



# **Recommendations for Sustainable Kidney Care**

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**[www.ekha.eu](http://www.ekha.eu)**

Chronic kidney disease (CKD) is a major and growing health burden in Europe. One in 3 Europeans is at an increased risk of developing CKD. A striking 1 in 10 already has impaired kidney function severe enough to affect their health status. The current rise in diabetes, obesity and ageing will further worsen this situation unless there is greater focus and concerted action by European health policy-makers.

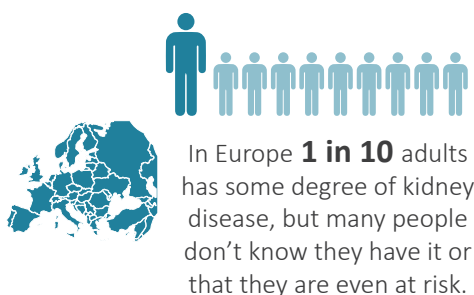
Being a 'silent disease' with few or no symptoms until it is too late, CKD receives little attention, particularly when compared with other chronic diseases. These *Recommendations for Sustainable Kidney Care* defined by the European Kidney Health Alliance (EKHA) are a common effort by stakeholders to propose solutions for the challenges of CKD in Europe through effective prevention and a more efficient care pathway intended to facilitate the provision of appropriate and affordable treatment to all Europeans equally, while promoting the highest quality of care.

## BURDEN OF CKD IN EUROPE

One in 10 Europeans have at least one clinical sign of existing CKD, such as the presence of protein in the urine – an indicator of reduced kidney function. Perhaps even more startling is that an estimated 90% of these individuals are unaware they have early-stage CKD, as they experience few or no symptoms.

Nevertheless, from its early stages onwards, CKD is associated with an increased risk of complications and death, to a large extent attributable to an ensuing cardiovascular event. Diabetes is the leading cause of kidney disease, followed by high blood pressure (hypertension). The dismal prognosis faced by patients with CKD is linked with the effects of these concurrent diseases. Although progress has been made in recent years, end-stage kidney disease still kills more people each year than breast cancer, prostate cancer or even road traffic accidents. [Ref]. Globally there was an 82% increase in the number of deaths from CKD between 1990 and 2010<sup>1</sup>.

Patients who eventually reach end-stage kidney disease need renal replacement therapy (RRT) via dialysis or kidney transplantation. Data from the European Renal Association-European Dialysis and Transplant Association (ERA-EDTA) Registry shows that the prevalence of people on RRT across Europe increased by 3.3 % from 2011 to 2012 to reach 716.7 per million population<sup>2</sup>.



## WHAT DOES KIDNEY DISEASE COST?

The cost of treating CKD is formidable. Hospital-based haemodialysis – the most common form of dialysis – alone costs up to €80,000 per year per patient. Moreover, this does not take into account the lost productivity caused when CKD interferes with time at work, or prevents patients from working altogether.

Dialysis is resource-heavy, costing up to



EUR per year, per patient, depending on the country and method.

In general, RRT consumes 2% of overall healthcare expenditure in Europe, for only 0.1% of the population. The total 'direct' cost of RRT across Europe is unknown, but one estimate puts it at up to €15 billion per year. There are additional healthcare costs of co-interventions needed to sustain RRT and to treat its complications, indirect costs associated with the time patients are absent from work while undergoing treatment, and ancillary costs such as transportation to and from the clinic. These figures also exclude the medical costs incurred before patients reach end-stage CKD – a population estimated to be around 100 times larger than the population on RRT.

In England, for example, the cost of CKD to the healthcare system was estimated at £1.44 to £1.45 billion (2009–2010 prices), representing around 1.3% of all spending<sup>2</sup>. Importantly, more than half this sum was spent on RRT provided for only 2% of the CKD population, illustrating the high cost of RRT. High costs were also associated with the cardiovascular complications associated with CKD. It was estimated that in one year in England, approximately 7000 excess strokes and 12 000 excess heart attacks occurred in the CKD population, as compared with matched individuals without CKD.

<sup>1</sup>Lozano R, et al. Global and regional mortality from 235 causes of death for 20 age groups in 1990 and 2010: a systematic analysis for the Global Burden of Disease Study 2010. *Lancet* 2012;380:2095–128.

<sup>2</sup>Jager K. Renal replacement therapy in Europe: a summary of the 2012 ERA-EDTA Registry Annual Report. *Clin Kidney J* 2014; 7:227–38. [http://www.era-edta-reg.org/files/annualreports/pdf/Noordzij\\_Annual%20Report%202011%20paper\\_CKJ\\_2014.pdf](http://www.era-edta-reg.org/files/annualreports/pdf/Noordzij_Annual%20Report%202011%20paper_CKJ_2014.pdf)

<sup>3</sup>Kerr M, et al. Estimating the financial cost of CKD to the NHS in England. *Nephrol Dial Transplant* 2012;27 Suppl 3:iii 73-80.

## THE CASE FOR CHANGE

CKD imposes major challenges for patients, the medical community and society owing to its high but underestimated prevalence, its frequent late recognition, the negative impact on quality of life, and the high cost of its complications and treatment. The close relationship between CKD, diabetes, high blood pressure and cardiovascular disease means that CKD must be addressed in conjunction with multifaceted, co-ordinated health policy initiatives targeting all of these chronic diseases.

EKHA believes that specific actions can be done to prevent CKD, to improve early detection of CKD, and to provide more efficient treatment to help reduce the predicted tide of new cases of kidney failure needing costly and invasive RRT. To do this, collaborative efforts which draw upon the patient's experience-based expertise as well as medical knowledge are required to address deeply entrenched problems with the planning and delivery of RRT services across Europe, namely:

- A striking variation between Member States in the accessibility of kidney transplantation, the treatment of choice for end-stage CKD.
- A lack of choice for many people facing dialysis, leading to their allocation to a treatment that is neither preferred nor cost-efficient.

- A substantial variation between Member States in the availability of home dialysis, even though this treatment modality is associated with lower costs, a reduced need for specialist personnel, improved quality of life for patients, and greater flexibility in quantum of dialysis treatment as compared with hospital dialysis.

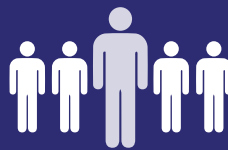
The **EKHA Recommendations for Sustainable Kidney Care** aim to address these and other challenges by focusing on increasing early detection of CKD, removing barriers to care for people with CKD, making savings for national health budgets and improving health outcomes over time. Each recommendation addresses an area where physicians and patients agree that action is needed, and where there are clear potential benefits for people with CKD.

The Recommendations are clustered into four focus areas to address the full continuum of care:

1. Prevention and early detection
2. Choice of renal replacement therapy
3. Increasing access to transplantation
4. Treatment reimbursement strategies



**1 in 3** people with diabetes has kidney disease.



**1 in 5** people with high blood pressure has kidney disease.

People with CKD are more likely to have cardiovascular problems such as angina, heart attack, stroke or heart failure. **3x**

## THE IMPACT OF CKD ON AN INDIVIDUAL'S LIFE

The patient with CKD faces a long and difficult path. As CKD worsens there is a gradual increase in the medication needed — eventually this can amount to more than 20 pills per day. Many patients also need to follow a special diet, which is very restrictive and may come with its own negative side-effects. Patients often feel very poorly, with fatigue, exhaustion and inability to concentrate being common complaints.

Most patients who reach kidney failure have to undergo dialysis, either by haemodialysis or peritoneal dialysis. Although life-saving, dialysis comes with a vast downside which must be endured. First, patients need surgery to provide access for the dialysis. Indeed, some patients need more than 20 surgical interventions during the course of their disease. Dialysis is typically performed three times per week and each session lasts 4 hours — time that is lost for the patient. In-hospital dialysis entails considerable additional time travelling to and from the dialysis unit.

Transplantation restores much of the kidney function lost due to CKD. However, the repair is incomplete and there still may be a need for additional interventions. The medication burden after transplantation remains substantial, and some medications may produce disturbing side effects. In addition, transplanted kidneys last on average only 10–15 years, after which many patients face a return to dialysis or re-transplantation.

In short, the quality of life for a person with end stage kidney disease is rarely satisfactory, despite the improvements made in care in recent years. This reality underpins the critical need to improve awareness and prevention of CKD amongst EU citizens and to ensure that kidney patients are treated in a holistic way, with particular attention given to reduce the negative psycho-social impact of CKD.

# Recommendation cluster 1: Prevention and early detection

## Prevention

Europe must invest in disease prevention. Currently, 97% of healthcare expenditure is on treatment and only 3% on prevention. A paradigm shift from disease care to health care is needed. Evidence suggests that even a relatively minor increase in funding for disease prevention will result in considerable health gains and reduced future healthcare costs.

Population-wide measures to eliminate smoking and excessive use of alcohol, to lower the consumption salt, fat and sugar, and to increase daily physical activity are the most cost-effective actions to prevent kidney disease and all related chronic diseases.

- Primary prevention of CKD in the general population should focus on actions that stimulate and facilitate the adoption of healthy lifestyles.

However, efforts to improve prevention cannot succeed without improving the health literacy of the population. People with low health literacy, which tends to be the case in vulnerable and socially deprived populations, in whom the risk factors for CKD are more prevalent, are less able to use preventive health services, take adequate care of their condition, or may have difficulty navigating the health system.

Thus, health literacy, which involves improving the ability to seek out and interpret health information, is crucial to both primary and secondary prevention efforts. People need simple instructions about what they need to do to stay healthy and avoid disease. Furthermore, those who are already living with an illness need information on managing their condition.

- To reach these aims appropriate education to improve health literacy should be provided.
- Educational initiatives should especially focus on vulnerable and socially deprived populations, in whom the risk factors for CKD are more prevalent.

## Early detection

The EU should support Member States in designing and implementing programmes for CKD screening and early diagnosis.

- Harmonised approaches to screening for CKD should be implemented throughout Europe.
- CKD screening programmes should target individuals with CKD risk factors in order to optimise cost-effectiveness.
- Creating a robust EU-wide registry of stage 3-4 CKD is an essential element of an effective early detection programme.
- Once CKD has been detected, appropriate therapeutic measures should be implemented to slow or stop disease progression, particularly avoidance of its main causes – hypertension, diabetes and acute kidney injury. This should be approached through a combination of lifestyle measures<sup>4</sup>, diet and drug treatment according to current ERA-EDTA Clinical Practice Guidelines<sup>5</sup>.

## RISK FACTORS FOR CHRONIC KIDNEY DISEASE

- Age 60 years or older
- Diabetes
- Heart disease
- High blood pressure
- Obesity
- Smoking
- Previous of family history of kidney disease

<sup>4</sup>Dunkler D, et al. Modifiable lifestyle and social factors affect chronic kidney disease in high-risk individuals with type 2 diabetes mellitus. *Kidney Int* 2015 Apr;87(4):784-91.

<sup>5</sup>KDIGO Clinical Practice Guidelines 2013. <http://kdigo.org/home/guidelines/ckd-evaluation-management/>

# Recommendation cluster 2: Choice of treatment

## Promoting home dialysis and self care

EKHA is committed to the principle that patients should be able to choose their treatment pathway. Currently, a choice between different modes of RRT is not available in all Member States, largely because of financial and resourcing constraints. In particular, the lack of access in some regions to home dialysis can be regarded as inequitable, depriving some patients of the most flexible and cost-effective form of dialysis.

Providing dialysis at home costs far less than hospital-based dialysis after the first year. A US study showed that over time home dialysis would save payers between \$7612 and \$12,403 over hospital-based dialysis per patient/year<sup>6</sup>. Moreover, patients who receive home dialysis need to travel less and are able to return to work or to continue in the workforce. Their sense of freedom and independence to manage their life as they choose is much higher.

The frequency and duration of dialysis also play a role: patients who receive dialysis during the night often feel better and have more energy during the day. Therefore, increasing the use of home dialysis (where clinically appropriate) will potentially improve patients' quality of life and productivity while reducing the costs of CKD to the healthcare system.


- The EU should support Member States to share and implement best practices which encourage increasing availability of home care for kidney patients.

## Conservative care

A substantial fraction of patients who reach end-stage kidney disease may not receive dialysis or transplantation. This may be due to the patient's own choice or to their poor clinical condition, which would make chances for a positive outcome bleak. These individuals should have access to a supportive non-dialysis, non-transplantation care pathway (also referred to as 'conservative' care) that includes information and palliative, patient-centred care for the patients and their families to optimise their wellbeing during this phase.

- RRT, including pre-emptive kidney transplantation, should be started only after careful patient selection and appropriate timing.
- RRT should only be started when necessitated by the symptoms of end-stage CKD (e.g. fluid overload and malnutrition).
- RRT, with all it entails, may not be appropriate for patients in whom the outcome is expected to be dismal.
- Shared decision-making: the decision to start or avoid RRT in patients with an uncertain prognosis should be taken only after open and supportive dialogue with the patient and family concerning the advantages and disadvantages of each option, and impact on their daily life.

Selected measures of health-related QoL for dialysis patients is

 **27% - 49%**

worse than that for the general population (age and gender matched) and is a predictor of hospitalization and mortality in dialysis patients.



Dialysis patients are often hospitalized and for extended periods of time, also incurring costs for the health system.

For those patients undergoing dialysis, there is:



a very high mortality rate



a decreased patient quality of life (QoL)



a high cost to society

The annual risk of death in dialysis patients is

**10 - 100x**

higher than the risk of death in the general population.

<sup>6</sup>Komenda P, Gavaghan MB, Garfield SS, Poret AW, Sood MM. An economic assessment model for in-center, conventional home, and more frequent home hemodialysis. *Kidney Int* 2012;81:307-13

## Recommendation cluster 3: Increasing access to transplantation

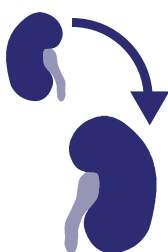
Kidney transplantation is the treatment of choice for end-stage kidney disease in suitable patients. Transplantation provides better clinical outcomes than dialysis and substantially reduces the healthcare costs of CKD by avoiding or delaying dialysis and allowing patients to resume activities, including work<sup>7</sup>.

Nevertheless, rates of kidney transplantation vary dramatically between EU Member States. The reasons for this variation are believed to largely reflect the resourcing of transplant units, the availability of specialised staff (e.g. transplant coordinators), attitudes amongst health professionals, and a lack of public awareness and communication about organ donation.

Increasing organ donation is a critical component of ongoing efforts to increase kidney transplantation in Member States. While culture plays a major role in this issue, the fact remains that Member States which implement a policy for 'opting out' from donation schemes succeed in achieving more kidney donations/transplantations per year than those which rely on 'opting in' donation.

- **Access to kidney transplantation should be equally guaranteed to all valid candidates**
- **Kidney transplantation should be encouraged and promoted by all means, including EU-wide strategies to:**
  - Educate the general public, patients and healthcare professionals about the benefits of transplantation and the need to increase organ donation
  - Provide financial incentives encouraging Member States or regions to increase and improve their transplantation programmes.
- **Living donor transplantation should be promoted by:**
  - Pre-emptive donor exchange programmes
  - Compensation of costs for living donors such as medical care or absence from work
  - Creating an optimal legal environment for living donation.
- **Deceased donor transplantation should be promoted by improving awareness of this need and augmenting organ retrieval policies:**
  - Implementation of 'opting out' schemes for deceased kidney donation
  - Acceptance of expanded deceased donation (e.g. 'non-heart beating' donation).
- **Member States lagging behind on either living or deceased donor transplantation should be supported to make all necessary efforts to stimulate these options.**

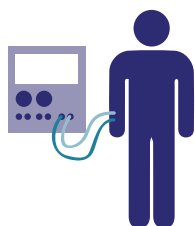
Many of those will progress to end-stage renal disease (ESRD) and require renal replacement therapy (RRT) in the form of dialysis or transplantation just to stay alive.



↑60

Frequency of kidney disease dramatically increases after the age of **60**.

Kidney transplant is the preferred treatment, but when not possible or while waiting for a suitable organ, patients will need to undergo dialysis.



The prognosis, including life expectancy and quality of life, is exceedingly better after kidney transplantation than dialysis.

<sup>7</sup>Haller M, et al. Cost-effectiveness analysis of renal replacement therapy in Austria. *Nephrol Dial Transplant* 2011;26:2988-95.

## Recommendation cluster 4: Treatment reimbursement strategies

EKHA maintains that all therapies with proven efficacy should be accessible to all patients throughout Europe, irrespective of their financial means or social status. In order to safe-guard this right, a better distribution of healthcare spending and cost savings is required.

EKHA advocates for a change in philosophy from market- and hospital-oriented care, to society- and patient-oriented care. Member States should favour reimbursement strategies that incentivise fair access and distribution of care modalities, correct implementation of conservative care, the start of patient-centred RRT at the correct point in the course of CKD, and technological and social innovation of treatment modalities.

- Health policies and incentives should promote increased access to transplantation and home dialysis, as these are both cost-effective and associated with good outcomes for patients.
- Reimbursement of treatment should be based on an accurate estimation of the total direct and indirect costs of CKD and its treatment.
- Differences in reimbursement between different treatment pathways (e.g. hospital-based dialysis, home dialysis, peritoneal dialysis, self-care) should be justified.
- If bundling of reimbursement is considered, the clinical consequences should be carefully considered and checked to avoid counterproductive effects.
- Reimbursement systems should support technological innovations with positive socio-economic implications.



### ABOUT EKHA

European Kidney Health Alliance (EKHA) is an alliance of non-profit organisations representing key stakeholders in kidney health issues, including patients, nephrologists, researchers and healthcare workers. Our mission is to work together to reduce the incidence and impact of kidney disease in Europe by influencing policies that improve awareness, prevention, treatment, education/training and research. The founding members of EKHA are:

- European Renal Association - European Dialysis and Transplant Association (ERA-EDTA)
- European Dialysis and Transplant Nurses Association/European Renal Care Association (EDTNA/ERCA)
- European Kidney Patients Federation (EKPF)
- International Federation of Kidney Foundations (IFKF)

In addition, EKHA has the support of 14 national Associate Member organisations, including national renal and patient associations from the European region.

The EKHA *Recommendations for Sustainable Kidney Care* are a common effort by stakeholders to propose solutions for the challenges of kidney disease through effective prevention, and a more efficient care pathway that provides access to the appropriate and affordable treatment for every affected individual, while promoting the highest quality care.

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