



CALL TO ACTION

**IMPROVING PREVENTION,
TREATMENT & CARE OF**

CHRONIC KIDNEY DISEASE

IN THE AFTERMATH OF COVID-19

26 February 2021

Introduction

The current pandemic has shed light not only on the weaknesses of our healthcare systems to prevent and address infectious disease outbreaks but also on the shortcomings in the delivery of care of major chronic diseases, such as Chronic Kidney Disease (CKD). The following call to action, led by the European Kidney Health Alliance (EKHA), provides sustainable and cost-effective recommendations to address the pressing and long-term challenges surrounding CKD in Europe in light of the COVID-19 pandemic:

- ▶ Augment efforts on CKD prevention;
- ▶ Collect and share data on CKD at EU level;
- ▶ Promote home therapies, transplantation and the uptake of digital tools;
- ▶ Make research and innovation in Kidney Replacement Therapy an EU priority.

CKD is a serious condition where the kidneys are damaged and cannot purify the blood properly. A staggering 75 million¹ people suffer from CKD in Europe whilst the worldwide frequency has been estimated to 700-800 million people,^{2,3} with a projection that CKD will become the 5th cause of death globally in 2040.⁴ The COVID-19 outbreak has further worsened the situation. **Recent data show that CKD patients are at higher risk than those with other known risk factors, including chronic heart and lung disease⁵. Mortality rates are worryingly high: 20% in kidney transplant recipients and 21% in patients on dialysis⁶.** Furthermore, **Acute Kidney Injury (AKI) has been reported to affect 58%⁷ of hospitalized COVID-19 patients** with an associated mortality rate of more than 30%⁷. As many patients with AKI later develop CKD, COVID-19 patients surviving AKI are likely to experience the same evolution and increase the overall CKD burden in Europe.

The need for immediate action is now more urgent than ever

The crisis has also heavily impacted both dialysis care and organ donation and transplantation activities:

- ▶ Haemodialysis centers became a source of infections due to the inherent model of repetitive treatment in a closed community;
- ▶ Peritoneal Dialysis (PD) insertions, which could have protected CKD patients as they allow dialysis outside the hospital, were postponed as non-urgent procedures;
- ▶ The need to shift the focus of intensive care units - where most organ donors are found - to COVID-19 care coupled with the difficulties in ensuring safety for transplanted patients led to a reduction in donation and transplant activities as high as 80% in some Member States⁸.

It is crucial to address the heavy burden of CKD in Europe which has hitherto been neglected. This is key to address not only the short and long-term challenges of the ongoing pandemic but also to mitigate the negative consequences of the subsequent economic crisis.

'COVID-19 painfully exposed the vulnerability of the population with kidney disease, urging more awareness and innovation on this devastating condition.'

Raymond Vanholder, EKHA President

Did you know?

58%

of hospitalized COVID-19 patients suffer Acute Kidney Injury (AKI) with an associated mortality rate of 30%.

Endorsers

MEP Group for Kidney Health

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Organisations

- Agence de la Biomédecine – French Agency of Biomedicine
- ARGE Niere Österreich (ANÖ) – Austrian Kidney Patients' Federation
- Associação Portuguesa de Insuficientes Renais (APIR) – Portuguese Association of Renal Failure Patients
- Associació Catalana d'Infermeria Nefrològica (ACIN) – Catalan Association of Nephrological Nursing
- Association Polykystose France (PKD France) - Polycystic Kidney Disease France
- Associazione Nazionale Emodializzati (ANED) – Italian National Association for Haemodialysis
- Belgian Society of Nephrology (BVN-SBN)
- Belgian Transplantation Society (BTS)
- Cooperative European Paediatric Renal Transplant Initiative (CERTAIN)
- Czech Transplant Team (CTT)
- Deutsche Gesellschaft für Nephrologie (DGfN) - German Society of Nephrology
- Donation and Transplantation Institute (DTI)
- Eesti Nefroloogide Selts – Estonian Society of Nephrology
- Eurocarers
- European AIDS Treatment Group (EATG)
- European Chronic Disease Alliance (ECDA)
- European Dialysis and Transplant Nurses Association and the European Renal Care Association (EDTNA/ERCA)
- European Kidney Patients' Federation (EKPF)
- European Liver Patients' Association (ELPA)
- European Network for Smoking and Tobacco Prevention (ENSP)
- European Public Health Association (EUPHA)
- European Renal Association and the European Dialysis and Transplant Association (ERA-EDTA)
- European Renal Association and the European Dialysis and Transplant Association Registry (ERA-EDTA Registry)
- European Society for Organ Transplantation (ESOT)
- European Society of Anaesthesiology and Intensive Care (ESAIC)
- European Society of Paediatric Nephrology (ESPN)
- European Society of Surgical Oncology (ESSO)
- Federación Nacional de Asociaciones para la Lucha Contra las Enfermedades del Riñón (ALCER) - Spanish Federation of Kidney Patients
- Federation of European Patient Groups affected by Renal Genetic Diseases (FEDERG)

- France Transplant
- Groupement des Néphrologues Francophones de Belgique - Group of Francophones Nephrologists of Belgium (GNFB)
- Gyvastis – Lithuanian Association of Nephrology Patients
- Instituto Português de Sangue e da Transplantação (IPST) – Portuguese National Transplant Coordination
- Instituto De Investogación Sanitaria Valdecilla (IDIVAL) - Health Research Institute of Cantabria
- International Diabetes Federation Europe (IDF Europe)
- International Society of Nephrology (ISN)
- Kidney Care UK
- Lietuvos Inkstų Fondas – Lithuanian Kidney Foundation
- Lietuvos Nefrologijos, Dializes ir Transplantacijos Asociacija (LNDTA) - Lithuanian Nephrology, Dialysis and Transplantation Association
- Macedonian Society of Nephrology, Dialysis, Transplantation and Artificial Organs (MSNDTAO)
- Munuais- Ja Maksaliito – Finnish Kidney and Liver Association
- Nacionalinio Transplantacijos Biuro (NTB) – Lithuanian National Transplant Bureau
- The Nederlandstalige Belgische Vereniging voor Nefrologie (NBVN) – Belgian Dutch-speaking Society for Nephrology
- Nierstichting Nederland - Dutch Kidney Foundation (DKF)
- Njurförbundet - Swedish Kidney Association
- Noncommunicable Diseases Alliance (NCDA)
- Norsk Nyremedisinsk Forening – Norwegian Society of Nephrology
- O'zbekiston Nefrologiya Xizmati – Uzbekistan Nephrology Society
- Organización Nacional de Trasplantes (ONT) – National Transplant Organization
- Polskie Towarzystwo Nefrologiczne (PTN) – Polish Society of Nephrology
- Polycystic Kidney Disease Charity UK (PKD Charity UK)
- Polycystic Kidney Disease International (PKD International)
- Radboud University Medical Centre (Radboudumc)
- Red de Investigación Renal (REDinREN) – The Renal Research Network
- Shoqata Shqiptare e Nefrologjise - Albanian Society of Nephrology
- Slovenská Nefrologická Spoločnosť - Slovak Society of Nephrology
- Slovenská Transplantologická Spoločnosť (STS) - Slovak Transplant Society
- Sociedad Española de Nefrología (SEN) – Spanish Society of Nephrology
- Sociedade Portuguesa de Transplantação (SPT) – Portuguese Society of Transplantation
- Società Italiana di Nefrologia (SIN) – Italian Society of Nephrology
- Società Italiana di Nefrologia Pediatrica (SINePe) – Italian Society of Paediatric Nephrology
- Türk Nefroloji Derneği – Turkish Society of Nephrology
- Udruženje ljekara za Nefrologiju, Dijalizu i Transplantaciju Bubrega u Bosni i Hercegovini (UNDT BiH) – Society for Nephrology, Dialysis and Transplantation of Bosnia and Herzegovina
- Universitair Ziekenhuis Gent (UZGENT) – Ghent University Hospital
- University of Nicosia Medical School
- Ελληνική Νεφρολογική Εταιρεία Νοσηλευτών (ENEN) – Hellenic Nephrology Nursing Association (HENNA)
- Νεφρολογική Εταιρεία Κύπρου – Cyprus Renal Association
- Παγκύπρια Οργάνωση Νεφροπαθων (ΠΟΝ) – Cyprus Kidney Patients' Organisation
- РоссийскоеДиализное Общество (РДО) – Russian Dialysis Society



ACTION 1

Augment efforts on CKD prevention

Early reports indicate that chronic disease patients, and most particularly CKD patients, are at increased risk of COVID-19 infection, hospitalisation, severity and mortality^{9,10}. This vulnerability is strongly emphasised in the opinion of the Independent Expert Panel on Effective Ways of Investing in Health¹¹ established by the European Commission. **This is particularly alarming considering that one in three⁹ Europeans currently suffers from chronic disease and that only 3% of health spending across the EU is earmarked for disease prevention¹².**

Each year, 790 000 EU citizens die prematurely from key lifestyle-related risk factors such as tobacco smoking, alcohol consumption, unhealthy diets and lack of physical activity¹³. It is important to note that the majority of deaths within the Non-Communicable Disease (NCD) group are associated with metabolic syndrome, a cluster of conditions that raise the risk for CKD, diabetes and cardiovascular diseases.

The COVID-19 pandemic should be a wake-up call on the benefits of prevention over cure. Not only is it favorable for patients, but it also reduces costs and would prevent the healthcare system's overburden in the aftermath of the pandemic. Integrated approaches and targeted investments at both EU and National levels to eliminate key lifestyle-related risk factors for major chronic diseases should come first on the political agenda during and in the wake of the pandemic.

'I am an optimistic who believes in progress and change. We can do more for patients with Chronic Kidney Disease (CKD). Prevention plays a big part in this. We must eliminate CKD risk factors via integrated approaches and we have to do this at European level. As we are all witnessing: diseases know no borders, which makes the need for European cooperation greater than ever.'

Hilde Vautmans, Member of the European Parliament and Chair of the MEP Group for Kidney Health

Recommendations:

- ▶ Implement EU and National awareness-raising campaigns to encourage high-risk patients to have their kidneys checked and improve the delivery of kidney tests such as eGFR and UACR at National level;
- ▶ Establish an EU framework for the prevention of NCDs, in particular those associated with metabolic syndrome, as a complement to existing initiatives such as the Steering Group on Health Promotion, Disease Prevention and Management of NCDs;
- ▶ Integrate prevention of NCDs, in particular those associated with metabolic syndrome, into the COVID-19's response and future pandemic's preparedness plans;
- ▶ Adopt a mandatory EU-wide Front of Pack nutrition labelling system as recommended by the Commission in the Farm to Fork strategy and the Europe's Beating Cancer Plan;
- ▶ Raise minimum excise duties on NCDs risk factors (smoking, alcohol, salt & sugar) to the highest possible level;
- ▶ Use the opportunity that cancer and many other chronic diseases share common risk factors to support health promotion and disease prevention measures included in the Europe's Beating Cancer Plan and push forward the prevention pillar in the activities of the European Parliament's Special Committee on Beating Cancer (BECA).

Did you know?

Currently, only **3%** of health spending across the EU is earmarked for disease prevention.

ACTION 2

Collect and share data on CKD at EU level

The pandemic has highlighted the lack of reliable and comparable data in the field of chronic disease and in particular CKD at EU level. **Despite initiatives emanating from civil society, such as the ERA-EDTA registry, which collects data on patients receiving Kidney Replacement Therapy (KRT)¹⁴ via the National and regional registries in Europe and the ERACODA database, which collects individual data on KRT patients who developed COVID-19, their impact remains limited due to the voluntary participation from individual respondents or organisations.**

In 2012, a report mandated by the European Commission confirmed the significant lack of comparable and sustainable data on chronic disease prevalence in the EU¹⁵. The need for an institutional EU-wide platform for chronic disease data collection must be addressed as such a system is the absolute precondition for the development of evidence-based policies to respond to public health threats.

The European Statistical Office of the European Union (EUROSTAT) already provides a great coordination basis as it promotes the harmonisation of statistical methods across Member States and publishes relevant data on chronic diseases. Nevertheless, CKD is rarely represented and, if mentioned, is often underestimated, which conveys an erroneous impression of the real burden of kidney disease in Europe.

Recommendations:

- ▶ Create an institutional EU system to collect and compare chronic disease data through an extended mandate of the European Center for Disease Control (ECDC) that would cover chronic diseases, as desired by many health organisations¹⁵ and in line with the objectives of the European Health Data Space;
- ▶ Publish regular EUROSTAT statistics on CKD and collaborate with kidney medical societies and kidney patient organisations when collecting and analysing this data.

'It is a small step into the era of digital transformation with healthcare claims & registration data but structural data collection on chronic diseases including Chronic Kidney Disease would be a big leap towards the understanding of kidney health and kidney failure in Europe. Modern technologies and Artificial Intelligence are ideal to advance knowledge for millions of Europeans to preserve kidney health.'

Christoph Wanner, President of the European Renal Association (ERA-EDTA) & EKHA Board member and Kitty Jager, ERA-EDTA Registry Managing Director



We need an integrated approach to address the significant lack of comparable and sustainable data on chronic disease prevalence in the EU.

ACTION 3

Promote home-therapies, transplantation and the uptake of digital tools

Transplantation remains the best treatment option for kidney failure and should be encouraged whenever possible and appropriate. Nevertheless, when patients who are in need of KRT are not eligible or cannot be transplanted in the short-term, dialysis is the only life-saving alternative. The COVID-19 pandemic resulted in an increase of this patient population due to the frequent missed transplant opportunities¹⁶. **Currently within the European Union, only 45% of patients with kidney failure are transplanted while 55% are dialysed**¹⁷.

Home dialysis, either through haemodialysis or peritoneal dialysis, is a cost-effective way to reduce visits at the hospital and improve the quality of life of patients. In addition, home dialysis helped protect patients throughout the pandemic by reducing their exposure to COVID-19 and guarantee the continuity of care. This is readily apparent from recent data which show that **the risk of patients under dialysis in hospitals to be infected by COVID-19 was almost three times higher than that of patients using peritoneal dialysis**¹⁸. Digital technologies (such as remote monitoring, teleconsultation, Artificial Intelligence assistants and mhealth apps) are complementary tools to home therapies as they allow remote patient management whilst increasing patients empowerment. Unfortunately and despite the available evidence, European health systems do not sufficiently target and incentivise home dialysis & the uptake of digital tools. **Currently, only 12% of European dialysis patients undergo home treatment**¹⁹.

This underrepresentation of home therapies can at least in part be attributed to a lack of awareness among CKD patients, although patient awareness without policy measures will not be enough²⁰. There is an urgent need for a paradigm shift towards home dialysis treatments & telehealth to better respond to CKD patients' needs in the near and long-term.

Recommendations:

- ▶ Promote the use of home therapies as the safest option for CKD patients in times of pandemic through the EU-wide pandemic preparedness plan;
- ▶ Encourage Member States representatives to share best practices in promoting home therapies in times of pandemic in the opinions and guidelines published by the Health Security Committee;
- ▶ Support initiatives, for example through the EU4Health programme, that encourage the uptake of digital tools and propose digital health literacy trainings to health professionals, patients and carers;
- ▶ Initiate a second EU action plan on organ donation and transplantation as this treatment, when possible, offers a better quality of life, increase survival, lower the costs and the risk exposure to COVID-19.
- ▶ At National level, support telemedicine consultations, digital options and home-therapies uptake with appropriate policy and reimbursement strategies.

'We need to be able to adapt the huge burden of treatments to the life of kidney patients. Whilst transplantation constitutes the best treatment option for kidney failure and should be pushed forward, it is not a viable option for all patients. Therefore home-therapies, which have proved to be the safest during the COVID-19 pandemic, should be strongly encouraged. Chronicity should be managed at home whenever it is possible. Nobody should be left behind of digital tools and new technologies that can improve their lives.'

Daniel Gallego, President of the European Kidney Patients' Federation (EKPF) & EKHA Board member

Did you know?

Patients undergoing dialysis at the hospital are three times more likely to be infected by COVID-19 than patients treated with peritoneal dialysis at home.

ACTION 4

Make research & innovation in Kidney Replacement Therapy an EU priority

Despite the ever-increasing CKD burden, the technology to treat end-stage kidney disease has not substantially evolved since 1945, the year when the first life-saving dialysis treatment was performed. There is a pressing need to stimulate innovation in this field, in particular in home-dialysis treatments which certainly increase the autonomy of patients in comparison with in-centre dialysis, but currently remain burdensome and difficult to use for patients. New studies have shown promises in developing wearable, portable and more environment-friendly dialysis machines²¹ but more research is needed to fully unlock their potential. Moreover, recent scientific advances in regenerative medicine, that could allow the creation of new therapeutic approaches by tissue engineering, have demonstrated that more options than dialysis and classical transplantation could be available for kidney patients and should be explored further.

The US Kidney Health Initiative is an inspiring example of a public-private consortium between the American Society of Nephrology and the US Food and Drug Administration which aims to accelerate innovation, including in home-dialysis, by developing safe and effective patient-centred therapies for CKD patients. The main outcome of this partnership is the creation of the Kidney X Accelerator, a funding mechanism that rewards innovation in the prevention, diagnosis and treatment of kidney disease through a series of prize competitions. This momentum should serve as an example to be followed by the European Union, where CKD continues to remain absent from EU research funding priorities.

'Although necessary in many cases, dialysis treatments remain costly and have a huge impact on the life of CKD patients. In addition, CKD patients with kidney failure have a 5-year life-expectancy which is worse than that of most of cancer patients. For all these reasons, measures to boost research and innovation in Kidney Replacement Therapy are urgently needed.'

Tom Oostrom, Managing Director of the Dutch Kidney Foundation (DKF) & EKHA Board member and Edita Noruišienė, President of the European Dialysis and Transplant Nurse Association/ European Renal Care Association (EDTNA/ERCA) & EKHA Board member

Recommendations:

- ▶ Include CKD among the research priorities of Horizon Europe and the Strategic Research Agenda of the new Health Innovation Partnership (IMI 3);
- ▶ Foster research in the application of regenerative medicine for kidney disease and innovation in home-dialysis (e.g. wearable dialysis devices) through the Horizon Europe research projects;
- ▶ Draw on the US Kidney Health Initiative to develop, in collaboration with patient organisations and medical societies, an EU funding mechanism similar to the Kidney X Accelerator that would allow to spur innovation in KRT;
- ▶ Encourage research projects on the numerous direct and indirect links between cancer and kidney diseases (cancer can cause CKD through the adverse effects of therapies and CKD is a risk factor for cancer) in the cancer mission of the Horizon Europe research programme.



More research is needed to fully unlock the potential of portable dialysis machines and regenerative medicine for CKD patients.

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About EKHA

EKHA is an alliance of European and national societies dedicated to reducing the burden of kidney disease in Europe and improving the outcomes for kidney patients. It brings together patients, nurses, foundations and physicians to provide consensual and authoritative advice to policymakers on all aspects of kidney disease: prevention, treatment, access to care, education and research.

As EKHA, we are committed to sensitising the European Parliament and the Commission to the importance of kidney health, and ensuring that they assist national governments in listening to the needs of the European renal community.

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