

Event
Report

2017

European Kidney Forum

Patient Choice of Treatment

Hosted by the MEP Group for
Kidney Health

EU Thon Hotel, Brussels

11 April 2017, 17:00 – 21:30



Summary and Context



There is a wide range of treatments for kidney disease, each with its own advantages and disadvantages which must be considered for the treatment choice to align with the patient's needs and lifestyle. However, not all patients across Europe are given a choice. In some countries, treatment choice is determined by reimbursement or structural constraints, rather than a true patient-centred approach to patient care.

The European Kidney Health Alliance (EKHA) carried out a **multi-country survey to build a snapshot of Renal Patient Choice in Europe**. The **2017 European Kidney Forum** - the annual multi-stakeholder meeting of EKHA, hosted by the MEP Group for Kidney Health - was the occasion to present the results of the survey.

In 2015, EKHA launched *Recommendations for Sustainable Kidney Care*. The 2017 Kidney Forum, held on the 11th of April, was devoted to the second cluster of Recommendations: **Patient Choice of Treatment**.

The Forum brought about discussions on the **importance of patient-centred decision-making, the health economic factors behind treatment choice and how to address health inequalities across Europe** and improve access to care.

This is aligned with the **launch of the EU-funded EDITH pilot project** (*the "Effect of Differing Kidney Disease Treatment Modalities and Organ Donation and Transplantation Practices on Health Expenditure and Patient Outcomes"*), which aims include comparing, from a macro-economic perspective, the various treatment modalities for chronic kidney disease in EU countries, by investigating factors that influence treatment choice, and the impact on healthcare budgets.

Welcome

MEP Hilde Vautmans, Co-Chair of the MEP Group for Kidney Health



As host of the Forum, MEP Hilde Vautmans welcomed the audience gathering scientific experts, healthcare professionals, patients, EU policy-makers, as well as representatives of health advocacy groups.

She stressed the **importance of patient choice of treatment** and to ensure the availability of a variety of treatment options to meet their specific needs and lifestyles. Mrs Vautmans also pointed at the need to address organ trafficking.

Turning to the role of the MEP Group for Kidney Health in making links between Members of the European Parliament and the medical professionals, and the role of the European

Parliament in addressing kidney health issues, she noted that the **MEP Group creates awareness among other MEPs, so they can act as influencers at national level.**

She also highlighted that the European Parliament has a role to play in facilitating and **ensuring an equal availability of treatment options across Europe** and therefore a same level playing field between EU countries in providing access to care to their citizens.

Addressing health inequalities in Europe

The work of the European Commission

Jürgen Schefflein, Team Leader for Health Inequalities, DG SANTE



Jürgen Schefflein introduced the role of the European Commission in addressing health inequalities in Europe by firstly providing an **overview of the [Health at a Glance in Europe 2016 report](#)**. Published in November 2016 and jointly developed with the Organisation for Economic Co-operation and Development (OECD), the report is a milestone of the European Commission's State of Health in the EU cycle and provides an updated analysis of the health status of Europeans and the performance of health systems. Key messages include:

- **More effective prevention and quality care are needed** to achieve further gains in population health and reduce health inequalities in EU-countries;
- Maintain or achieve universal health coverage by **reducing financial and geographic barriers to needed care and ensuring effective and timely access to services** is critical to reducing health inequalities;
- **Achieve further efficiency in health spending** to meet growing demands with limited resources

Mr Schefflein presented specific data on the issue, including figures showing that limited access to primary care is linked with avoidable and costly hospital admissions. Building on the key findings of the report, he noted that **health inequalities persist between EU countries and within countries between population groups**, while **social gradient is an important vector of inequalities**. Latest statistics from Eurostat also indicate that in terms of self-reported unmet medical needs, the situation has improved

during the period 2011-2014 for some Member States while for some others, the situation has worsened during the same period with widening discrepancies particularly for aging and other vulnerable groups.

Mr Schefflein further highlighted the different evidence-based strategies identified by a recent Lancet report to **minimise the impact of social hierarchy on health** and address social determinants of health. A preventative approach includes investing in children, promoting healthy lifestyles, strengthening local communities or ensuring universal access to high quality primary care.

Finally, outlining some of the EU-level activities to support Member States in their actions to reduce health inequalities, Mr Schefflein provided details on the upcoming **EU-funded Joint Action on Health Inequalities** which will address topics such as Health-in-All Policies Governance, healthy life environments, migration and health.

Questioned on the matter, Mr Schefflein stressed that while the European Commission has prioritised chronic diseases as a whole in its activities in the health field, the European Parliament can on its part raise awareness on chronic diseases separately, in a complementary approach.

Snapshot of patient choice in RRT across Europe - Results of EKHA's Survey in 8 countries

Prof. Em. Raymond Vanholder, EKHA Chairman



Chairman of EKHA Prof. Em. Raymond Vanholder gave an overview of the results of the Multi-Country Survey of Patient Choice of Renal Replacement Therapy (RRT) in Europe conducted by EKHA, which aimed at **better understanding the reality of inequalities in choice of kidney care in the EU.**

As Prof. Vanholder explained, the overarching goal of the initiative was to explore and address the patient choice of treatment (or lack thereof) in a handful of Member States (France, Greece, Lithuania, Netherlands, Portugal, Slovenia, Spain, UK) and look at how it relates in the context of the sustainability of kidney care, economic impact on health systems, and outcomes impact on the patient and his or her quality of life. In this sense, the survey tackled issues such as patients' inability to continue work or study because of dialysis dependence, time lost at dialysis (including traveling to and from and waiting), inability to be mobile/travel, health implications, personal cost implications and implications for family.

The project took the form of **two surveys (one for patients, one for healthcare professionals in the 8 countries)** to compare and contrast the results, and was conducted online after being translated in the local languages. Due to too few answers received to the Portuguese surveys, the data compiled for the country was not used during the analysis which focused on comparison country by country.

The **majority of responding patients stated being living with a functioning kidney transplant** when asked for the RRT they were currently on (among in-centre haemodialysis, conservative care, peritoneal dialysis, home and self-care haemodialysis). However in Greece, the main treatment method of respondents was in-centre haemodialysis. Most patients said they were informed of the different treatment options before starting on RRT, which

is a positive finding, noted Prof. Vanholder. Though, when questioning the patients about each treatment method separately, it seems that information is provided in varying depth and time frames which suggest that **improvement is needed to ensure that all patients are educated in depth about each option and that they are made aware of this in adequate time to make an informed choice.**

Overall, the results of the survey show a **substantial disparity between countries. In not a single country of the eight surveyed, were all renal replacement therapy options offered at 100%.** The results also indicate a **lack of patient education about sustainable options.** Some sustainable options such as peritoneal dialysis are not offered due to a lack of interest by the hospital management or dialysis provider or a lack of adequately trained staff. **Amongst transplantation options, living donation is often discriminated.** It also seems clear from the findings that **not offering an option is often part of a vicious circle** (no patient information, no demand. No demand, no offering, therefore no patient information... and so on). Additionally, **free choice is often hampered by financial drivers and lack of trained staff.** It also appears that the opinions of the patient and his/her family are often neglected. When patients wanted to change treatment, their wishes seem not to have been addressed by the healthcare professional in several countries including Greece, Slovenia, and the results are mixed in other countries.

The results show a discrepancy in the perception of medical professionals and of patients, whereby the impression of the professionals about a same issue is more optimistic than that of the patients.

The health economic factors behind treatment choice

Prof Lieven Annemans, Health Economist, Gent University



Prof Lieven Annemans focused his talk on the economic factors driving patient choice of treatment. He firstly pointed at the large number of patients who must pay out of pocket for treatment, noting that this actually goes **against the UN Declaration of Human Rights** which provides in its 25th Article that *“Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing, medical care and necessary social services”*.

He then explained the “3D approach” to address the issue of patient choice and inequalities, which consists in an analysis of the three dimensions: population covered, services covered, direct costs covered.

Prof Annemans highlighted the **crucial balance to be found between the health effect of a treatment and the limitations of the healthcare budget** when defining what to be covered on the healthcare system. He further explained the **concept of cost-effectiveness** using the QALYS (Quality Adjusted Life Years) index to define the health effect of a treatment. Prof Annemans noted that the Netherlands conducted the first attempt for modulated societal limits to pay for health.

Data indicate that 19,2% of people at risk of poverty in Belgium delay or cancel healthcare for financial reasons, against 6,5% of the total population, he further pointed. Building on the findings of a study published in Plos One and indicating that providing therapy insurance to people with chronic diseases who have no insurance appears to increase appropriate use of and adherence to therapy, he outlined that **the shift of financial responsibility to patients can lead to underuse of potentially important medications in people with chronic conditions.**

In order that essential treatment is available for all patients, he brought the attention of the audience to the **potential of the value-based health insurance model**, before giving a snapshot of different new payment systems for health providers, such as pay-for-performance models.

Finally, he noted that **“prevention that acts on persons indirectly, by altering their physical or social environment, is most cost-effective”**, and concluded his speech by stressing the **urgency to rethink our ways of investing in health.**

From patient compliance to treatment compliance

Gerard H.F. Boekhoff MSc, Board member, Neo-Kidney Foundation

Mr Boekhoff centred his presentation around the important notions of patient perspective and compliance. A kidney transplant patient himself, he **highlighted the life change he experienced after receiving a kidney transplantation** and emphasised **the importance of taking into account the patient views throughout the care pathway**. Indeed, he especially noted that the views of healthcare professionals can be different from the patient's perspective who are living in the reality of their condition. Both need to **dialogue** to find the renal replacement treatment option fitting with the patient's needs and lifestyle.



How to Move from Concept to Reality? EKHA's Policy Recommendations

Prof Em. Raymond Vanholder, Chair, EKHA

Building on the results of the multi-country survey, Prof Vanholder led the audience through EKHA's recommendations to improve patients' access to choice of treatment. In relation to treatment reimbursement strategies, **EKHA maintains that all therapies should be accessible to all patients throughout Europe**. In order to safe-guard this right, guidance and policy support from the European level, cascading down the Member State level is needed, and a **better distribution of healthcare spending at national level to encompass the full range of options including innovations or home strategies which might be cheaper and produce better outcomes**. To this aim, EKHA policy asks include:

- Patient-centred decision-making in renal replacement therapy;
- Fair access and distribution of care modalities across regions;

- Social impact should be considered in the search for technological innovation;
- Option for conservative care if appropriate

While home care is not widely available although it has many benefits, including flexibility and lower cost, EKHA recommends to **share and implement best practices which encourage home care for kidney patients; and educate health care professionals on home care, including information on conservative care**.

Last but not least, EKHA advocates for **increased access to transplantation**. Transplantation is the treatment of choice for end-stage kidney disease as it allows a better quality of life for patients and implies lower costs than other treatment options. In this regards, EKHA calls on policy-makers to **fund programmes that help increase organ donation** (both living and deceased) and encourage opting-out donor policies in Member States.

Interactive discussion

After lively discussions in-between the presentations and moderated by the EU journalist Peter O'Donnell, the audience was invited to exchange with the speakers on the different issues raised during their talks.

It was agreed that **healthcare systems need to focus on patients and therefore shift towards patient-oriented models** versus economic-oriented schemes which neither benefit the patient nor the healthcare systems

due to the frequent lack of patient adherence to treatment associated with greater costs of care. Participants noted that healthcare professionals have the responsibility to take into consideration and combine in the best possible way on one side the patient' views and his/her feelings in relation to the treatment which would be life-enhancing; and on the other side the sustainability of the healthcare system.



EKHA is a common effort by stakeholders to propose solutions for the challenges of Chronic Kidney Disease 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. EKHA works on the principle that the issue of kidney health and disease must be considered at European level and that both the European Commission and European Parliament have vital roles to play in assisting national governments with these challenges.

CONTACT US

Rue du Luxembourg 22-24
Brussels 1000 - Belgium
Tel 1: +32 2 213 1398
Tel 2: +32 2 213 1320
info@ekha.eu

EKHA is grateful to the following sponsors for making the 2017 European Kidney Forum possible:

Baxter

AMGEN

B | BRAUN
SHARING EXPERTIS

NIPRO

