Kidney Cancer Roundtable

Tuesday 29th November 2022

SPINELLI Building, European Parliament, Brussels

Introduction

Dr Rachel Giles, Chair, IKCC

The International Kidney Cancer Coalition (IKCC; ikcc.org) is a global umbrella non-profit organisation for patient groups who serve those affected by kidney cancer, collectively representing 1.2 million kidney cancer patients. Among the EU and EU candidate countries, IKCC has 17 affiliated organisations. The purpose of this Kidney Cancer Roundtable, the first of its kind organised by IKCC, was to draw awareness to:

1. The growing burden of kidney cancer to the EU, which has the highest rates of kidney cancer in the world;
2. The value of patient engagement to strengthen collaborations between clinicians, patient advocacy groups, clinical associations, and legislators within health care systems;
3. The EU research funding gap between kidney cancer and other cancers with a similar incidence;
4. Mission Cancer and the European Beating Cancer Plan, as a means to address kidney cancer disparities;
5. The connection between another major non-communicable disease, namely kidney disease, and kidney cancer;
6. Early detection and treatment for kidney cancer is key to improving survival of this deadliest of urological cancers.

Dr Giles thanked all the speakers and attendees, in particular the Hon. Nicolás Casares, MEP, for hosting this event.

Kidney cancer stats in the EU on the rise

MEP Nicolás Casares (Group of the Progressive Alliance of Socialists and Democrats in the European Parliament)

It is estimated that 79,000 adults (about 51,000 men and 28,000 women) will be diagnosed with kidney cancer in the European Union (EU) in 2022. Worldwide, it was estimated that 431,288 people were diagnosed with kidney cancer in 2020. Kidney cancer is the sixth most common cancer for men and the ninth for women. The average age at diagnosis is 60, and most people are of working age.

Occupation, lifestyle, and environmental factors are important drivers of kidney cancer. Between 9-16% of all kidney cancers are hereditary. The average age of diagnosis for these patients is much younger, at 39.

The number of new kidney cancers in the EU has been increasing for several decades. Between 2009 and 2018, rates rose by around 1% each year. It is one of the fastest growing cancers in terms of incidence: https://pubmed.ncbi.nlm.nih.gov/27727232/ and https://news.cancerresearchuk.org/2017/04/24/kidney-cancer-rates-are-increasing-so-whats-fuelling-the-surge/.

In 2020, an estimated 179,368 people died from kidney cancer worldwide. For kidney cancer that is detected before the tumour has spread beyond the kidney (localised kidney cancer), the 5-year survival rate is 76% in the EU. If the kidney cancer has spread to a distant part of the body, the 5-year survival rate is 14%.

Since there are no symptoms with early-stage kidney cancer, more than 70% of cases are found incidentally through imaging of the lungs or abdomen or for other reasons. Approximately one third of kidney cancers are preventable. A healthy lifestyle based on an adequate diet, physical activity, and reduced use of alcohol and tobacco could change kidney cancer numbers in Europe. Exposure to toxins and pollutants in the environment needs to be solved as soon as possible.

We need to improve early diagnosis. Currently there are no screening programmes and there is no evidence to support screening of the general population. This could change with the identification of biomarkers. We need to continue investing in research to find more effective treatments, even for the most advanced stages of the disease. The report from this committee can be seen as a starting point for improvement of the management of kidney cancer and equality in accessibility to medicines across Europe.

The importance of the 'patient voice'

Claudia Ungarelli, ANTURE, Italy

Ms Ungarelli from the ANTURE kidney cancer patient organisation in Italy highlighted the importance of the patient voice in the care and management of kidney cancer. She began by quoting Dr Michael Jewett from the Princess Margaret Hospital, Toronto, Canada, and the International Kidney Cancer Coalition (IKCC)'s inaugural European Association of Urology (EAU) conference 2022 as saying: "Patient engagement is a potential blockbuster treatment that urologists should prescribe for their cancer patients". This thesis was supported by a randomised study of over 700 American cancer patients with metastatic disease, half of whom had access to a reporting system that allowed earlier therapy change. There was an overall survival benefit of about 10% compared with those who had standard care.

Patient care programmes also reduce anxiety and depression (Basch E, et al. Effect of Electronic Symptom Monitoring on Patient-Reported Outcomes Among Patients With Metastatic Cancer: A Randomized Clinical Trial. JAMA. 2022 Jun 28;327(24):2413-2422. doi: 10.1001/jama.2022.9265. PMID: 35661856 and Basch E, et al. Overall Survival Results of a Trial Assessing Patient-Reported Outcomes for Symptom Monitoring During Routine Cancer Treatment. JAMA. 2017 Jul 11;318(2):197-198. doi: 10.1001/jama.2017.7156. PMID: 28586821). Beyond the clear psychosocial benefits that patient engagement can bring, a body of data points to hard clinical benefits as well. Physicians, professional bodies, and legislators should be advocating to engage patients in all aspects of care.

Challenges in kidney cancer care include long intervals between CT scan results and the appointment with the oncologist, the lack of a multidisciplinary approach to patient care, and disregard for psychosocial issues related to the disease. To address these challenges, patients often seek advice from advocacy groups on second opinions, information about treatments and management of their side effects, and access to clinical trials. Patients sometimes have a sense of abandonment and lack of empathy on the part of the clinician regarding the cancer diagnosis and end of life. This highlights the need for a long-term point of contact within the oncology team to help patients, even after they are discharged from the hospital. This person should be able to answer urgent questions, provide emotional support, and help manage side effects. In other countries, this role is often fulfilled by an oncology nurse practitioner, but currently, hospitals in Italy do not have this position.

We need to recognise the importance of collaborations between clinicians, patient advocacy groups, clinical associations, and legislators within the healthcare system. We are more credible when we work together.

How research has advanced the treatment of metastatic kidney cancer

Dr Rachel Giles, Chair IKCC

Dr Giles, Chair of the IKCC, spoke about how research has advanced the treatment of kidney cancer. Kidney cancer prevention, screening, and early diagnosis remain unmet needs. About two thirds of people are diagnosed early and are potentially curable, but about a third are diagnosed with advanced disease and are difficult to treat.

Appropriate and timely treatment is needed. Sometimes there are long waits for treatment, which can disadvantage patients. Effective adjuvant treatments are needed to reduce the risk of recurrence, as well as treatments for advanced kidney cancer that allow long-term remissions, maintain quality of life, and are accessible and affordable.

The IKCC strengthens the kidney cancer community; collectively, the groups are stronger and louder, facilitating change. During our annual World Kidney Cancer Day this year IKCC focused on treatment options, and obstacles to access. The IKCC performs a global patient survey every two years, with data from >2000 patients, the results of which are fed into European Guidelines panels to improve treatment plans.

IKCC can help Europe build awareness of kidney cancer and advocate for best practices through patient education and evidence-based information. IKCC patient advocates can add their voice to research, clinical trial design, and patient reported outcomes by working together. The IKCC can provide the patient voice at the regulatory level, with new perspectives and real-world evidence, and address inequalities across Europe by supporting the needs of patients, organisations, and associations.

Europe has the highest rate of kidney cancer in the world. The incidence is highest in the Czech Republic, perhaps due to industrial pollutants. It is the most rapidly increasing cancer and the deadliest of all the urological cancers. It not only affects elderly people, but also people in their middle age. Each year there are about 115,000 new cases and a quarter of a million Europeans are living with kidney cancer. It is the seventh most common cancer in Europe and nearly 50,000 Europeans die from the disease each year. Risk factors for kidney cancer include smoking, obesity, hypertension, and toxic agents. Chronic kidney disease (CKD) is also a risk factor and rising, as well as genetic factors (about 10% of kidney cancers).

There is a funding gap between kidney cancer and other cancers with a similar incidence, such as melanoma. Between 2007 and 2020, the average melanoma research grants were €11 million/year compared to €2 million/year for kidney cancer research: a difference of more than 5-fold. Over the last decade, the incidence of kidney cancer has increased by 29%: https://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/kidney-cancer#heading-Zero. We would like to understand this discrepancy and why urological cancers are out of step with research funding compared to other rare and less common cancers.

All first-line therapies for kidney cancer are combination therapies, which are expensive and side effects are difficult to manage. Triplet combinations are now also in development. The combinations are particularly toxic, with three quarters of patients experiencing serious or life-threatening side effects, and 1% dying from treatment. Some people have long term remission, but this is less than 10% of patients.

Orphan medicines will be reviewed in Spring 2023, and this will be interesting for rare and hereditary kidney cancers. The ENVI Committee will hold an exchange of views on the pharmaceutical package on 30 November 2022. Belzutifan for VHL disease-associated kidney cancer was approved by the FDA over 18 months ago, but there is no access to this medicine in Europe. This is very distressing for patients, and some are even moving to the US to access the drug.

EU Missions: Concrete solutions for our greatest challenges

Prof. Christine Chomienne, Mission Cancer Board

Professor Chomienne is the Vice Chair of the EU Mission Cancer Board. EU Missions bring solutions to some of the EU's greatest challenges through research and innovation, combined with governance, collaboration, and engaging citizens. Mission Cancer aims to improve the lives of more than 3 million people by 2030 through prevention, cure and to help those affected by cancer, including their families, to live longer and better.

The Mission-oriented research and innovation approach provides solutions and an opportunity to address the numerous challenges faced by people in their daily lives. Mission Cancer's goal is to involve citizens and stakeholders in setting research priorities, which will lead to equal access to the best of European innovation, research, and global know-how.

Using information from various sources, including patient organisations, the European Parliament and the Beca leadership team, a European plan for Mission Cancer was recommended. This included five intervention areas including three pillars: prevention, diagnosis and treatment, and quality of life of patients, survivors, and carers and two over-floors: understand and equity.

The EU has already started to implement actions on these 5 intervention areas, such as developing new methods and technologies for screening and diagnosis or pragmatic clinical trials to optimise treatment for cancer patients. Other work in the pipeline includes developing and validating quality of life instruments for cancer patients, the creation of a European cancer patient digital centre, improving and upscaling prevention of cancer, and strengthening research capacities. We need to better understand cancer risks and the biology of cancer.

Mission Cancer is also collaborating with the European Beating Cancer Plan on prevention, early detection, diagnosis and treatment, and quality of life for patients and survivors. Funding has already been secured for a number of these activities, such as prevention and early diagnosis, personalised medicine and genomics, and quality of life. These are ambitious goals for all EU citizens, patients, survivors and carers, and collaboration is key.

Mission Cancer and the European Beating Cancer Plan work with the Steering Group on Health Promotion, Disease Prevention and Management of Non-Communicable Diseases (SGPP) Cancer Subgroup, Cancer Implementation Group, stakeholder meetings, and patients and citizens workshops to help understand what the needs and issues are, which stakeholders are concerned, what can be done for effective implementation, and how to measure and adapt implementation.

Kay Duggan Walls, MSc, DG RTD

Ms Duggan Walls talked about how patient organisations can get involved with Mission Cancer. There are €110 millions of European funding available to enhance cancer prevention, clinical trials, diagnostics, and improve quality of life for childhood cancer. Engaging citizens is one of the main objectives of the Mission. Patient organisations and patients are included in the implementation and design of clinical trials and developing care solutions for patients. There is patient and public involvement in communication and dissemination through networks.

Mission Cancer is a research and innovation programme that supports policy development. The European Beating Cancer Plan is supported by EU4Health and includes Mission Cancer. This collaboration supports implementation of policies and best practice and uptake of innovation and research. Health Innovation Digital Europe drives innovation in Europe in partnership with Mission Cancer, while funding is provided by Horizon Europe.

Non-Communicable Diseases: Kidney Disease and Cancer

Eveline Scheres, MBA, European Kidney Health Alliance (EKHA)

Ms Scheres from the European Kidney Health Alliance (EKHA) spoke about the connection between chronic kidney disease (CKD) and kidney cancer. EKHA is the European nephrology advocacy platform in which organisations and individuals work together for healthy kidneys and for the benefit of people with kidney disease. There are 5 members, some of which are umbrella organisations. Collaboration is key, working on patient needs and voices, political programmes, and healthcare dynamics. Their mission is to reduce the number of people who develop kidney disease. 1 in 10 people in Europe have CKD. They engage with European politicians to create awareness, prevent, and lower the socio-economic burden of CKD.

Their main aims are prevention, improvement in disease management, better treatments that are accessible for all patients in Europe, and prioritisation of CKD. CKD costs society 50% more than all cancers combined, but there is no funding. Current treatments are not lifesaving and life expectancy is low. Despite this, research is not a priority. CKD is a silent killer. People only notice problems when they have stage 4 or 5 CKD. At stage 5, dialysis is needed. CKD is the eighth cause of death in high income countries worldwide and rising. It is a silent killer.

CKD can be concomitant with high blood pressure, cardiovascular disease, and kidney cancer. There is lack of awareness that these groups could develop CKD. Cancer treatments can damage the kidneys by causing inflammation leading to CKD. Also, CKD is a risk factor for kidney cancer because of immunosuppression treatment after kidney transplant.

There needs to be more awareness that cancer and its treatments may cause CKD. Kidney cancer patients need to have their kidney function checked regularly and there needs to be more research on the effect of cancer treatments on kidney function. Collaboration is key to solving these problems.

HTA Regulation – A case study in delayed access to innovative kidney cancer treatments

Mónica Suengas, ALCER, Spain

Ms Suengas from ALCER, Spain, described the positioning statement they have released on combination therapies for kidney cancer (https://alcer.org/wp-content/uploads/2022/07/ALCER-Las-terapias-combinadas-de-medicamentos-en-el-tratamiento-del-cancer-de-rinon-VF-26-11-2021.pdf; Stance summary/positioning: https://alcer.org/wp-content/uploads/2022/07/Resumen-Posicionamiento_ALCER.pdf). Around 8,000 people are diagnosed with kidney cancer in Spain each year, and 2,000/year die. Combination therapies have a significant impact on survival, but most remain unavailable to patients in Spain. The Spanish health system takes much longer to approve new medicines than other countries (14 months in Spain versus 7.7 months) and patients are losing out. The position statement requested fast track approval, and early access to medicines. However, finances prevent these requests.

The EU has approved regulation on health technology appraisals (HTAs), and this should be implemented across all EU countries. ALCER has sent a legislative report to the Spanish government but hasn't received a reply. These are urgent proposals for kidney cancer treatment: streamlined and early access, access to innovation, inequalities of access, specific financing for combination therapies, cost/effectiveness assessments, research incentives, clinical trials, and better information.

IKCC
International Kidney Cancer Coalition

Early detection and treatment of kidney cancer

Professor Dr Hein Van Poppel, EAU Policy Office Chair

Professor Van Poppel, EAU Policy Officer Chair, took the audience through the symptoms, diagnosis, surgical (open and laparoscopic (robot-assisted), ablative) treatment of kidney cancer. He mentioned active surveillance for small slow growing renal masses to avoid surgery and the use of renal biopsy. The EAU guidelines are for professionals but have been translated by the EAU's Patient information Working Group into patient understandable information in 17+ languages.

There needs to be a patient-centred multidisciplinary approach for the management of kidney cancer. Close collaboration of multiple specialists is required to decide treatment options to offer individual patients. We need to minimise over treatment of low-risk disease and under treatment of high-risk disease. Treatment costs of older patients can be reduced by preventing treatment related side effects, hospitalisation, and loss of autonomy. Follow-up should be tailored to individual patients.

He spoke about the risk of kidney cancer, and those that are preventable, such as smoking, obesity, hypertension, industrial toxins. CKD and genetic factors are also risk factors. Screening for kidney cancer in the general population is impossible. However, people with a family history of RCC should be screened for inherited conditions, e.g., von Hippel-Lindau (VHL) syndrome. People with end-stage disease, on dialysis for more than 3-5 years, have a kidney transplant, smokers and those exposed to industrial toxins should have annual scans, where kidney ultrasound could serve as a cheap screening tool: "Until we can find a cure for metastatic disease, screening high-risk populations is a better investment than spending money on end-of-life care with non-curative treatment" (EAU policy).

What is needed to improve kidney cancer care?

- Public awareness of kidney cancer and risk factors
- Policy makers' attention for awareness campaigns and more funding for research. Kidney cancer is underfunded
- An acceptable and affordable early detection strategy, e.g., screening people at risk, more research on early detection, screening of kidneys while screening for lung cancer using CT.

Recommendations

Europe's Beating Cancer Plan and the Cancer Mission Board provide unique opportunities for Europe to support people impacted by kidney cancer through delivering the following recommendations:

- Ensuring increased **funding for research into kidney cancer** through the Cancer Mission, including for active participation of patient organisations;
- Providing funding to test acceptable and **affordable early detection strategies for kidney cancer.** Further to the updated EU Cancer Screening Recommendations in December 2022, which includes lung cancer screening using low dose CT scans, more research could be conducted to test feasibility of screening of kidneys while screening for lung cancer using CT as the risk group is the same;
- Ensure that kidney patients have access to high quality, comprehensive care through the **Comprehensive Cancer Centres** and network planned across the EU;
- Ensure that kidney cancer patients **benefit from multi-disciplinary teams** and that the results of the INTERACT-EUROPE project (EU Projects (europeancancer.org)) is scaled up to deepen **inter-specialty cancer training,** where patients are at the centre of care;
- Through the **EU Pharmaceutical Legislation Revision**, ensure that regulatory approval processes are fit for purpose so that European kidney cancer patients have access to safe and effective medicines as soon as possible;
- Ensure that new therapies for kidney cancer benefit as soon as possible from the joint scientific assessment foreseen under the **Health Technology Assessment Regulation**;
- Provide **capacity building support and resources so that patient organisations have capacity to contribute to the HTA and regulatory processes**.

We thank the following funders who have supported IKCC in 2022 with equal Sustaining Partnerships:
BMS, Exelixis, Merck KGaA, MSD, Pfizer, Roche