

OPEN LETTER

To:

President of the European Commission, Ms. Ursula Von der Leyen, European Commissioner for Health and Food Safety, Ms. Stella Kyriakides, German Federal Minister of Health, Mr. Jens Spahn & Health attachés of the 27 EU Member States, European Parliament President, Mr. David Sassoli, ENVI & ITRE Committee chairs, coordinators & members, EU4Health & Horizon Europe rapporteurs & shadow rapporteurs.

5 key recommendations to improve prevention, treatment & care of Chronic Kidney Disease (CKD) in the aftermath of COVID-19.

Chronic Kidney Disease (CKD) is a serious condition where the kidneys are damaged and cannot filter blood properly. Kidney disease has long been a major public health challenge in Europe, with a staggering 75 million Europeans¹ suffering from CKD. Worldwide frequency of CKD has been estimated at 700-850 million people.²³

The pandemic has dramatically worsened the situation. Data show that CKD patients are at higher risk for COVID-19 mortality than those with other known risk factors⁴, significant disruptions in access to care were observed during the lockdowns⁵ and shortages of dialysis material occurred in some cities⁶. As such, COVID-19 shed light on the high vulnerability of CKD patients and the existing shortcomings in prevention, treatment and care of CKD in Europe.

As negotiations on the various instruments of the EU recovery plan are well underway within your respective institutions, we, the European Kidney Health Alliance (EKHA), would like to urge you to address the needs of kidney patients through ambitious and robustly funded EU4Health and Horizon Europe programs and bring to your attention 5 key recommendations that we believe should be reflected in future EU policies and initiatives:

1. Increase funding for innovation in Kidney Replacement Therapy (KRT)

Despite its ever-increasing burden, CKD continues to be absent from EU research funding priorities⁷.

- **Research projects on next generation KRT (e.g. development of artificial implantable kidney) should be fostered in the upcoming Horizon Europe program.**

The [US Kidney Health Initiative](#)⁸ (KHI) is an inspiring example of a private-public consortium that aims to accelerate innovation by developing patient-centered therapies with a particular emphasis for treating more patients at home.

- **A similar initiative should be set up at EU level which would not only improve outcomes for kidney patients but also strengthen European leadership in research and innovation.**

2. Set up an EU-level data collection system on chronic disease including CKD and risk factors

Common European data on CKD and risk factors are cruelly lacking. The [ERA-EDTA registry](#), which collects data on patients receiving KRT via the national and regional registries in Europe and the [ERACODA](#) database, which collects individual data of COVID-19 patients who receive KRT, are good examples of data sharing and pooling mechanisms across countries that could be set up as EU initiatives.

- **An EU-wide data collection system on chronic disease registering CKD frequency and risk factors, built on the same model as the European Network of Cancer Registries (ENCR) is needed to improve the quality, comparability and availability of CKD data.**

¹ International Society of Nephrology, CKDu network (i3C). Available from: https://www.theisn.org/initiatives/what-is-ckdu/ckdu-network-3c/?qclid=CjwKCAIwsans5BRAQEWALzomX_3BtsC4QPZXCsi5HUV05M-902_FXANANQsl6nq2Dqiel_T5nLBoC0zYQAvD_BwE#the-health-atlas

² Jager KJ, Kovesdy G, Langham R et al. A single number for advocacy and communication-worldwide more than 850 million individuals have kidney diseases. *Nephrol Dial Transplant* 2019; 34: 1803–1805. Available from: <https://academic.oup.com/ndt/article/34/11/1803/5574389>

³ Bikbov B et al. Global, regional, and national burden of chronic kidney disease, 1990–2017: A systematic analysis for the Global Burden of Disease Study 2017. *The Lancet* 2020; 395(10225):709–33. Available from: [https://www.thelancet.com/article/S0140-6736\(20\)30045-3/fulltext#%20](https://www.thelancet.com/article/S0140-6736(20)30045-3/fulltext#%20)

⁴ Gansevoort, R.T., Hilbrands, L.B. CKD is a key risk factor for COVID-19 mortality. *Nat Rev Nephrol* (2020). Available from: <https://doi.org/10.1038/s41581-020-00349-4>

⁵ Hannah Calkins. COVID-19's impact on the kidneys: An interview with Brent Miller, MD, nephrologist and professor of clinical medicine, May 08 2020. Available from: <https://medicine.iu.edu/blogs/the-beat/covid-19-impact-on-the-kidneys>

⁶ David S. Goldfarb, Judith A. Benstein et al. Impending Shortages of Kidney Replacement Therapy for COVID-19 Patients. *CJASN* June 2020, 15 (6) 880-882. Available from: <https://cjasn.asnjournals.org/content/15/6/880>

⁷ European Commission. Health Research and Innovation: Why the EU supports research and innovation. Available from: https://ec.europa.eu/info/research-and-innovation/research-area/health-research-and-innovation_en

⁸ Kidney Health Initiative, KHI's mission. Available from: <https://khi.asn-online.org/>

As proposed by other health organizations, this EU-level data collection system could be the responsibility of the European Centre for Disease Prevention and Control (ECDC) under an extended mandate that would cover chronic disease to ensure this data is uniform and interoperable.

3. Promote best practices that encourage different modes of KRT and better patient choice

Transplantation remains the best treatment for kidney failure but when patients are not eligible and require dialysis, they should be given the choice to receive it at home (either through hemodialysis or peritoneal dialysis). Home therapies are a cost-effective way to reduce visits at the hospital, improve the quality of life & helped to reduce patients' exposure to COVID-19 and guarantee the continuity of care during the lockdowns.

- **The EU should support Member States in sharing best practices and implementing home-preferred policies which encourage increasing availability of home care treatments.**
- **Kidney transplantation, by offering a better quality of life, increasing survival, lowering societal costs and the risk exposure to COVID-19, should also be put forward by the EU, for example as part of a 2nd EU action plan on organ donation and transplantation.**

4. Support digital transformation of kidney care

Digital tools (remote monitoring, teleconsultation, AI assistants, mhealth apps) and services also help to reduce hospital visits while increasing patient engagement and empowerment.

- **The EU4Health program and preparedness plans for future outbreaks should facilitate the availability of effective and affordable telemedicine services for kidney patients together with health literacy programs for healthcare professionals, patients and carers. Germany's new Digital Healthcare Act is an inspiring example of what Member States can do to embrace digital transformation of kidney care.**

5. Augment efforts on CKD prevention & control

It is now established that CKD, together with other chronic diseases, is an important risk factor for negative outcomes of COVID-19. However, only 3% of health spending across the EU is currently earmarked for disease prevention⁹.

- **Increased EU investments as well as regulatory measures to eliminate key lifestyle-related risk factors such as smoking, excessive use of alcohol, high consumption of salt, fat & sugar and inadequate daily physical activity should be implemented.**
- **Health promotion and disease prevention at EU level should be strengthened as a way of reducing healthcare costs and prevent healthcare systems' overburden in the aftermath of COVID-19.**

The lessons learnt during the COVID-19 outbreak represent an opportunity to bring about positive change for kidney patients in Europe. CKD is currently estimated to become the 5th cause of death worldwide by 2040¹⁰ – unless determined action is taken at this critical juncture and in view of the increasing challenges posed by COVID-19, this estimation will likely become a reality even sooner. We count on your support to take these recommendations at heart and ensure that kidney patients' needs are not overlooked in current negotiations.

Yours sincerely,



Prof. Raymond Vanholder, EKHA President

⁹ European Commission. State of Health in the EU: Companion report 2019. Available from : https://ec.europa.eu/health/sites/health/files/state/docs/2019_companion_en.pdf

¹⁰ Foreman, Kyle J, and Marquez, Neal, et al. "Forecasting life expectancy, years of life lost, and all-cause and cause-specific mortality for 250 causes of death: reference and alternative scenarios for 2016-40 for 195 countries and territories". *The Lancet*, vol.392,no.10159, 2018, pp. 2052-2090. doi:10.1016/S0140-6736(18)31694-5. Available from: <https://www.sciencedirect.com/science/article/pii/S0140673618316945>