

ERCPA Manifesto for a patient-centric management of Chronic Kidney Disease



Healthcare systems are facing a number of challenges, including demographic change with an ageing population, an increase in chronic diseases, patients having higher expectations on healthcare delivery and above all major pressure on public finances to slow increasing healthcare expenditures. Such developments require major policy reforms in order for healthcare systems to be able to cope with the vast and growing demands they are being placed under. These challenges are particularly apparent in the treatment of Chronic Kidney Disease (CKD), the management of which is a huge economic burden to healthcare systems globally and in Europe.

Globally, more than 3.2 million people are treated for end-stage renal disease (ESRD), with more than 560 000 in Europe alone. Literature quotes total CKD prevalence to be in the range of 10% of the population, which is around 100 times as high as ESRD prevalence. The vast majority of these are unaware of their condition until it develops to an advanced stage. As the rates of correlated conditions (or comorbidities) such as diabetes and hypertension increase, together with an aging population in the more developed countries, many European Union Member States are seeing increases in their CKD patient populations at 4 to 5 times the rate of general population growth.

ERCPA therefore calls for the EU to: promote **integrated care for CKD** and for chronic diseases in general, encourage Member States to support the **availability of all treatment modalities**, and improve **transparency on medical outcomes**.

Integrated management of Chronic Kidney Disease

With an ageing European population, CKD is foreseen to reach epidemic proportions and will represent a significant burden for both patients and health systems. As CKD is caused by or coexists with other major chronic conditions (diabetes, hypertension, cardiovascular disease, etc.), it is imperative to develop a coordinated CKD management strategy within the EU. CKD is a “silent disease”, which is often diagnosed too late, as patients start to feel symptoms when already about 50% of their kidney function has been lost. Early stages of CKD are detectable, and easier to manage, whereas delayed diagnosis leads to increased morbidity, mortality and higher healthcare costs. The number of patients with end-stage Chronic Kidney Disease in the EU is projected to grow by about 15% by the year 2020.

Management of CKD thus requires more focus on prevention and early detection as well as on more effective treatment of the end-stage disease. Prevention should also include raising awareness on not only the causes of CKD but also the consequences of the disease (e.g. life-long dependency on dialysis, or organ availability and immunosuppression associated with transplantation). Patients whose kidney function starts to deteriorate need guidance at the pre-dialysis stage and the transition to maintenance dialysis on how to preserve residual kidney function. Informed decision-making on the most appropriate treatment modality suited to the patient’s specific medical condition and circumstances is crucial. The overriding consideration in the management of CKD is meeting the individuals’ perception of high quality of life.

Due consideration needs to be given to the integrated treatment of multiple comorbidities (as well as poorly modifiable factors such as advanced age, diabetes, and hypertension) that are highly prevalent in the CKD and dialysis population. The entire disease treatment regime and outcomes should be accessible to the patient as well as to the different experts who provide their treatments. Such sharing of data (also via e-health) allows a continuous improvement of CKD management and empowers patients when making decisions over their own health. Such coordination would ensure a more effective and transparent use of limited healthcare budgets.

Together with higher awareness of CKD, patient empowerment and therapy quality improvement, a more holistic approach to dialysis care would decrease the burden of disease to patients and payers. We believe that the European Commission should further encourage Member States to develop national policies focused on multimorbidity care and patient-centric management, and specifically promote integrated care management of CKD patients. This would help to reduce the incidence of ESRD, optimise transitions of care, develop cost-effective alternative therapies, increase renal transplantation rates and reduce the costs associated with caring for the advanced and at-risk renal disease population. ERCPA strongly advocates for CKD being included in all EU-level chronic disease discussions and actions. Prevention being one of the Commission’s key priorities in health policy, it should particularly be the case for CKD, as there is still a lot to improve in its early detection.



Choice of most appropriate treatment modality

There are many modalities, or treatment options, available to CKD patients who have progressed to the stage where renal replacement therapy is required. Options include dialysis at home or in centre, and peritoneal or haemodialysis, or transplant if a suitable donor can be found. The option that is best suited to the individual patient typically depends on a combination of the patient's health, family and institutional support network, and personal preferences. Although receiving a "new" kidney through a transplant is usually considered the best option, for medical reasons most CKD patients are not suitable for transplantation. Even for those who are generally eligible for donor kidneys, the problem of organ availability and time on transplant remain major limiting factors. Therefore, it is essential to manage care pathways that optimise both the pre- and post transplant states.

However, in many Member States, not all treatment

modalities are equally available to individual patients. For example, in Portugal peritoneal dialysis is not reimbursed in an outpatient setting. Very few Member States reimburse premium treatment (like haemodiafiltration), which is particularly suitable to some patients. In many countries, nocturnal haemodialysis, which can allow working patients to dialyse overnight, leading to less interruptions in their working and personal lives, is not supported by public payers. Having patients informed about all the treatment modalities available to them can empower them when making decision on their own health.

We believe that patients should have the possibility to choose the most appropriate treatment modality for them and that these modalities should be offered and supported equally by public payers in all Member States. An efficient implementation of the cross-border healthcare directive would be a first step in the right direction.



Transparent outcomes for care excellence

In contrast to many chronic disease management programs, for renal care there are a set of generally accepted quality parameters which define what constitutes a high-quality dialysis treatment. Generally accepted parameters include treatment time and frequency, Kt/V (a measure of treatment adequacy) and, for haemodialysis patients, the absence of catheters and achieving minimum blood flow rates during treatment. Performed correctly, high-quality dialysis treatments are correlated with better patient health and quality of life, reduced hospitalisations, and improved survival rates.

In the EU today, there is little alignment between the Member States which support national registries on the incidence, prevalence, and survival rates among ESRD patients. Registries like these can help to facilitate continuous transparent comparison, and give the opportunity for data-based dialogue and improvement targets among national nephrology groups. However, some Member States, such as Germany and Poland, do not support a national registry. Even within the existing registries, the data collected is rarely comparable and is sometimes even lacking essential information. For

example, data on access types including catheter rates – a basic statistic – is often not collected or shared. The collection and transparent reporting of outcomes metrics within and across countries and providers would enable comparability and could foster discussion, cooperation, and competition, supporting both best practice identification and innovation, but also an improved level of care for all patients.

In the near term, we believe that it is critical that the Commission support the development and harmonisation of ESRD patient registries in all Member States. The current initiative led by Sweden in the Council on Health Systems Performance Assessment is a step in the right direction. We further recommend that Member States collaborate to define, collect and publish outcomes data in a transparent and comparable manner. In the long term, we believe that reimbursement systems should reward outcomes and performance, rather than be simple "pay per treatment" models. We believe the Council can be a key proponent of examining innovative ways to include quality and performance metrics and rewards in the broader CKD management discussion.

ERCPA was founded in 2014 as a joint initiative of private providers of renal care services, such as dialysis, in the European Union. We partner with policy makers and civil society to discuss, inform and educate on effective and efficient chronic disease management. Our goal is to support patients suffering from Chronic Kidney Disease by ensuring access to safe, effective and personalised care of the highest quality, and by promoting choice in treatment modality.



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