the targeted process-based outcomes for CKD patients – with PCPs attaining the recommended targets in about 96% of cases.[15, 20] These encouraging results suggest that government commitment and a coordinated care framework have great potential to improve the quality of CKD care, although it is too early to measure the impact of this initiative on clinically relevant outcomes.[15, 20] Not all countries will be able to support a coordinated national approach to CKD management (eg, those where regional authorities have primary responsibility for care delivery),

6. Educational materials

Patients and providers consistently identified a lack of educational materials to guide people with earlier stages of CKD. If patients are to be more engaged in their care, such materials will be critical. The findings of the inventory suggest an opportunity for each country to develop relevant educational materials for its citizens – ideally with input from a broad range of allied health personnel and from experts in behaviour change.

7. Building workforce capacity

Sufficient workforce capacity is essential to any NCD care initiative.[23] There is emerging interest in multidisciplinary care for NCD care generally and for CKD care specifically. Multidisciplinary teams appear to improve process-based outcomes and may be more economically efficient than physicians working alone, although available data do not permit a firm conclusion about the latter. Findings from the survey demonstrate substantial variability between countries in current use of multidisciplinary teams for CKD care, and also in capacity to scale up the use of such teams. Based on the perceptions of survey respondents, three key strategies could be used to increase workforce capacity: increasing the number of providers (especially allied health professionals); allowing all providers to work to their full scope of practice; and increasing efficiency by improving communication between PCPs and nephrologists (see below). For undergraduate and postgraduate medical curricula to include modules on the benefits of multidisciplinary care might be a useful long term goal, as would attempts to educate policymakers about such benefits.

8. Improving collaboration between primary and specialist care

Relationships and collaborations between PCPs, other specialists involved with CKD care and nephrologists need to improve. As this happens and MDTs (dieticians, pharmacists, counselors, nurses, vascular access practitioners, nurses, etc) are implemented, care delivery will be enhanced in all countries, particularly for patients with advanced stages of CKD. A key example of a relevant initiative that has boosted collaboration and partnerships between PCPs and nephrologists is the UK national service framework on CKD.[20]

9. CKD and global health

This inventory included only relatively affluent nations, but its findings may have implications for global CKD health. Many of the opportunities and obstacles identified may apply equally to less developed nations, where RRT is unavailable or unaffordable. Future work should consider how the key conclusions of this inventory could be applied to health systems in low- or middle-income countries.

10. Research needs

In the last few decades, renal research has concentrated mainly on basic aspects of disease (pathogenesis and pathophysiology), epidemiology (defining disease measures, burden population trends and outcomes) and therapeutics (clinical trials to prove effective interventions). This emphasis has resulted in high-quality information on pathophysiology and development of evidence-based guidelines for CKD care. Given the gaps in care observed in the current inventory (as well as between-country variability in how care is organized and delivered), what is most needed now is high-quality research on optimal care structures, care pathways, behaviour change (for providers and patients) and guideline implementation.

C. Towards a sustainable CKD policy: challenges and pitfalls

A global CKD care policy confronts multifaceted challenges and pitfalls. First, defining a unified approach to the common challenges identified is difficult: how care is organized and delivered is not uniform within and across countries, nor are financial and political commitments by regional and national authorities to investment in healthcare.

Second, the level of inputs into chronic disease care in general may be misleading in that inputs quite often are not commensurate with outputs (improved care efficiency or better health outcomes). In this study, the highest spenders on healthcare among the EU nations and Canada might not necessarily have the best organized system for CKD care delivery. For instance, the UK had among the best organized systems while ranking 11th in total healthcare spending. This is difficult to benchmark, however. Specific inputs (investments in chronic disease care) would often differ based on the priorities of the political leaders, and the overwhelming absence of data on process indicators and outcomes particularly for CKD did not allow for any reasonable degree of comparisons across countries.

Third, it is in general difficult to compare policies across nations because of differences in structural, cultural, political and economic factors. Nations differ in their approach to health systems measurements and reporting, and all of them tend to present the best outlook to the outside world. Further, healthcare systems even within a single country tend to be complex, which often is reflected in how care is organized for all chronic diseases, not only CKD. This is compounded by the clinical complexity of CKD care as the disease has a very wide spectrum and poorly defined measures and targets at present.

However, these challenges can be surmounted through commitment, focus and effective leadership. This inventory calls upon the global nephrology community and the relevant key global bodies including the ISN and its sisters in global chronic disease advocacy (International Diabetes Federation [IDF], World Heart Federation [WHF], World Hypertension League, etc). Cooperation of the global bodies such as the UN, OECD, WHO, the World Bank is needed, as is strong political will on the part of national governments. The paramount importance of international and national political will is showcased by significant successes recorded over the last decade in the arena of communicable diseases such as HIV/AIDS through initiatives such as the President's Emergency Plan on HIV/AIDS Relief (PEPFAR), charitable supports such as the Bill & Melinda Gates Foundation and national governments' commitments. Such initiatives are often spearheaded through UN and WHO resolutions.

Uremia may be eliminated around the globe if only it can be given the attention it deserves among the NCDs. Recognition of the serious consequences of CKD as a driver for CVD and related mortality, a cause of the most expensive lifetime treatment (RRT) and of poor quality of life) can promote effective and sustainable policies to stem its tide across the globe.

D. Summary

The inventory outlines several common challenges identified in the participating countries, and a corresponding list of potential opportunities. Some countries are further ahead than others, but all have considerable work to do. Progress will require concerted efforts in each country at the national level – and would be facilitated by leadership by a credible, respected and impartial international organization (such as ISN or ERA/EDTA) that can use lessons learned in one country for the benefit of others.

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Kidney Health for Life (KH4L)

Chronic Kidney Disease Multinational Inventory

APPENDIX

Appendix

A: Steering committee members

Adeera Levin
Professor of Medicine and Head, Division of Nephrology
Department of Medicine, Faculty of Medicine, The University of British Columbia
Consultant Nephrologist, St. Paul's Hospital, Providence Health Care
Executive Director, BC Renal Agency, Vancouver, BC, Canada

John Feehally
Professor of Renal Medicine
University Hospitals of Leicester NHS Trust
Leicester General Hospital, Leicester, LE5 4PW, UK

Tilman Drueke
Professor and Emeritus Director, Research
Inserm Unit 1088, UFR Médecine/Pharmacie, Université de Picardie, Amiens, France

Johannes Mann
Professor of Medicine, Friedrich Alexander University of Erlangen
Head, Department of Nephrology, Hypertension & Rheumatology
Munich General Hospitals, Kolner Platz 1, 80804 Munchen, Germany

Charles Kernahan
Former Chief Executive, Kidney Research UK

Gerard London
Professor, INSERM U970, Hôpital Européen Georges Pompidou, Paris, France

Christian Frenzel
Geschäftsführer Bundesverband Niere e.V.
Weberstr 2, 55130 Mainz, Germany

Jitka Pancirova
Executive Director
European Dialysis and Transplant Nurses Association/
European Renal Care Association

Michal Cesana
Abbvie Laboratories

Alexandra Moutet
Patient Engagement and Care, Western Europe & Canada Abbvie

B: KH4L External Advisors

Lars Rydén
Karolinska Institute, Cardiology Unit
Stockholm, Sweden

Peter Rossing
Steno Diabetes Centre
Gentofte, Denmark

Paul Roderick
Professor of Public Health
University of Southampton, UK

C: National KH4L leaders (Reviewed country chapters)

Austria

Alexander Rosenkranz
Head, Division of Nephrology
Department of Internal Medicine
Medical University Graz
Auenbruggerplatz 27, A-8036 Graz

Gert Mayer
Head, Department of Internal Medicine IV (Nephrology and Hypertension)
Cluster Internal Medicine
Medical University Innsbruck
Anichstrasse 35, A – 6020 Innsbruck

Belgium

Michel Jadoul
Professor, Clinical Medicine
Université catholique de Louvain
Head, Department of Nephrology
Cliniques Universitaires Saint-Luc Service De Nephrologie
Av. Hippocrate 10, B-1200 bruxelles

Canada

Paul Komenda
Assistant Professor of Medicine
University of Manitoba
Medical Director, Home Hemodialysis Program and
Research Director
Seven Oaks General Hospital

Denmark

Bo Feldt-Rasmussen, MD, DMS
Professor and chief of Nephrology
Rigshospitalet, University of Copenhagen

Stinne Kvist
Head of Department
Department of Nephrology
Aarhus University Hospital
Brendstrupgaardsvej 100, 8200 Aarhus N

Finland

Kaj Metsärinne
Head of section
05 Operational Division: Medicine /
Section: Department of nephrology and dialysis treatment
Turku University Hospital

Heikki Saha
Division Head
Department of Internal Medicine / Renal Clinic
Tampere University Hospital
PO Box 2000, FI-33521 Tampere

France

Maurice Laville
Professor, Nephrology - Hypertension - Hemodialysis - Pavilion P
CHU - Hôpital Edouard Herriot
Claude-Bernard University
69437 Lyon Cedex 03

Eric Thervet
Professor of Medicine, Head, Kidney Disease Program
Service de Néphrologie, Hôpital Européen Georges Pompidou Université Paris Descartes
Institut National de la Santé et de la Recherche Médicale [INSERM]
UMR S775, Centre Universitaire des Saints-Pères, Paris

Philippe Zaoui
Professor of Nephrology
Clinique de Néphrologie CHU Grenoble
CA AGDUC
Université J Fourier Relations Internationales

Germany

Markus Ketteler
Professor of Medicine
Division Chief, Nephrology Klinikum Coburg
Head, KfH–Dialysis Center Coburg

Werner Riegel
Professor and Director
Medical Clinic III internal Medicine and Nephrology
Grafenstraße 9, 64283 Darmstadt

Greece

Christos Iatrou
Head, Center for Nephrology
G. Papadakis General Hospital of Nikaia-Pireaus, Athens
6 Themistokleous str Athens, GR 15342

Kostas C. Siamopoulos
Professor of Medicine/Nephrology
Department of Nephrology
Medical School, University of Ioannina
University Avenue, Ioannina, GR451 10

Ireland

Liam Plant
Consultant Renal Physician, Cork University Hospital
National Clinical Director, HSE's National Renal Office (NRO)

Austin G. Stack
Professor & Chair, Department of Medicine
Consultant Nephrologist
Graduate Entry Medical School (GEMS)
Faculty of Education & Health Sciences, University of Limerick

Israel

Eliezer Golan
President, Israel Society of Nephrology & Hypertension
Department of Nephrology & Hypertension
Meir Medical Center, Kfar-Saba 44281

Talia Weinstein
Director, Hemodialysis Unit
Tel Aviv Medical Center

Italy

Rosanna Coppo
Professor, Director, Nephrology, Dialysis and Transplantation Unit
Regina Margherita Children's University Hospital, Piazza Polonia 94,Turin 10126

Diego Brancaccio
Professor or Nephrology
Faculty of Medicine, University of Milan
Renal Division, Ospedale San Paolo
8 Via di Rudiní, IT–20142 Milan

Netherlands

PM ter Wee
Internist Nephrology
Professor, Department of Nephrology
VU University Medical Centre
De Boelelaan 1117, 1081 HV Amsterdam

Norway

Sadollah Abedini
Section of Nephrology, Department of medicine
Vestfold Hospital, Tønsberg, Norway

Solbjørg Sagedal
Department of nephrology, Oslo University Hospital
Ullevål, Oslo 0407

Portugal

Rui Alves
Professor, Department of Nephrology, Faculty of Medicine
University of Coimbra, Coimbra, Portugal

Fernando Nolasco
Professor of Medicine
Faculty of Medical Sciences, Universidade Nova de Lisboa
Nephrologist, Hospital Curry Cabral

Spain

Alberto Martínez Castelao
President of the S.E.N.
Associate Professor of Medicine, University of Barcelona
Chief of Dialysis division, Nephrology Department
Hospital Universitari de Bellvitge
Feixa Llarga, s/n., 08907 Hospitalet de Ll. (Barcelona)

Jose Luis Gorriz
Servicio de Nefrologia
Hospital Universitario Dr Peset, Valencia

Sweden

Maria Svensson
Docent/överläkare
Njurmedicin
Sahlgrenska Universitetssjukhuset
413 45 Göteborg

Britta Hylander
Docent
Njurmedicinska kliniken
Karolinska universitetssjukhuset Solna
171 76 Stockholm

Switzerland

Michel Burnier
Professor, Nephrology (NEP)
Faculty of Biology and Medicine, University of Lausanne
Quarter UNIL-CHUV, Rue du Bugnon 17
CH-1005 Lausanne

Bruno Vogt
Head and Chairman, Professor
INSELSPITAL, Universitätsspital Bern

Turkey

Siren Sezer
Professor of Nephrology, Department of Nephrology
Baskent University

Gültekin Süleymanlar
Akdeniz University Medical School
Department of Medicine, Renal Division
Dumlupinar Caddesi
07070 Antalya

United Kingdom

Donal O'Donoghue
Professor of Renal Medicine, Kidney consultant
Salford Royal Foundation Trust
National Clinical Director for Kidney Care from 2007-2013

D: Other reviewers

(not identified as national leaders by the KH4L secretariat, but got involved on the invitation of the AKDN)

Belgium

Kathleen Claes
University Hospital Leuven
Department of Nephrology and Renal Transplantation
Herestraat 49, 3000 Leuven

W. Van Biesen
Chair of ERBP
Renal Division, University Hospital Ghent
De Pintelaan 185 9000 Ghent

Canada

Manish M Sood
Assistant Professor of Medicine
University of Manitoba
St Boniface General Hospital
Nephrologist, Manitoba Renal Program
Winnipeg, Manitoba R2H 2A6

Denmark

Jon Waarst Gregersen
Consultant / Lecturer
Department of Medicine, Viborg hospital

Israel

Alexander Aviram
Scientific Director
Israel National Institute For Health Policy Research
Tel-Hashomer, Israel 52621

Italy

Carmine Zoccali
Director, Division of Nephrology
Hypertension and Renal Transplantation
National Research Council – IBIM at Riuniti Hospital
Reggio Calabria

Francesco Locatelli
Head, Department of Nephrology, Dialysis and Renal Transplant
Alessandro Manzoni Hospital, Lecco, Postgraduate Professor of Nephrology,
Universities of Brescia and Milan

Netherlands

CAJM Gaillard
Internist Nephrologist
Professor of Nephrology
University Medical Center Groningen/ Department of Nephrology
PO Box 30001 / Groningen

R.T. Gansevoort
Internist Nephrologist
University Medical Center Groningen/ Department of Nephrology
PO Box 30.001 / 9700 RB Groningen

Portugal

Margarida Goncalves
Hospital Santa Cruz, Department of Nephrology Carnaxide
Nefroclínica-Estoril, Diaverum, Estoril

Spain

Angel LM de Francisco
Professor, Servicio de Nefrologia
Hospital Universitario Valdecilla, Santander

Luis Ruilope
Associate Professor, Internal Medicine,
Complutense University, Madrid,
Head, Hypertension Unit, 12 de Octubre Hospital, Madrid

Turkey

Hıdır Arslan
Sorumlu Hekim ve Klinik Müdürü
Diaverum Türkiye Ultra Diyaliz Merkezi
Bahçelievler Mahallesi
Hacer Hanım Sokak No:9
34180 Bahçelievler, İstanbul / Turkey

United Kingdom

Debasish Banerjee
Consultant and Reader
Renal and Transplantation Unit, Clinical Sub-dean
St Georges Healthcare NHS Trust; St Georges.
University of London

E: The AKDN team

Scientific:

Dr Marcello Tonelli

Dr Brenda Hemmelgarn

Dr Scott Klarenbach

Dr Braden Manns

Dr Aminu Bello

Technical:

Arash Afshar

Labib Faruque

Rosie Hernandez

Ghenette Houston

Dawn Opgenorth

Sophanny Tiv

Natasha Wiebe