7th IKCC Expanding Circles in Supporting Kidney Cancer

DAY 1 - Thursday 6th April 2017

Welcome

Speakers: Dr Rachel Giles (NL), Katarzyna Teodorczyk, Gladiator (PL)
Patient perspective: Marcin Wlodarczyk, Gladiator (PL)

Dr Rachel Giles, chair of IKCC opened the 7th Expanding Circles Conference by welcoming everyone to the Mercure Hotel in Warsaw, Poland. This year, there were over 80 delegates and more than 50 patient advocates from 26 countries, bringing together leaders from patient groups, medical experts, health care professionals, and industry specialists, with an interest in kidney cancer. New IKCC members were welcomed from Latvia, Macedonia, South Korea, Turkey and USA.

The IKCC is a global organisation, established with the mission to improve the quality of life of kidney cancer patients and their families; it raises awareness, provides information, empowers national kidney cancer organisations, advocates for the best care, and facilitates and promotes research. Not all patient groups represented by the IKCC are at the same stage of development - some are in their infancy, while others are able to influence national healthcare policy. Since nine of the top ten countries for the highest incidence of kidney cancer are in Eastern Europe, it was decided to hold the 7th IKCC Expanding Circles Conference in Poland to support the local patient organisations.



There followed an introduction to the local support group, Gladiator, whose primary focus was originally prostate cancer, but who now support people with kidney cancer. Volunteers run urology health awareness campaigns throughout Poland, and medical forums are organised in collaboration with the Polish Association of Urology and the European Association of Urology (EAU). **Marcin Wlodarczyk**, a member of Gladiator, spoke about how Gladiator had supported him during his experience with kidney cancer.

Kidney cancer update - Introductory session

Speakers: Dr Roman Sosnowski (PL), Dr Jakub Dobruch (PL)

Dr Roman Sosnowski, associate professor of uro-oncology at the Maria Skłodowska-Curie Memorial Cancer Center and Institute of Oncology in Warsaw, opened the session with an introduction to kidney cancer. Cancer develops from damaged cells that proliferate uncontrolled. The burden of kidney cancer worldwide is almost 400,000 cases per year, and it is the ninth most common cancer in men. The median age of patients is 71, and clinicians are seeing many more cases, the majority of which are confined to the kidney.

American data show that surgical removal of small kidney cancer tumours results in a 98% cure rate; however, the cure rate in Poland is not so good. Most patients want to know their prognosis; metastatic kidney cancer is not curable, but if the tumour is found early, and it is small and contained within the kidney, then the potential for cure is very good. He mentioned that work by Dr Michael Jewett had shown that small renal tumours could grow slowly, and patients could be followed by active surveillance and did not necessarily require intervention.

Patients also ask “How long have I got?” This depends on the stage (growth and spread) of the cancer; patients need to find out as much information about their disease as possible. He suggested that patient advocacy groups could help to persuade members of the public to stop smoking, since this is the highest risk factor for people getting kidney cancer, followed by obesity.



Dr Sosnowski then gave a live demonstration of the use of ultrasound for imaging the kidney. He also went on to describe how biopsies may be carried out to determine kidney cancer subtypes, or to provide more genomics information.

Dr Jakub Dobruch, Head of Urology at the Center of Postgraduate Medical Education in Warsaw, talked about advances in the management of kidney cancer over the last 50 years, from simple removal of the kidney to partial nephrectomy with robotic surgery, and modern systemic treatments. Urologists always try to spare the adrenal gland, where possible, and radical nephrectomy is carried out for large tumours.

Dr Dobruch then introduced **Professor Hendrik Van Poppel**, the EAU Adjunct Secretary General from University Hospitals Leuven, who talked about the European Association of Urology (EAU) guidelines for renal cell carcinoma (RCC). The EAU has around 16,000 members and their guidelines are used worldwide and accepted by urology clinicians in 28 countries, including Australia, New Zealand, China, and India. The EAU also provides educational courses around the world to help educate urologists. The EAU guidelines are not used in the USA, where other organisations are responsible for education, professional guidelines and patient information (e.g., American Urological Association, AUA, and Société Internationale d'Urologie, SIU). However, most urologists and oncologists adhere to EAU guidelines. The EAU patient information portal is also very useful for patients (http://patients.uroweb.org/).

The USA guidelines differ in several respects from the EAU guidelines, and are more advisory, rather than an actual guide for the management of kidney cancer. Patient advocacy groups could work to encourage the adoption of the EAU guidelines in their respective countries to negate worldwide variations in care.

Kidney cancer update - Advanced session

Speakers: Dr Michael AS Jewett (CA), Dr Eric Jonasch (USA)

Dr Michael AS Jewett, Professor of Surgery (Urology) from the University of Toronto, Canada, and **Dr Eric Jonasch**, Professor of Medicine, University of Texas MD Anderson Cancer Center, USA, presented a case study and discussed the decision-making steps in the real world management of a patient from diagnosis of localised kidney cancer to treatment of metastatic disease.



Dr Jewett initiated the discussion. The patient was a 70 year-old man with an incidental renal mass. He presented to his family doctor with abdominal pain; an ultrasound examination showed a right renal mass. This was confirmed on a contrast-enhanced CT scan. More than 50% of patients present with a T1 kidney tumour (less than 7 cm), while about 25% present with a tumour that has spread to local tissue or more distant organs (T3 or T4). The patient had mild local pain to the kidney area, no blood in his urine, normal blood pressure and body mass index. He had mild renal failure and his urine was clear. There was no family history of kidney tumours, and no hereditary conditions to predispose him to kidney cancer.

Various diagnostic tests (laboratory tests on blood and urine samples, X-ray/CT scan) were carried out and malignancy was confirmed using image-guided percutaneous needle biopsy. Some hospitals don't routinely biopsy, and would treat a benign tumour as if it were malignant and remove it. Recent studies have proven biopsy to be a safe procedure and concerns for it causing cancer spread are unfounded.

The patient had high grade RCC on biopsy, and an open partial nephrectomy. When deciding on the type of surgery, patients should opt for the best surgeon, not the best procedure! Number of procedures performed is a good quality marker for surgeons (high volume centres/networks). The gold standard for treating kidney cancer is radical nephrectomy, but the popularity of partial nephrectomy is increasing for small tumours, and conserves renal function. Open partial nephrectomy has been shown to be as effective as removing the whole kidney. Delivery of the radical/partial nephrectomy can be via open surgery or laparoscopic/robotic surgery (only available in more affluent countries). Follow-up (surveillance) after surgery is dependent on stage of disease and risk of recurrence.



Dr Jonasch discussed the three main systemic treatments available to people with advanced RCC; antiangiogenic therapies that block blood vessel growth (sunitinib, pazopanib, cabozantinib, axitinib); immunotherapies that stimulate the T cells of the immune system (nivolumab, cytokines); and mTOR inhibitors that slow down cancer cell growth (everolimus, temsirolimus). The benefit of adjuvant treatment to prevent recurrence following surgery remains questionable due to conflicting trial results (ASSURE versus S-TRAC), and the implications of adjuvant therapy for subsequent systemic treatment for metastases are not known.

The patient in the case study had lung nodules, which were confirmed as RCC metastases on biopsy. Treatment for RCC that has spread is dependent upon various risk factors that give an indication of prognosis. Temsirolimus is recommended for high-risk patients with poor prognosis, sunitinib or pazopanib for patients at low or intermediate risk. Active surveillance can be used for patients at low risk of spread and can potentially delay treatment for around 22 months. Sunitinib or pazopanib are recommended as first-line systemic treatments for advanced/metastatic RCC, nivolumab, axitinib, everolimus and cabozantinib are recommended as second- or third-line treatments.

Keynote Address:
Global burden of kidney cancer - Are we facing an epidemic of kidney cancer?

Speaker: Prof Dr Hendrik Van Poppel (BE)



Professor Hendrik Van Poppel, EAU Adjunct Secretary General from University Hospitals Leuven, gave the keynote address, and reminded us that we are all working together to reduce the global burden of kidney cancer.

Prof Van Poppel opened his presentation with a recap on the function of the kidneys and the incidence of kidney cancer worldwide (338,000 new cases/year). Incidence is predicted to rise by 22% by 2020 due to an aging population, and an increase in hypertension and obesity. RCC is the most common type of kidney cancer (90%), and has a huge impact on quality of life in terms of tumour symptoms and treatment side effects. There is also a high cost of diagnosis, treatment and follow-up, particularly for those patients who present with metastatic RCC (about 20% present with mRCC and 10-20% who have surgery go on to develop mRCC), and the 5-year survival rate for people with kidney cancer is around 63%.

The incidence of RCC in men varies from 1/100,000 in Africa to >15/100,000 in North and Eastern Europe and USA. The pattern is similar for women, but rates are about half that for men. Incidence is highest in the elderly (>75 years), but more young adults are getting RCC. Increasing use of imaging in Western countries accounts for incidental findings, and about 50% of RCC is diagnosed this way. More early cancers are seen today; however mortality continues to increase in some countries. Mortality is dependent on access to treatments and the gap in mortality rates between emerging and developed countries is widening due to availability of targeted therapies and immunotherapies.

Smoking and obesity are the main risk factors for kidney cancer. Other risk factors include hypertension, occupational exposure to various chemicals (e.g., asbestos, petroleum products, heavy metals), acquired cystic kidney disease, chronic renal failure and dialysis, hereditary syndromes (e.g., Von Hippel-Lindau, Burt-Hogg-Dubé, tuberous sclerosis), family history, analgesic use (e.g., NSAIDs), high salt intake, and kidney stones (papillary RCC). Alcohol in moderation seems to have a protective effect.

There are 5 main subtypes of RCC; clear cell (75-85%), papillary type I and II (12-14%), chromophobic (4-6%), oncocytic (2-4%) and collecting duct (1%), which has the worst prognosis. RCC is asymptomatic until it is locally advanced. Typical symptoms are flank pain, gross haematuria, and a palpable mass in the abdomen. The lungs are usually the first sites of spread. Imaging (ultrasound, CT) is used for diagnosis and MRI may aid staging and differential diagnosis, but two thirds of the world's population does not have access to imaging. Renal biopsies are useful for determining the subtype and grade of small renal masses, which has implications for subsequent treatment, i.e. surgery versus active surveillance of indolent tumours. Screening the general population for kidney tumours would be too costly, but could be useful for people with inherited conditions.

Surgery is the standard treatment and can be curative for small renal tumours. Ablation can be used for small renal masses. The use of partial nephrectomy (to conserve renal function) and ablation is increasing, while radical nephrectomy is decreasing. Active surveillance can be used for small slow-growing tumours, and high-risk surgical patients, elderly patients, and patients who refuse surgery. Active surveillance is the least expensive treatment, while robot-assisted surgery is the most expensive.

For locally advanced RCC, open radical nephrectomy is standard treatment, and neoadjuvant/adjuvant treatment needs further investigation. For metastatic disease, nephrectomy provides palliation of local symptoms, and improves response to immunotherapy. Metastasectomy can be used for the removal of a limited number of metastases, or residual disease after a partial immunotherapy response to improve survival. Bone metastases occur in around a third of people with mRCC, and most of these people have skeletal-related events (SREs), such as bone pain, fractures, and spinal cord compression requiring radiotherapy or surgery and associated costs. The role of cytoreductive nephrectomy for people with metastatic kidney cancer is being investigated.

Systemic treatments for mRCC include cytokines, such as interferon and interleukin-2. These have been superseded by targeted (anti-angiogenic) therapy, such as sunitinib, pazopanib, sorafenib, axitinib, everolimus, temsirolimus, and bevacizumab with interferon, in the last 10 years. Targeted therapy improves survival rates (> 2 years) and has a better safety profile than cytokines, although they are not available/affordable in many parts of the world. Immune checkpoint inhibitors (CTLA4, PD-1 and PD-L1) enhance the anti-cancer immune response and a durable response can be seen in about one third of patient. Cancer vaccines are in development. Targeted therapies and immunotherapies have been shown to improve overall survival and response rates, but they are expensive drugs and the cost of kidney cancer treatment is increasing. A patient-centered, multidisciplinary approach should be used to decide the optimal treatment for each patient.

Professor Poppel talked through some strategies for tackling the global burden of kidney cancer, such as:

- Improvement of diagnosis and treatment through training surgeons/physicians, focusing on early detection and curative therapy, engage policy-makers for allocation of resources, and support for research and cost-effective strategies
- Maintain a conducive EU research environment for kidney cancer
- Prevention strategies, such as promotion of healthy lifestyles, identification of high-risk populations for screening
- Eliminate disparities in kidney cancer care across the world
- Involve multidisciplinary teams, patient advocates and patient organisations – disseminate kidney cancer guidelines
- More accurate diagnosis and therapies – risk-prediction tools and biomarkers for personalised management of kidney cancer.

In conclusion, he suggested that the key messages should involve patients; the burden of kidney cancer is on families, not only patients; there is a growing burden of kidney cancer on global healthcare systems; the focus should be on awareness and prevention, and early detection; and patient advocates can play a vital role in clinical trial design.

IKCC special announcement: World Kidney Cancer Day

Speaker: Anne Wilson (AU)

Anne Wilson, Secretary/Treasurer of the IKCC, announced the first World Kidney Cancer Day (WKCD), which is taking place on 22 June 2017. The aim of the day is to raise global awareness of kidney cancer; its prevalence, symptoms, and risk factors, through IKCC affiliated organisations. Ms Wilson outlined the theme, design and elements of the day, along with the toolkit that will be made available to affiliated organisations. Key targets for this awareness event are:

- People aged 50+, with a skew towards males
- Those with risk factors, such as obesity and hypertension
- The research and clinical communities
- Funders, including government
- Patient and carer groups



The IKCC has commissioned an evidence-based article examining the literature on the burden of kidney cancer globally: “The global burden of kidney cancer: a call to action”. The publication will be officially launched to the clinical community and other relevant stakeholders as part of the WKCD.



The overarching theme of WKCD is unanswered questions around kidney cancer, i.e., questions and answers (Q&A). Questions create engagement, provoke thought and force responses, all of which develop awareness and knowledge. The quiz will be held on a dedicated World Kidney Cancer Q&A Day website, and links distributed through IKCC databases, advertising, PR channels, social media and professional recommendation in online communities. For each quiz completed, $5 will be donated to research. The quiz is already translated into French, Portuguese and Spanish, and can be translated into other languages. A WKCD toolkit, including various advertising items and campaign ideas, will also be available on the website and can be translated and used locally by affiliated organisations. Juliet Ibrahim was welcomed as the first global ambassador for WKCD.

Surveillance: Putting the patient voice into guidelines

Moderator: Dr Rachel Giles (NL)
Speaker: Prof Dr Michael Staehler (DE)



Dr Michael Staehler, Professor of Urology and Head of the Interdisciplinary Centre on Renal Tumours at the University of Munich, talked about the work of the Grading of Recommendations Assessment, Development and Evaluation (GRADE) working group; an informal collaboration of people with an interest in addressing the shortcomings of grading systems in health care. The working group has developed a common, sensible and transparent approach to grading quality (or certainty) of evidence and strength of recommendations. These recommendations include patients’ ideals, values, and preferences, and address the benefits and harms of assessment from a patient’s perspective.

The rationale for surveillance has changed since the 1990s; patients with metastatic RCC no longer die from the disease and there is overall survival benefit with systemic therapies. Surveillance can improve overall survival. Computerised tomography (CT) is the standard of care for imaging kidney cancer and contrast-enhanced ultrasound can be used for characterisation of small renal masses, tumour thrombus and differentiation of unclear renal masses. Various surveillance protocols are recommended by the European Association of Urology (EAU), the National Comprehensive Cancer Network (NCCN), the American Urological Association (AUA) and the UCLA Integrated Staging System (UISS) for follow-up of people with RCC, based upon risk profile as determined by stage of disease and the type of surgery (partial versus radical nephrectomy, or ablation). The guidelines recommend annual (or 6 month for high risk patients) follow-up for 5 years, with a mixture of CT (mostly for high risk patients), ultrasound and chest X-ray. The new EAU guidelines do not recommend chest X-rays, and follow-up continues beyond 5 years with a CT scan every 2 years for intermediate and high-risk patients.

Around 65% of disease recurrence is detected during follow-up, and most of these patients (72%) go on to have systemic treatment. Patients diagnosed in the follow-up period show a better prognosis and are good candidates for systemic treatment. The risk of recurrence relates to the Leibovich risk score, i.e. 92% of patients with a low Leibovich score remain free from metastases after 5 years, while 80% of patients with a high score progress within 5 years. Papillary II and sarcomatoid RCC are classified as high risk of recurrence, while clear cell and papillary I are low risk. Real world data show a trend towards systemic treatment of metastases, rather then metastasectomy; however, when detected early during surveillance, removal of metastases can be curative in 10% of cases.

Dr Staehler concluded that surveillance protocols are not standardised globally and the duration of follow-up in surveillance protocols is unclear. Surveillance is cost intensive and there are questionable survival benefits. The patient’s perspective on surveillance is still unknown.

Think treatment, think trials

During this session, clinical trials were discussed from the perspective of the researcher, the patient advocacy group and the patient.

Researcher's perspective: The importance of clinical trials

Speaker: Dr Eric Jonasch (USA)

Dr Eric Jonasch opened the session by explaining why we do clinical trials, for example, to help develop and gain access to new therapies, develop a greater understand of disease, and develop new tumour measurement tools. Clinical trials need to move from a drug-centric to a patient-centric research model, and trials should be based on the needs and wellbeing of the patient, and not solely on therapeutics. Trials designed without taking the patient into consideration result in poor recruitment, e.g. CARMENA and SURTIME; the data cannot be analysed and the results are inconclusive making research difficult. Researchers need to look at areas in the treatment pathway that can be improved to make the trial more patient-centric, e.g. the 6-12 week wait from diagnosis to start of treatment during which time the cancer could be growing and spreading.

To improve our approach to treating people with cancer; we need to understand the mutations in tumour cells; how cancer cells affect blood vessel formation; whether cancer cells are escaping into the bloodstream; and how cancer cells affect the immune system. We need to improve how information is collected from patients by using more sophisticated tumour tissue imaging, new scanning techniques and liquid biopsies to speed up movement from the bench to the bedside and back. Instead of testing many patients with the same drug, treatment needs to be personalised for specific patients in real time by assessing changes in tumours.

Dr Jonasch's take home messages were; patient participation in clinical trials is critical to the development of new therapies; a lot of work remains to develop new therapies and new tools to track the cancer response; and if we work as team, we can move from a drug-centric to a patient-centric model.

Patient advocacy perspective

Speaker: Berit Eberhardt (DE)

Berit Eberhardt, from Das Lebenshaus in Germany, followed with a presentation on clinical trials from a patient advocacy perspective. Clinical trials are often the only way to access innovative treatments, and are needed for regulatory approval and reimbursement. She used the analogy of a leaky pipe to explain that 10 patients need to be screened for 1 patient to be randomised in a trial, and of 100 patients identified, only 7 will complete the trial due to screening failures, unwillingness to take part, and drop outs. Barriers to trial participation include; uncertainty of experimental treatment; lack of information and understanding; treatment preferences and fear of being randomised to the 'wrong' treatment (i.e., placebo); concern about the impact on quality of life; fear or burden of diagnostics/tests; time needed to take part and conflicts with patient's life (e.g., work, mobility); and being treated as a human guinea pig.

Trial design can be a barrier to participation, since trials are often not designed in the patient's best interest. Well-designed trials recruit patients, but they tend to be a highly selective group of patients. Patient organisations can support patients with basic education about clinical trials, e.g. information about availability of trials, trial language, and translating informed consent. They can also support patients by helping to reduce anxiety and promoting trials as a standard of care. They can help trial recruitment by advertising upcoming and available trials and being involved with the design of informed consent forms/trial design.

Patient organisations need to be involved early in clinical trial design. They can also support collection of real world data (e.g., patient registries), and help educate patients about clinical trials. Patient organisations can act as navigators for clinical trials by helping to explain what is required of the patient to improve protocol adherence. Patient organisation can help in the design/translation of informed consent forms, clinical trial design and trial results. Patient organisations can also improve the transparency of clinical trials by directing patients to suitable clinical trials, disseminating trial results, and encouraging the publication of results, even if negative.

Ms Eberhardt's take home messages were to think about patient first; change the language of clinical trials (e.g., patients not subjects), give patients the opportunity to report side effects online, facilitate communication between patients, change the experience of patients coming off a trial, and improve dissemination of trial results to patients.

Patient perspective
Speaker: Deb Maskens (CA)

Deb Maskens, Kidney Cancer Canada and Vice Chair of the IKCC, spoke about taking part in clinical trials from a patient's perspective, the lived experience of being on a kidney cancer clinical trial, and how patient organisations can help with clinical trial design. Patients have mixed feelings about clinical trials; some want to leave a legacy to help other patients, most want to stay alive, some don't like the idea of being 'experimented' on and would prefer to take an approved treatment.

Ms Maskens has slow-growing, indolent papillary RCC, and had her kidney removed in 1974. In 2006 she was enrolled on her first trial with sorafenib (Nexavar) in Canada. She was very motivated to get on the trial, but her experience differed significantly from her expectations; she had significant side effects to sorafenib (alopecia, joint pain) and had to take medical leave from work, and, after 15 months on the trial, she had minor shrinkage of her tumour, but with significant quality of life issues. She decided to come off drug and opted for surgery instead. In 2009 she enrolled on a National Institute for Health (NIH) trial for papillary RCC in America. Enrollment in the trial was a more complex and stressful process. After reading the informed consent form in great detail, she was terrified of the potential side effects (deep vein thrombosis, pulmonary embolism, vision changes, heart changes etc.) and she expected the worst based on previous trial experience. However, with support from another patient on the trial and the medical team, she was on the drug for 3 years with barely any side effects (but she didn't always tell the truth about how she was feeling!). The drug stopped growth, with long-term stability.

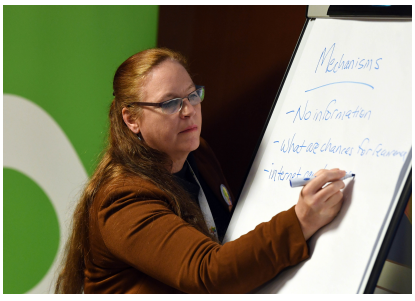
Patients shouldn't expect their doctor or medical team to know about all available trials, or to refer them. Patients can negotiate some (not all) elements before joining a trial, and there are risks of participating and risks of not participating. Patient organisations are in the best position to help patients find trials. Patients will find one another on trials and support each other by sharing experiences. Researchers need to measure clinical trial experience, identify issues and improve the patient experience. Good communication between researchers and patients, or a patient navigator to help guide the patient through the trial procedures, can help to reduce anxiety levels.

In summary, patients need help finding and exploring clinical trials and patient advocates can help researchers design better trials and improve the patient experience. Patient organisations can also support research and researchers by making patients aware of clinical trials and opportunities. When trials report, patient organisations can help to share both positive and negative results (care needs to be taken when communicating negative results to ensure patients are not discouraged from taking part).

DAY 2 - Friday 7th April 2017

Kidney cancer survivorship: Coping with 'we got it all'

Moderator: Dr Rachel Giles (NL)



Dr Rachel Giles gave a very interesting presentation about what happens to cancer patients when they have finished treatment, and how they cope as survivors. She talked about managing expectations; living in a "world of cancer shock", the anxiety surrounding follow-up scans (scanxiety), living with the fear that the cancer might come back, the feelings of abandonment following discharge from hospital, and getting emotional support to help cope with these feelings. There is no information about the risk of recurrence, and the Internet can be scary. Online support groups, such as Smart Patients, can help with feelings of isolation, as can facilitated discussions with other patients. Discharge summaries in patient-friendly language, a "body journal" and/or a care pathway can help with feelings of abandonment following discharge from hospital.

A diagnosis of cancer can also affect family, work and self-image. The family might see the patient as a different person; children might perceive them as being frail. At work, cancer patients have feelings of low self-worth; they don't feel the same as they were before cancer, and they might have less energy. Patients will have had to confront their own mortality, and may need to adjust their self-image. Sexual health may suffer as a result. Patients might also feel that their body has let them down, and find it difficult to cope with changes to body image. Rehabilitation programmes (including nutrition, psychology, and exercise) and counseling can help patients cope with feelings of depression, grief and anxiety. Caregivers and family members may also need emotional support, such as facilitated support to help them cope with their feelings following discharge.

Dr Giles concluded by suggesting that every patient is different, and cancer rehabilitation is individual; patients/families/caregivers have individual needs, wants and desires. Surveillance is inconsistent; patients are often given the responsibility to take care of themselves. She also mentioned that patients need support to help them avoid a sense of loss or isolation.

Components of supportive care: Advanced kidney cancer

Moderator: Rose Woodward (UK)

This session discussed the various components of supportive care, such as emotional, spiritual, social and information-based care, which are part of the wrap-around services for cancer patients, in addition to cancer treatment.

IKCC decision aid tool: My treatment, my choice

Speaker: Deb Maskens (CA) presenting Lisa Murphy's slides

Deb Maskens formally launched the first version of the decision aid tool to the IKCC affiliate organisations. This project came about following a lively session on shared decision-making at last year's annual IKCC conference in Chantilly, France, where Dr Bekker talked about patient values and preferences in decisions about treatment and care.

The kidney cancer treatment landscape is becoming increasingly complex with new drugs and interventions. Clinicians and patients now have complicated decisions to make about which is the right treatment for an individual patient. Information is needed to help patients navigate through the decision matrix. Clinicians often have a favourite treatment, but do not know the patient's values; true collaboration is needed between the clinician (expert in field, evidence-based practice) and patient (expert in their own life, needs, values, priorities) to ensure the right decision is made for the patient. Decision aid tools help people participate in decisions about their own health in ways they would prefer; they support complex decisions, are evidence based, facilitate informed choice and informed consent, and empower the patient/caregiver/family to make decisions that are right for the patient. Patient decision aids consider the patient's values and lifestyles, improve knowledge about treatment, decrease decisional conflict, reduce inappropriate use of treatment, are non-biased, and are good tools to share with the family. Decision aids help people become involved in decisions about health care options and complement professional consultations. They do not advise people to choose one option over another, or replace the healthcare professional consultation. There are already decision aid tools online for other conditions/cancers e.g., prostate cancer and kidney disease.

The IKCC decision aid project is a 3-year project; Phase 1 is the production and launch of My Treatment, My Choice – a kidney cancer decision aid tool based on EAU guidelines and validated by patient organisations, clinicians and patients; Phase 2 is the development of educational tools for healthcare professionals. The decision aid will be evaluated over the long term and it is hoped it will ultimately change the face of decision-making in kidney cancer. The development of the decision aid has been overseen by an international steering committee with members from the IKCC and Kidney Health Australia (KHA). KHA also provided an advisory board, and ensured the decision aid tool met the International Patient Decision Aid Standards (IPDAS). The project was funded by grants from pharmaceutical companies who had no input to the development of the tool. This is an international project; however, shared decision-making is not a reality in some healthcare systems and all treatments mentioned will not be available in every country.

My Treatment, My Choice was distributed to all delegates at the IKCC conference, who were asked to complete a paper survey. The survey is now available online for other patients, carers and healthcare professionals to feedback (https://www.surveymonkey.com/results/SM-GBP9KGBB/). Following feedback from affiliate organisations, version 2 will be hosted on the IKCC website, along with healthcare professional training for up-skilling and a means for formal evaluation of the decision aid.

Supportive/palliative care

Speaker: Prof Dr Saskia Teunissen (NL)



There followed an emotive presentation by **Dr Saskia Teunissan**, Professor of Palliative Care/Hospice Care from the University Medical Center in Utrecht. She told Pete's story: Pete (aged 46) had advanced kidney cancer and was on a sunitinib trial. He had progressive disease and suffered from the side effects of the drug – he felt hopeless. He was not able to handle questions from people in his social circle about his prognosis/remaining lifetime, he was anxious all the time, and worried about his family. His hopelessness was due to lack of insight into the future - no one was open with him or able to discuss his prognosis with him; he asked for help. He was in the transition from curative/restorative treatment to the palliative phase of disease where it is difficult to set goals, discuss effective treatments and prognosis.

Palliative care is often defined as terminal care, but it also includes disease palliation, symptom palliation, and bereavement care. Palliative care is an approach that improves the quality of life of patients and their families facing problems associated with life-threatening illness through the prevention and relief of suffering. Dr Teunissan compared curative care, where the aim is to cure the patient and the emphasis is on quality of treatment, with palliative care, where the aim is living the best possible life, and treatment is only given if clinically relevant.

The most common symptom in palliative care is fatigue, followed by pain, which becomes less prevalent during the last weeks of life, and lack of energy/weakness. Anxiety becomes a problem during the last weeks of life, and is experienced by about a third of patients. There are four dimensions of palliative care: physical, psychological, spiritual, and social. Total care involves collaboration between patients and their families with multidisciplinary teams in the context of the patient's symptoms, needs, wishes, priorities, and family, including shared decision-making. The aim of palliative care is a better quality of life, a better quality of death, and a better quality of bereavement for the family. Palliative care is about resilience, and about hope.

New roles for radiation therapy in kidney cancer

Moderator: Joyce Graff (USA)

Warsaw was the birthplace of Marie Skłodowska-Curie, the first women to win a Nobel Prize (in 1903) and the only women to win it twice and in two different sciences (physics and chemistry). She studied in Paris and was awarded degrees in mathematics, physics, and chemistry. She described the theory of radioactivity, and designed mobile X-ray units for use in field hospitals during World War I. She was the first person to carry out studies into the radiation treatment of neoplasms, and she died in 1934, aged 66, from aplastic anaemia due to radiation poisoning.

Different types of radiotherapies

Speaker: Dr Mateusz Spałek (PL)



Dr Mateusz Spałek, a Radiation Oncologist at the Marie Skłodowska-Curie Memorial Cancer Center and Institute of Oncology in Warsaw, gave a very technical presentation about radiotherapy. Radiotherapy involves a number of different specialisms, including radiobiology (the effect of radiation on tissues), clinical and surgical oncology, palliative care and medical physics. There are two types of radiation: photon radiation (gamma rays and X-rays) and particle radiation (electrons and protons). There are three types of radiotherapy; external beam radiotherapy, brachytherapy, and radioisotope therapy (nuclear medicine specialism).

Radiotherapy has a direct effect on tissues; free electrons damage cell DNA. It also has an indirect effect; free electrons cause water radiolysis within the cell releasing free radicals, which damage cell DNA. The aim of radiotherapy is cell death. The radiation dose is divided into fractions that are given every day for 5 days, followed by 2 days to recover. This is called fractionation and gives time for healthy tissue to recover between radiation doses. Cancer cells are usually more sensitive to radiation and don't recover. The aim of irradiation is to precisely deliver a radiation dose to the target tissue with minimal damage to surrounding healthy tissues. Radiotherapy can be curative, palliative, anti-inflammatory, and can prolong life.

Dr Spałek went on to describe treatment planning and the use of different imaging modalities to increase the precision of radiotherapy, e.g., PET/CT, PET/MR etc. and showed examples of each technique. He then described delineation/contouring of the target areas to be treated, and radiotherapy techniques to improve precision, such as orthovoltage radiotherapy, 3D conformal radiotherapy, intensity-modulated radiotherapy (IMRT), volumetric modulated arc therapy, image-guided radiotherapy, radiosurgery (stereotactic radiotherapy, CyberKnife, gamma knife), and tomotherapy (a type of CT-guided IMRT). He also described some new techniques, such as gating (4D radiotherapy) and the use of gold markers to follow organ movement and increase precision.

Radiotherapy has a number of uses, such as the palliation of bone pain and brain metastases, definitive radiotherapy for the treatment of cancer with curative intent, and before surgery (neo-adjuvant) to allow organ sparing and after surgery (adjuvant) to prevent recurrence and destroy micro-metastases. It can also be used for the treatment of benign conditions, such as meningioma, fibromatosis, and giant cell tumour of bone due to its anti-inflammatory actions. Dr Spałek concluded with a discussion about future trends in radiotherapy. Particle therapy, e.g. proton therapy, delivers significantly less radiation than conventional radiotherapy. Heavy ions is an experimental technique that is very expensive, but delivers 2-3x higher biological effect than photons with a better dose distribution.

Role of radiotherapy in advanced kidney cancer
Speaker: Susan Poteat (USA)

Susan Poteat is a Medical Physicist in radiation oncology and Co-founder of KCCure. Her husband, also a Medical Physicist, has had metastatic renal cell carcinoma (mRCC) since 2007. Since her husband's diagnosis, Ms Poteat left her full-time hospital job and now works as a temporary physicist in 16 cancer centers throughout the US. Ms Poteat's presentation focused on changes in radiotherapy equipment, and radiotherapy for mRCC.



Traditional radiotherapy has limited use in RCC and only 30% of RCC patients receive radiotherapy, versus over 50% for other cancers. This is because radiation after surgery has not been found to be beneficial for RCC patients and RCC appears to be 'resistant' to older radiotherapy techniques. Ms Poteat described 'advanced radiotherapy' techniques, such as stereotactic radiosurgery (SRS), stereotactic body radiotherapy (SBRT), and hippocampus-sparing whole brain radiotherapy, which require advanced radiotherapy equipment (on-board imaging, arc therapy, multi-leaf collimator) not accessible to all patients. Multi-leaf collimators are computer-controlled and can change beam shape as the treatment unit rotates. On-board imaging can improve accuracy to protect healthy tissue. Multi-leaf collimators combined with arc therapy allows radiation dose to be shaped resulting in higher, more direct tumour doses, and lower healthy tissue dose.

Radiotherapy can be used for palliative symptom control giving relief from pain and distressing symptoms to improve quality of life. It can be used to treat the brain (headaches, seizures), bone metastases (pain, fracture, spinal cord compression), viscera (pain), and lungs (cough, obstruction). Around 30% of mRCC patients develop bone metastases, which are usually lytic and painful, and RCC causes 10% of all pathological fractures. Palliative radiotherapy controls pain in up to 84% of cases; however, the duration of relief from pain is about 3 months, and palliative radiotherapy can be useful near end of life. SBRT can be used to treat bone metastases, but is only available in large academic centers. The response rate is 75% at 24 months (36% for palliative radiotherapy). 15% of RCC bone metastases are in the spine, which can be painful and debilitating and result in spinal cord compression. SBRT is highly effective for spine metastases and in 90% of treated patients the metastases don't grow/progress over 3 years. Full arc treatments spare the spinal cord with very short treatment times.



Approximately 10% of mRCC patients have brain metastases. Craniotomy or SRS is common for solitary metastases, whole brain radiation for multiple metastases, but survival is around 4 months. With whole brain radiotherapy, side effects can be hair loss, headache, fatigue, and neurocognitive decline (11% risk of dementia over 12 months). As patients now live longer, the risk of neurocognitive decline increases. SRS for brain metastases is highly effective, with 90% tumour control, and median survival of 8-12 months. Hippocampus sparing whole brain radiation can

reduce the neurological side effects of whole brain radiotherapy (memory loss results from damage to the hippocampus, which is more sensitive to radiation injury than the cortex). SBRT may be an alternative to surgery for patients with 1-3 brain metastases, and may be used for kidney primary rather than partial nephrectomy. SBRT may extend useful life of a drug if sites of progression are limited. Radiotherapy combines well with systemic drugs (no increase in toxicity) and might improve response rates of immunotherapies due to its immunological actions. SBRT costs about 15% more than a usual course of radiotherapy, but could save on the cost of systemic drugs.

In conclusion, Ms Poteat emphasised that improved access to advanced radiotherapy is needed. Palliative radiotherapy can be useful for symptom control near the end of life, and mRCC patients may benefit from multi-modality treatment. Patients with a low tumour burden and good performance status benefit from SRS, SBRT and hippocampus sparing whole brain radiotherapy, which are cost effective treatments for mRCC, and as advocates we can inform and educate others about radiotherapy options.

World cafe



During this workshop, the delegates were divided into 4 groups and each group was given the following topics to discuss.

What do you plan to do for kidney cancer patients when you get home?
Professor Michael Herbst, Cancer Association of South Africa (CANSA) led a discussion with each group in turn about what each patient organisation intends to do for kidney cancer patients when they return home. Some of the things mentioned by participants were:

- Advertise the World Kidney Cancer Q&A Day 22nd June locally via various media. Build awareness of own organisation and what we do
- Cascade IKCC information to local kidney cancer patient community
- Adapt what we have learned to make it patient- and culture-specific to empower patients and respect our local culture
- Never forget the cancer patient throughout the treatment pathway
- Recognise the gaps that exist in support services and address gaps with action
- It is important to collaborate with the IKCC, other patient groups, medical fraternity, health care teams, patients/carers/families etc.

Improving patient centricity in your country
Ms Vandana Gupta, V Care Foundation, India, led a discussion about patient-centred care with each group in turn. She started the discussion by asking 'What is patient centricity?'

- The patient is the focus of decisions concerning treatment/care, not the disease
- The patient is empowered with relevant information about their disease; however, doctors do not have enough time to educate the patient during consultations. Patient advocates/educators are needed to empower patients with relevant information
- Clinical trials need to be patient-centred and incorporate the needs, wants and experience of patients. Pharmaceutical companies should involve patients in the design of clinical trials
- Patient information sheets are often not understood by patients - patient input is required to ensure patient information sheets are patient-friendly
- Patient centricity from a care/treatment point of view – consideration of visiting hours, hospital food, caregiver accommodation in hospital improve patient-centred care
- Advantages of patient centricity are improved outcomes for patients, improved quality of care/treatment, patients feel more secure, patients and families feel empowered
- Patient centricity is a Western concept – doctors ask the patient how involved they want to be in treatment decisions.

Save the kidneys!

Ms Joyce Graff from Powerful Patient in the USA hosted a discussion about how best to look after the kidneys. Some of the discussion points were:

- Often, signs and symptoms related to problems with the kidneys are not an emergency situation. People should slow down and seek a second opinion; find an expert and get right answer
- Know the risks of kidney cancer, especially genetic risks, and understand and use them for the benefit of your health
- Know your treatment options, e.g., partial nephrectomy, watchful waiting, oncology options
- Campaign for kidney care can be linked to other conditions, e.g., diabetes, hypertension
- In resource limited areas/countries, non verbal materials, e.g., cartoons can be used to help people appreciate what the kidneys do for us
- Early diagnosis of kidney cancer, e.g. using biomarkers or a simple urine/blood test to protect kidney health; however, there are cultural barriers to seeing a doctor for such tests
- Keep calm and save the kidney!

Building awareness of kidney cancer

Ms Anne Wilson, from Anne Wilson Associates in Australia, led a discussion about building awareness of kidney cancer within affiliate countries. Some of the ideas put forward were:

- Using social media, e.g., a common hashtag for Twitter to trend on World Kidney Cancer Day to encourage people to complete the Q&A quiz
- Target patient populations to raise awareness, e.g., people over 65, people at high risk, using all forms of social media, e.g., thunder clap, flash mob
- Engagement of global ambassadors - people in the public eye engage their friends to make a noise about kidney cancer, i.e., Juliet Ibrahim
- Use of a common symbol for kidney cancer in media releases
- Offer of a free ultrasound scan for World Kidney Cancer Day (not feasible in countries with a state/national health service, or in countries where resources are restricted)
- Communicate the Global Burden of Disease publication to government, clinicians, public, patients
- Posters and flyers in public places/waiting rooms/clinics etc.
- Viral media, e.g. the Movember campaign to raise awareness of men's health issues
- Fundraising tool on FaceBook
- Radio and TV commercials/public awareness campaigns, concerts to raise money/awareness
- Focus awareness campaigns on risk factors for kidney cancer.

Capacity building

Moderator: Berit Eberhardt (DE)

Connecting to kidney cancer experts/medical societies

Speaker: Dr Michael AS Jewett (CA)

Dr Michael Jewett spoke about building relationships with kidney cancer experts and professional medical societies. When collaborating, we need to think about what we will gain from the relationship, as well as the benefits for the clinical experts/medical societies. From a patient's perspective, we might be able to access reliable and up-to-date scientific/medical information about the disease or treatment, or a reliable list of experts/centres of excellence (high volume centers). The relationship might facilitate access to appropriate care/innovative treatment that improves quality of care, bring ideas to research projects, and enable us to participate in scientific/research events. For experts, the relationship might improve the visibility of their expertise and facilitate dissemination of information to patients (i.e., informed decision-making, recruitment of patients, collection of tissue samples). It could also help fund research projects, support training initiatives, and help advocate to the national health authorities for access to treatments.

In collaborations with experts/societies, we need to consider that we are representing the kidney cancer organisation as well as the individual patient/survivor. Also, patient-centred care is not a universal concept and varies between cultures, institutions and healthcare professionals. Evidence of the impact of advocacy on patient outcomes will help in the development of the collaboration. During the development of the relationship, a champion needs to be identified to facilitate the collaboration. The partnership should be on a level playing field, peer to peer, and needs time to develop. The right key opinion leaders need to be on board, and no money should exchange hands. Once the experts have been identified, work together in a partnership, engage the experts, study the disease and relevant issues, focus on the positive and the importance of the patient journey.

Kidney cancer research: Projects and funding



Brian Lewis from Action to Cure Kidney Cancer, USA, talked about capacity building and campaigns to fund kidney cancer research. He spoke from a US perspective; each political system or environment is unique. Kidney cancer is a rare disease, but kidney cancer patients deserve equitable treatment with other cancer patients (for example, Defense Funding per mortality for prostate cancer is $2,905 and for kidney cancer, $77). Mr Lewis talked about tactics for funding, starting with identifying political stakeholders and using emotional and economic arguments, such as incidence rates, the impact of the disease on patients, family and friends, and the fact that research projects improve employment and business opportunities.

Mr Lewis then gave some tips on how to generate funding: Meetings with potential funders to educate and advocate on behalf of kidney cancer patients and their families. Personal stories have a strong impact and make connections to stakeholders. Email campaigns can be used to engage legislators. Finally, to be successful, you need to be persistent with your campaign. Mr Lewis finished by mentioning an annual $10million worldwide grant available through the US Department of Defense (Congressional Directed Medical Research Program) available via http://cdmrp.army.mil.

Bringing kidney cancer experts together for policy change: Mexico



Carlos Castro Sanchez from the Asociación Ale IAP, Mexico, presented their experience of bringing kidney cancer experts together for policy change. Asociación Ale was originally set-up to help disadvantaged Mexicans access organ transplantation and to influence public policy on kidney disease. They became involved with kidney cancer 3 years ago. The objectives of their campaign were to; raise awareness of the epidemiology of kidney cancer in Mexico; discuss with the experts what is being done, available treatments, and what is needed; make policy proposals to stakeholders; and raise awareness of kidney cancer via media and social networks.

Their strategy was to hold a breakfast press conference with medical experts to discuss treatments, disease burden, legislative work needed to change health policy, patient voice and challenges (e.g., only 50% of the population has medical insurance). This generated a lot of media coverage. An academic discussion forum involving medical experts from the most prestigious private hospitals in Mexico, followed the press conference. The objectives of the forum were to raise awareness of kidney cancer, the barriers to early diagnosis, prognosis and current treatment in Mexico. The patient voice needs to be strong, particularly in Mexico where legislators rely on the expert opinion of the medical community. In July 2017, Asociación Ale is meeting with congress to discuss the budget for kidney cancer treatment, especially for disadvantaged people. This is in collaboration with the Latin America Renal Cancer Group to strengthen the case for the necessity of health coverage for kidney cancer.

Meeting with government - advocacy/activism/action

In this presentation, **Deb Maskens** imparted her experience of meeting with government bodies to influence health policy change, along with some ideas for how to make it happen. Her lobbying experience comes from her work within Canada, which has a public healthcare system. She spoke about activism, with the HIV/AIDS experience as an example; taking to the streets, marching and protesting are not necessarily effective in the modern world, and patient organisations need to do more to influence public health policy, for example come to the table with evidence, budgets etc.

An advocacy strategy should start with an advocacy plan, detailing whom to advocate to (who has responsibility/jurisdiction for your issue), a contact pan (seek government allies in finance and health) and three key messages for each audience aligned with key cultural values. For rare cancers, need to be persuasive and go armed with background to the disease (incidence, mortality, what does this mean from a healthcare perspective), what you are proposing (how will it improve quality of life and survival. What is the impact on the healthcare system? Costs?), who is involved, who to advocate with (clinicians, patients, carers, other patient organisations), and when (pick your moment, election timing). Face-to-face meetings, letters (handwritten), and telephone calls have the greatest impact, e-advocacy campaigns have low impact.
When deciding on your 'ask', choose something tangible, something you can follow-up and prove. Keep it simple, achievable and action-oriented. Ms Maskens then discussed setting up meetings with government, remaining firm and persistent with the ‘ask’, look for opportunities, stay focused, anticipate objections and provide new information. Build the relationship as a trusted partner.

Day 3 - Saturday 8th April 2017

Kidney cancer risk factors: Prevention including practicalities of screening

Moderator: Dr Rachel Giles (NL)
Speaker: Prof Joanna Didkowska (PL)

Professor Joanna Didkowska, Head Department of Epidemiology and Cancer Prevention, Maria Skłodowska-Curie Memorial Cancer Center and Institute of Oncology in Warsaw, opened the third day of the conference with a presentation about kidney cancer risk factors. She started by highlighting the global burden of kidney cancer; the highest number of kidney cancer cases are found in more developed regions of the world (America, Australia, Europe) and high growth countries, such as the Czech Republic. Central/Eastern Europe has the highest mortality due to poor access to treatment. Incidence has increased dramatically since the late 1970s in the Czech Republic due to the use of ultrasound to detect kidney cancer, particularly in males. The Czech Republic has the highest incidence in world; however, mortality for both sexes is decreasing in all countries, including the Czech Republic and Poland. In Nordic countries, incidence and morbidity are stable.

There is a bimodal distribution of kidney cancer incidence by age, with a peak at 65-80 years, and there are twice as many men as women with the disease. In the Czech Republic, there is an increase in incidence of early stage (stages I and II) kidney cancer, but a decrease in the incidence of late stage III/IV disease since the 1990s, likely due to the increased use of ultrasound. This distribution is also seen in Poland and USA. Cigarette smoking increases the risk of kidney cancer twofold, while obesity increases risk fourfold. Physical activity has a positive effect. Other risk factors include genetic/hereditary risk factors, some chemicals used in industry, e.g., dry cleaners, trichloroethylene, cadmium, arsenic, asbestos, certain medical conditions, e.g., kidney dialysis, hypertension, paracetamol, diuretics, and non-steroidal anti-inflammatory drugs (NSAIDs). Survival rates are dependent on stage of disease, and 5-year survival rates are around 90% for stage I disease, and 15-20% for stage IV. In the UK, 5-year survival rates have almost doubled in the last 40 years.

Professor Didkowska concluded her presentation by talking about primary and secondary prevention: Smoking cessation can reduce the risk of kidney cancer by 30%, maintaining a healthy weight decreases the risk by 40%, and controlling blood pressure reduces the risk by 20%. Secondary prevention includes screening for kidney cancer; however, a routine screening test is not yet available, and, although kidney cancer is more common in smokers and people with autosomal dominant polycystic kidney disease, screening has not been shown to be effective for these risk groups. Annual ultrasound screening for patients with hereditary syndromes is recommended.

Building real world evidence

Moderators: Dr Rachel Giles (NL), Berit Eberhardt (DE)



Patient reported outcomes

Speaker: Prof N Cem Sönmez (TR)
Professor N Cem Sönmez, Head of Uro-oncology Division, Şişli Etfal Reaserch and Training Hospital, Istanbul, Turkey, gave a comprehensive review of patient reported outcomes using health-related quality of life instruments. Professor Sönmez is a member of an Advisory Board for Birkan, a Turkish kidney cancer organisation responsible for health policy, awareness, education, and patient support.

Patient reported outcomes (PRO) are outcomes that are important to patients. Treatments should be desirable; therefore, the wellbeing of the patient as well as clinical effectiveness should be measured. There is increasing importance of PROs. Standardised, self-report instruments are used to measure the intensity of symptoms, and how they affect the patient's capacity to function. These instruments give a unique insight into how therapy can affect the patient; how they feel and function, their wellbeing, emotional state, ability to live full life, level of comfort, and the impact of illness on loved ones. Self-report instruments capture information that is important to patients and needs to be measured specifically and objectively; deciding what to measure is critical.

Professor Sönmez highlighted various health-related quality of life (HRQoL) instruments currently in use. These instruments are multidimensional and measure aspects of physical, psychological and social function, treatment adherence and wellbeing. The subjective nature of HRQoLs should not be confused with a lack of validity. Quality of life may change over time; this can be captured using HRQoLs. HRQoL instruments can be general standardised questionnaires or disease-specific. The short-form-36 (SF-36) is the most widely used general questionnaire for all cancer types, but is too narrow for individual cancers. Other general instruments include the Nottingham Health Profile, Sickness Impact Profile, European QoL, and the WHO QoL questionnaire. Disease-specific questionnaires include questions important to the target group. Professor Sönmez then explained how best to use HRQoL instruments and how to deliver the questions to the patients.

Many health technology appraisals (HTAs) are now asking for real world evidence. However, many patient-reported outcomes measurements (PROMs) are developed without patient input. To ensure they measure outcomes that are important to patients, patients and patient groups need to appraise these instruments. There needs to be more collaboration with researchers and patients need to have more influence in development of PROMs to identify concepts of health that are most important to them and to endorse PROMs for HTAs. HRQoL should make sense to patients; this could mean the difference between positive and negative HTA decisions.

Results of National Kidney Cancer Patient Survey (Canada)

Speaker: Stephen Andrew (CA)



Stephen Andrew a kidney cancer survivor from Kidney Cancer Canada (KCC) presented their experience with a national kidney cancer patient survey. The survey was conducted in collaboration with the Princess Margaret Cancer Centre in Toronto, Canada. The objectives of the survey were to explore treatment awareness and choice, barriers to care, supportive care needs, unmet needs, and access to information. The survey was a questionnaire-based needs assessment in English and French, and directed at both patients with kidney cancer and caregivers affected by a diagnosis of kidney cancer.

Participants were invited to take part in the survey via email to the KCC membership, at the Princess Margaret Hospital clinics, and promoted to urologists and oncologists via the Canadian Urological Association conference in 2016 and various board meetings. KCC advertised the survey on their website and via social media. The survey opened on June 15 2016 and closed 31 August 2016. 465 people completed the survey, 368 of which were patients, and the majority completed the survey online (408 people). Mr Andrew presented the demographics of the survey population, along with information about the cancer journeys. Key findings from the survey were:

- Patients most often received information about their kidney cancer from their oncologist/urologist (67%), Kidney Cancer Canada (55%), their family doctor (50%), and other websites (35%). Information from their oncologist/urologist and KCC was rated most helpful
- Respondents preferred finding information about kidney cancer from the internet (54%) and most (71%) respondents were comfortable with this health information
- More than half of all respondents did not receive information about clinical trials and 20% enrolled in clinical trials
- Barriers to care included side effects to treatment (26%), health system delays, such as delay in diagnosis (26%), no access to treatments (25%) system delays to starting treatment (24%) and financial burden (24%)
- Unmet care needs were greater in women, younger responders, newly diagnosed or those receiving treatment

Mr Andrew concluded by highlighting the next steps for KCC, such as sharing the information with stakeholders, identifying areas for collaboration to reduce barriers to care and increase awareness, and to tailor information and support services. Real word evidence provides an opportunity to match evidence with action plans; a worldwide survey would be very useful.

End of conference

Moderators: Dr Rachel Giles (NL), Katarzyna Teodorczyk, Gladiator (PL)



Dr Rachel Giles and Katarzyna Teodorczyk, Gladiator (PL) closed the conference by thanking everyone for their active participation and for coming together to contribute to the international kidney cancer community. It was a great honor that IKCC decided to hold the conference in Warsaw, Poland. Meeting friends from around world provides the incentive needed to help patients with kidney cancer. Patient organisations can go home with the knowledge and belief imparted by the magnificent speakers.



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