

# Unmet needs & challenges in access to treatments in Europe: The case of Chronic Kidney Disease

Hybrid event moderated by Tamsin Rose



June 18, 2021  
Event report

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*The 2021 European Kidney Forum took place on June 18 and focused on unmet needs & challenges in access to treatments in Europe for Chronic Kidney Disease patients. A key theme which emerged from the conference was the need for healthcare policies to be based on a patient-centric approach which would ensure that Chronic Kidney Disease patients are fully informed on what their options are in terms of treatment and disease management. Guest speakers also stressed that the number of people with Chronic Kidney conditions was predicted to rise, with calls being heard for the Commission to prepare an EU action plan on Chronic Kidney Disease. Furthermore, providing equal access to treatment for all was stressed as an area that should be given priority, with participants also noting that more incentives were required for innovators to invent smaller dialysis machines, considering the technology has not changed much in 50 years. Such innovation could enable patients to undertake home dialysis in a less burdensome manner and thus allow for greater patient quality of life.*

## Opening Remarks

**Stella Kyriakides, European Commissioner for Health and Food Safety** said that COVID-19 had taught many lessons, most importantly that we are stronger together. Today, 1 in 10 Europeans suffer from Chronic Kidney Disease and the number of patients is set to grow. We need decisive actions at all levels to reverse this trend. Moreover, the current ambition has set out a programme for a strong and robust health Union

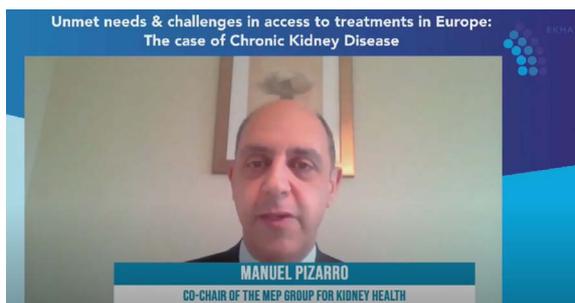


to support Member States in reducing mortality resulting from Non-Communicable Diseases. Member States are working together on joint actions and projects under the EU4health programme that will help people lead healthier lives. In addition, the EU cancer plan also showed the EU's dedication in the area of health. With the new Horizon Europe 2021-2022 work programme, there are more possibilities for research on Chronic Kidney Disease, including dialysis and home care.

All politics are fundamentally about people, and all approaches must be patient-centric. This concept fits Chronic Kidney Disease well as patients may need several types of health services. She recalled that kidney transplants are not possible for all patients and that dialysis remains a lifesaving procedure for many. Unfortunately, safe access to dialysis has been severely disrupted by the COVID-19 pandemic. COVID-19 has also impacted the transplant sector and the EU has supported Member States to ensure adequate access during this unprecedented event. The pandemic has amplified the need for more resilient, accessible and patient-centred health systems to be built up. The Commission will continue to support research and pooling of knowledge to improve the quality of life and life expectancy of Chronic Kidney Disease patients.

Please click [here](#) for the full text of the Commissioner's speech.

**Hilde Vautmans, Chair of the Members of European Parliament (MEP) Group for Kidney health**, echoed that Chronic Kidney Disease was a major health issue in Europe. Estimates show that this would become the world's fifth cause of death by 2040. To tackle this trend, cost effective therapies have to be made available to all patients. Currently, there are disparities concerning availability and access across Member States and specific social groups. Over the last 50 years, there has been little innovation in kidney disease therapies while most areas of healthcare have improved markedly. She added that she supported the launch of the Decade of the Kidney™ campaign in Europe which aims to put Chronic Kidney Disease under the spotlight for the next decade together with World Kidney Day. These valuable initiatives must be coupled with concrete and timely EU action. Ms Vautmans called on the Commission to give Chronic Kidney Disease the focus it deserved, and she called for an EU action plan in this regard. At global level, she noted that the EU could play a role in improving kidney health and access to treatment in Low and Middle Income Countries (LMICs) via the African, Caribbean and Pacific (ACP)-EU partnership and the Africa-EU partnership.



**Manuel Pizarro, Co-Chair of the MEP Group for Kidney Health**, stated that COVID-19 had exacerbated issues surrounding Chronic Kidney Disease and that mortality rates for these patients were worryingly high. The pandemic may increase the burden of this disease in Europe as those who had their kidneys damaged as a result of COVID-19 are at risk to develop Chronic Kidney Disease. An integrated approach and

targeted investments are needed to tackle lifestyle related risk factors. He highlighted the need for a 2<sup>nd</sup> EU action plan on organ donation and transplantation. He recalled the parliamentary question he submitted asking whether the Commission was planning to put forward such a plan. There is now a fantastic opportunity to build on the momentum of the European Health Union. He noted the positive step forward of the Horizon Europe programme that recently published a call with a reference to portable dialysis. Dr Pizarro concluded by stating that ground-breaking innovation was urgently needed in this field.

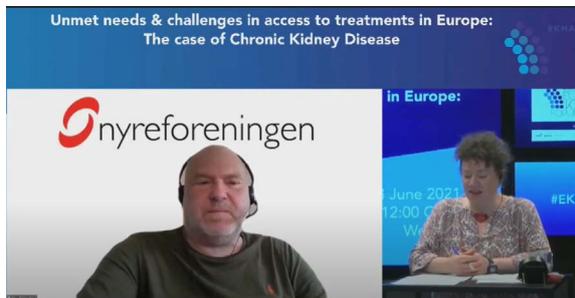
## ***Access to kidney care & the Decade of the Kidney campaign in Europe***

**Raymond Vanholder, President of the European Kidney Health Alliance & Emeritus Professor of medicine and nephrology at Ghent University**, noted huge differences between EU countries when it comes to the frequency of peritoneal dialysis or transplantation. Furthermore, there are different types of transplant donations, such as donations from living or deceased donors and also these are strikingly



different among European countries. There are thus many inequalities when it comes to availability and access across Europe. There are also inequalities in availability in different therapeutic options and particularly patient-oriented outcomes (complications that not necessarily increase mortality risk but are particularly cumbersome for patients) have for long been neglected. For example, itching is an issue that is often forgotten by nephrologists and for which few treatments exist. There are many other patient-oriented outcomes associated with Chronic Kidney Disease that should also be taken more into consideration such as pain, fatigue and lack of energy.

Inequalities among social groups, especially in vulnerable groups such as refugees or people with low income, are particularly high. In addition, inequalities in patient education and information persist. In an inquiry conducted by EKHA, about 35 percent of European patients said they were not happy with the information they received on peritoneal dialysis, a perception that was not echoed by the satisfaction of professionals about the information they delivered, that overall was better. Prof. Vanholder also mentioned the issue of reimbursement. Since 2011, equal reimbursement for all types of dialysis, including home dialysis, has been put into place in the United-States, resulting in an increased uptake of home therapies. However, equal reimbursement is not the sole and optimal solution. The Scandinavian countries for instance, which have a strikingly higher uptake of home dialysis in Europe, do not provide equal reimbursement but reimburse the real cost, and there is also a lot of focus on education, timely referral and benchmarking. Moreover, Prof. Vanholder above all stressed the need for awareness of the burden of kidney disease by both the general population and policy makers. He concluded by encouraging all participants to support the EKHA-lead Decade of the Kidney™ campaign in Europe.



**Henning Søndergaard, Representative of the Danish Kidney Association,** stated that he was

born with a spinal condition that rendered him paralysed from birth. He has been a dialysis user for the past ten years. He noted that the symbol for people with a disability was a wheelchair; however, for him, the wheelchair was a symbol for freedom. In his views, the symbol for disability should be a dialysis machine because, when

hooked up to it, he could do nothing. In-centre haemodialysis is the worst treatment option when it comes to quality of life and longevity. However, this type of treatment is received by 95 percent of End-Stage Kidney Disease patients worldwide. According to him peritoneal dialysis is slightly better than in-centre haemodialysis but also not the desirable option. The best dialysis option in his opinion is home haemodialysis as people can do it during the night while they are sleeping and avoid dialysis during the day when possible.

On improving dialysis treatment, investment into smaller, portable dialysis machines are needed so as to waste less resources and allow patients to be more mobile. The dialysis machine has remained the same size over the last 50 years and there have been no financial incentives to invest in smaller machines. Comparing the shrinking size of computers from the 1960s to now is an illustrative example of how better technology could be fit into smaller machines. Most medical devices became smaller, except for dialysis machines, which sometimes even increased in size.

## Panel discussion: How to tackle the current challenges in access to kidney disease treatments in Europe?

**Moderator Tamsin Rose** asked the audience what they would like to see achieved by the end of the Decade of the Kidney™ campaign in 2030. She gave five possible answers. First, health professionals and patients being better educated and trained. Second, more political and financial incentives for cost-effective treatment. Third, better availability of treatments across Europe. Fourth, home therapy defined as the first-line dialysis option. Fifth, increased use of telemedicine by both patients and professionals. The number one option chosen was home therapy dialysis, receiving 31% of votes. This was followed by better education and training for health professionals, with 21% of votes. The moderator asked then what were the remaining barriers to unlock access to better treatments.

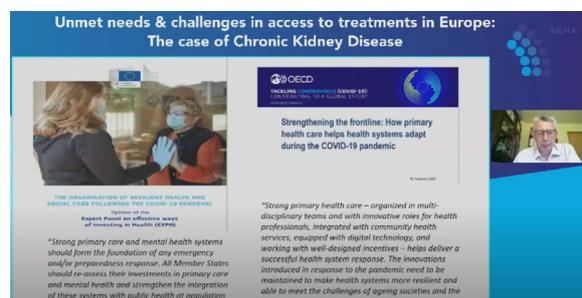


**Daniel Gallego, President of the European Kidney Patients' Federation (EKPF)**, noted that he had been undergoing dialysis since 1995. Healthcare facilities often decide that home therapies are too challenging and difficult. However, it is often more complicated for patients to go to the hospital. Nevertheless, a lot of space is needed for current home therapies and innovation is required to have wearable dialysis

machines. A lot of inequities exist throughout Europe and this has to be tackled. There are also financial and cultural barriers in many instances for switching to home therapies. Professionals need to understand that enabling home dialysis is a necessity.

**Moderator Tamsin Rose** said that one solution may be to prevent the onset of Chronic Kidney Disease and/or its progression. She asked how optimal access to primary and secondary prevention could be delivered in the primary care environment.

**Jan De Maeseneer, Chair of the Expert Panel on Effective Ways of Investing in Health (EXPH) of the European Commission & Emeritus Professor in Family Medicine and Primary Care in Ghent University**, underlined the importance of primary care. Hospitals and primary care should become complementary in addressing challenges. Both the EXPH and a recent OECD document emphasised the importance of strengthening primary care. Primary care has a critical role to play for Chronic Kidney Disease, for example in highlighting which patients are at risk, such as those with diabetes or those who are obese. All patients must visit family practices to obtain adequate monitoring and follow-up. However, reaching out to the most vulnerable populations still remains a challenge. Collaboration among healthcare professionals is also key to sharing knowledge and competencies. He supported the idea of increasing home care for patients and reaffirmed the need for technological progress to

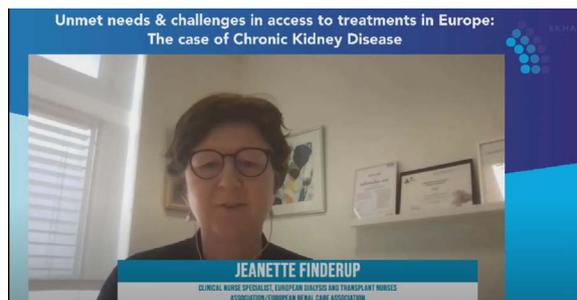


have new and more acceptable forms of home dialysis. Access in Europe also depends on financial resources: adequate facilities that are within easy reach of all patients are required and treatments need to be available at fair prices. More and more therapies are impoverishing people which is becoming a real problem.

**Moderator Tamsin Rose** asked how nephrologists could be better trained and receive more information on these issues.

**Raymond Vanholder** noted that this training should start when healthcare professionals are students. He stressed the role of nurses in this area. Teaching should include sessions on how to give complete information to the patient so they could make the appropriate choice.

**Moderator Tamsin Rose** asked Ms Finderup if there were gaps in terms of how patients were currently educated and informed.

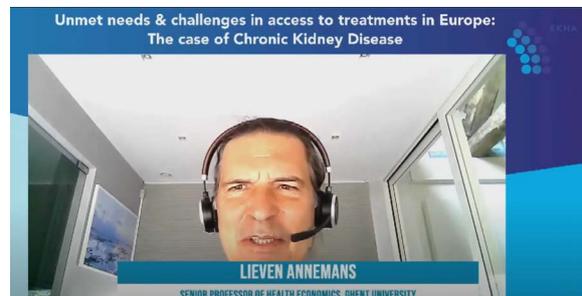


**Jeanette Finderup, Clinical Nurse Specialist from the European Dialysis and Transplant Nurses Association/European Renal Care Association (EDTNA/ERCA) & Aarhus University Hospital**, said that the short answer was yes. A programme is being implemented in Denmark which allows patients to meet with dialysis coordinators. Trained nurses are also on hand to deliver tailored interventions and ensure

that patients are involved in the decision-making process. It was found that, when involving the patients, 72% of patients chose home based treatment. Unfortunately, not all countries have patient decision aids. To her knowledge, the option of home dialysis is not offered to all patients throughout Europe. If patients choose a home-based modality, they should receive optimal training.

**Moderator Tamsin Rose** asked what were the economic factors that would influence the choice between different dialysis modalities.

**Lieven Annemans, Professor of Health Economics at Ghent University**, stressed that cheaper was not always better if this would not optimise the health of the affected population. The goal is to invest in health, and it should be remembered that this is an investment and not a cost. Sometimes, treatments are used because hospitals encourage a particular treatment. For example, some hospitals are financially incentivised to roll out in-centre dialysis. As such, reimbursement should be in line with real costs. Also, costs for patients should be minimized. Patients may be discouraged from choosing an option, if they have to pay more.



**Moderator Tamsin Rose**, asked how the European Commission could help address these imbalances. She also asked how the EU could ensure that each best practice becomes the gold standard in Europe.



**Stefan Schreck, Advisor for Stakeholder Relations, at DG SANTE, European Commission**, stated that the EU4Health programme is targeting imbalances and inequalities in access to healthcare in Europe. The EU could help exchange best practices and expertise and cooperate with Member States. However, the decision to act must be taken by Member States. The European Social Fund Plus,

Next Generation EU and the European Regional Development Fund are examples of programmes that support individual Member States. However, the planning under these programmes is decided on by Member States. Health projects to improve kidney care could be funded under the recovery and resilience plan, but once again this decision is up to Member States.

**Moderator Tamsin Rose** asked what lessons could be learned from the pandemic as chronic patients were at high-risk of severe outcomes and especially inpatient dialysis was disrupted.

**Daniel Gallego** replied that many patients with chronic disease died during the pandemic as they had to go to the hospital frequently for their treatment. Home treatment was much safer and a lesson learnt is that there is a need to implement better protocols to manage Non-Communicable Diseases at home. Telemedicine and phone consultations also need to be updated and digital tools used wherever possible. However, there is a risk to leave some patients behind as not everyone has a smartphone or a laptop.

**Moderator Tamsin Rose** asked whether digital health could help people to be better informed about their treatment options.

**Jeanette Finderup** said the answer was definitely yes. For example, in Denmark, the patients were involved in the development and evaluation of a mobile app. The average age of a patient in Denmark making decisions about dialysis is about 67 years old. As such, there is an issue of ensuring that all have the adequate digital skills and have access to a smartphone. Patient decision aid can help patients consider what choice to take but meetings with informed healthcare professionals are still critical.

**Moderator Tamsin Rose** said a member of the audience had asked how value could be best measured in the context of home therapies. Was patients' quality of life built into this?

**Lieven Annemans** stated that the goal was to incorporate quality adjusted life years (QALYs) into decision making. The QALY focuses on areas like pain, daily care and anxiety. However, it does not capture all elements of the patients' experience. The patient reported outcome should also be taken into consideration.

**Moderator Tamsin Rose** noted that Chronic Kidney Disease was often seen in the context of co-morbidities. She asked how an integrated approach could be developed.

**Jan De Maeseneer** noted that, during COVID-19, Belgium first vaccinated people at risk, and people with Chronic Kidney Disease were considered very high risk. The selection process involved

information received by General Practitioners (GPs). He wondered why not more countries targeted people with chronic conditions. Most of the time, people with Chronic Kidney Disease have multiple problems. However, care for them is often fragmented and this is an important issue. He emphasised the need to change the paradigm on how to approach patients with co-morbidities. What really matters to patients and their life goals should be well integrated into their care. More investments should be directed towards strengthening the horizontal primary healthcare systems so people could be treated in an integrated way.

**Moderator Tamsin Rose** asked how the effectiveness of kidney research could be doubled within the next decade.

**Raymond Vanholder** called on the EU to put Chronic Kidney Disease on its list of health-related research priorities, which is currently not the case. More awareness of the burden is needed, and this must be supported by more funding. It should also be possible to make a transparent comparison of research support for different diseases including Chronic Kidney Disease and allowing an assessment on how efficient they are.

**Moderator Tamsin Rose** asked whether a second EU action plan on Organ Donation and Transplantation could be rolled out.

**Stefan Schreck** replied that a lot of progress had been achieved under the original action plan from 2009 to 2015. However, not all Member States have fully implemented the action plan as of yet. A second EU action plan on Organ Donation and Transplantation is not currently in the pipeline. However, there is available funding for initiatives in the area, such as organising awareness-building events across the EU. The Commission also hosted a thematic network that brought stakeholders together to discuss common concerns and share best practices. Finally, the Commission is planning to strengthen the resilience of transplant practice in the EU.

**Moderator Tamsin Rose** asked how financial incentives impact the choice of treatment. Do financial incentives need to be changed?

**Lieven Annemans** said that the goal to improve the overall health of the population must be borne in mind. It is essential to promote early-detection for people at risk of Chronic Kidney Disease. A multi-disciplinary approach involving the GP is needed to select the optimal treatment for each patient. When one considers incentives, one must not be cost myopic, and an open view must be taken.

**Moderator Tamsin Rose** then gave the floor for the closing remarks.

## Concluding remarks

**Raymond Vanholder** said some of the key points touched on during this event were the need to avoid silo thinking and promote patient's choice. He thanked all participants and sponsors for their contributions.

**Moderator Tamsin Rose** stated that another take away from this event was the need for innovators to come up with new treatment designs, especially when it comes to dialysis machines, so that those suffering from such chronic conditions could have a better quality of life.



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