

Conference Summary Report

Day 1

Welcome to the 9th IKCC Global Kidney Cancer Summit 2019

Dr Rachel Giles (NL), Bernardo Carvalho, Portuguese Kidney Patients Association APIR (PT)

Patient perspective: Francisco Rodrigues

The IKCC welcomed over 50 patient advocates from 26 countries and 6 continents to the 9th Global Kidney Cancer Summit in Lisbon, Portugal. We are pleased to welcome new participants from Asia, Europe, and North America to our conference for the first time. Following last year's focus on the particular issues facing kidney cancer patients in Latin America, this year highlights our value of connecting patient groups, and collaborating with healthcare professionals and the healthcare industry.

Bernardo Carvalho welcomed everyone on behalf of the host country and the Portuguese Kidney Patients Association (APIR). A parallel meeting on Day 2 of the conference will bring the Portuguese kidney cancer experts together with patient advocates to bring attention to the treatment of patients and to foster collaboration.

Mr Carvalho introduced Francisco Rodrigues, a Portuguese patient who shared his kidney cancer journey and spoke of the strength he gained from belonging to a patient group. He ended by emphasising that we must work together to support patients.

Kidney cancer clinical updates

Moderator: Dr Tadao Kakizoe (JP)

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

Dr Jewett opened by summarising the diagnosis and treatment of non-metastatic renal cell carcinoma (RCC). He focused on the differentiation of small renal masses versus cancer, the role of tumour biopsy, active surveillance, ablation versus surgery, treatment of benign tumours, surgical techniques (radical versus partial, open versus laparoscopic), adjuvant and neoadjuvant treatment, and follow-up protocols.

Dr Jonasch completed this opening session with a presentation on the treatment of metastatic RCC. He highlighted the benefits and risks of 'watchful waiting' prior to treatment initiation, the use of combination treatments for metastatic RCC and their side effects, and the treatment of non-clear cell RCC with immunotherapy.

Kidney cancer patient organisation updates 2019 – Part 1 of 2

Moderator: Carlos Castro Sanchez (MX)

Speakers: Stephen Andrew (CA) and Natalia Gonzales (BR)

Mr Andrew opened this session by describing a video knowledge library project launched in November 2018. A patient survey indicated that information and support was an unmet need for Canadian kidney cancer patients. Common sources of information are oncologists and doctors, so KCC decided to put together a video library consisting of a series of questions about kidney cancer posed to an expert. Each video is about 40 seconds long and can be shared on social media. The library will also be available with French subtitles.

Ms Gonzales spoke about their research to better understand the patient journey in Brazil. The research consisted of an online questionnaire with patients and doctors and follow-up interviews by phone. The results were shared with the media and other stakeholders in Brazil to develop new ways to improve quality of life for patients.

The marketplace session

Capacity building and organisational issues for patient groups

Delegates were divided into three groups to discuss the following three issues in turn:

Writing grant proposals

Bryan Lewis (USA) and Deb Maskens (CA)

Mr Lewis and Ms Maskens used an example of how best to prepare a grant proposal based on the three major means of persuading people: 1. Using logical, reasonable and rational argument with facts and numbers (logos); 2. Appeal to the heart/emotions by incorporating the patient voice (pathos); 3. Establish credibility through partnerships with larger organisations (ethos). When working with a partner, remember to protect reputation and work ethically and transparently (cf. IKCC Code of Conduct).

Social media

Juliet Ibrahim (GH) and Dena Battle (USA)

Ms Ibrahim and Ms Battle spoke about the use of social media for connecting patients and building a following with shared interest. Analytical tools are helpful to gauge engagement and check what is of interest and who is following. Keep posts short to prevent boredom, use images and videos (less than 1 minute), make it personal, and use hashtags to buy into original followers. Use different social media for different generations.

Conducting patient surveys

Josephine Elliott (UK)

Ms Elliot described her experience of patient surveys. Survey aims need to be clearly defined, of benefit to patients, and questions need to be focused; there is no point collecting information that is not useful. Because only motivated/informed patients respond to survey, bias may be introduced. Questions can be misinterpreted and online surveys only involve patients who are technologically savvy. Surveys need to engage patients in rural areas/less informed patients. Oncology nurses/doctors can help to build awareness of surveys amongst their patients.

Kidney cancer patient organisation updates 2019 – Part 2 of 2

Moderator: Vandana Gupta (IN)

Speakers: Christine Battistini (BR), Ebru Yazar (TR), Megan Mager (USA)

Ms Battistini presented a powerful video about the role of patient support for cancer patients to reduce the feeling of isolation. The video used an analogy of being on a ship at sea and not knowing how to sail the boat through choppy water. The patient group is in the boat with them to help navigate and take care of the patient. Various means used in Brazil include a toll-free hotline and social media.

Ms Yazar spoke about KANKO's experience of hybrid crowd funding for a research study on cancer fatigue using a brief fatigue symptom inventory and self-reported scoring system. The study showed that fatigue is the most common side effect of cancer, and it affects patient's quality of life on a social and personal level. Patients were given a personalised programme to defeat fatigue.

Ms Mager presented the Max Access Solution Model – a patient-centred system of humanitarian access to unregistered oncology treatment using a network of specialist healthcare providers to increase access to (unregistered) treatments for cancer patients. The programme took off in 2018 with Sutent and Torisel and now supplies patients in Africa (80% of patients), Eastern Europe, Latin America, and Asia Pacific.

Day 2

Capacity building 1

Media training for patient organisations - workshop

Moderator: Juliet Ibrahim (GH)

Speaker: Stephen Andrew (CA)

In this session, Mr Andrew used his media experience for tips on how to write a good media release. Who, what, when, where, why and how? Is the media release relevant, timely, and topical? What is the focus/purpose of the release? Pick three points and decide target audience. Don't send attachments to publishers, and do not embargo. Use a headline and do not call it a 'media release'! Assume people will only read the first paragraph, so include all major points. Use familiar terms and avoid technical/institutional jargon. Write for a broad audience using simple conversational language and include quotes. One page is enough; use a background for additional information, add links etc. Proof, edit, check! And check again! Include a few sentences at the end to explain the organisation.

Future-proofing your organisation; changing landscapes for patient organisations worldwide

Moderator: Dr Michael Jewett (CA)

Speakers: Markus Wartenburg (DE) and Dena Battle (USA)

Mr Wartenburg spoke about the funding of patient groups in North America and Europe, and how to future-proof an organisation against change using strategic plans for the digital age. Consider organisational structure, digitisation, audience, cultural change, and education etc. Also consider changes in medicine/healthcare such as new technologies, patients and funding models etc. Three main areas of change include relationship with pharma, digitisation and social media, and personalised medicine/precision oncology.

Ms Battle talked about industry funding for patient groups, transparency and future laws/regulations that can hinder partnerships. She suggested diversifying funding streams and not being dependent on one source. Patient advocacy is a consulting service, and there is value in the relationship between industry and advocacy. Patient groups should work to preserve this relationship. In the US, the Patient Advocacy Transparency Act 2018 (yet to be introduced as legislation) states that industry has a responsibility to disclose funding.

Keynote address: Patient advocacy, patient activation, patient organisations and improving outcomes

Moderators: Dr Rachel Giles (NL) and Deb Maskens (CA)

Speaker: Dr Serena Barello (IT)

The keynote address from Dr Barello covered the big challenges in healthcare, such as dramatic increase in chronic diseases, rising costs and demands of care, longevity, and decreasing resources (financial and human). Patient engagement is important to face these challenges. She spoke about a patient-centered role where the patient is treated equally in their own healthcare, and the influencers of psychosocial outcomes for patients. She mentioned that engagement is a complex process involving organisational, social, and economic factors: The family/carer has a crucial role and needs support. Technology is an enabler of the engagement process. The IKCC can share guidelines and practice on patient engagement. Patient groups can educate patients to become active in their own healthcare.

Hot topics in kidney cancer

Moderator: Dr Christopher Wood (USA)

Decisions in localised kidney cancer: Biopsy, intervention, surveillance

Speaker: Dr Luke Lavallée (CA)

Dr Lavallée described the development of a shared decision-aid for the treatment of localised kidney cancer. Decision-aids educate and help patients and clinicians make quality decisions together in an unbiased fashion using management options and evidence-based outcomes. Decision aids take into account patient values, decrease decisional conflict, and reduce variation in care using simple language, figures and diagrams. Patients and clinicians should work through the decision aid together.

Management of brain metastases arising from RCC

Speaker: Dr Eric Jonasch (USA)

Using a case study, Dr Jonasch spoke about the management of brain metastases from RCC. Brain metastases can be single or multiple and can shorten lifespan. It is not known why 20-30% of RCC patients get brain metastases. Brain metastases can be treated with surgery, whole brain radiation, focused beam radiation, medication (TKIs and immunotherapy) or a combination of these treatments. Although side effects due to an interaction between radiation and targeted therapy can be severe (e.g. radiation necrosis), there is a trend towards improved outcome. More data is needed and the IKCC has commissioned a study on patients treated with 'light' radiation and TKI or immunotherapy for brain metastases.

New treatments in the pipeline - what can we expect for 2020 and beyond

Speaker: Dr Eric Jonasch (USA)

Dr Jonasch continued with a summary of new treatments in development for RCC. Current treatments do not act on the cancer cells themselves, but on blood vessels and immune cells. There are many potential interactions between immune cells and cancer cells. Complete response rates of up to 9.4% are achievable with combinations of immunotherapies. The aim is for 50% complete response rate with new treatments and combinations, such as HIF2 alpha inhibitors, HERV-E (human endogenous retro virus) immunotherapy/vaccine, and implanted faecal immune-microbiome. Other areas of research include identification of biomarkers, liquid biopsies, and novel imaging to measure immune response.

World Kidney Cancer Day 2019: Raising awareness globally and locally

Moderator: Anne Wilson (AU)

Speaker: Paul Fishlock (AU)

Paul Fishlock launched WCKD 2019, which is planned for Thursday 20th June. The objectives for 2019 are to get everybody talking about kidney cancer - "Kidney Cancer - We need to talk." We need to raise awareness, encourage clinical trials, and discussion around kidney cancer. There is a new online quiz in 10 languages and a toolkit. Affiliates are to identify local ambassadors to kick-start and expand the campaign.

Global patient survey - key findings from survey of 2000 patients worldwide

Moderator: Anne Wilson (AU)

Speaker: Deb Maskens (CA)

Ms Maskens presented the findings from the largest kidney cancer survey that has ever been done. The survey enables affiliates to provide evidence-based advocacy and to understand more about patient experience worldwide, identify best practices, and provide global country-specific data to build programmes. The focus of the survey was patient knowledge and understanding, clinical trials, barriers to quality care, opportunities to improve care, and shared decision-making. Ms Maskens presented key findings from this year's survey, such as women and younger patients took longer to be diagnosed and at time of diagnosis only 21% of patients understood their treatment options. These data will be used for WKCD 2019 and country level plans.

Special announcement: The Cecile and Ken Youner IKCC Scholarship

Moderator: Dr Michael Jewett (CA)

This is an annual award in honour of Cecile and Ken Youner (founding member of IKCC) to a student who intends to practice medicine, hopefully specialising in kidney cancer, to come to this meeting to present their research. Dr Lewis Au, from The Royal Marsden Hospital and the Francis Crick Institute, London, UK, received the first award.

Liquid biopsy in renal cell carcinoma

Speaker: Dr Lewis Au (UK)

Dr Au presented his research on the development of a liquid biopsy for RCC using blood-based free DNA fragments, which are released during tumour cell death or shedding. Detection of tumour DNA fragments is difficult in RCC due to low cell free DNA levels, low shedding, and technological limitations. Plasma samples from 100 patients were collected throughout the TRACERx study and used to predict relapse for patients with high-risk stage 3 and 4 cancer. The evolution of cancer results in genetic complexity, which can in turn explain the behaviour of the cancer. A liquid biopsy will enable forecast of RCC disease progression and may change the way RCC is managed.

Opportunities for improving global access with biosimilars and generics

Panel: Deb Maskens (CA), Markus Wartenberg (DE), Dr Rachel Giles (NL)

The panel discussed what might happen when Sutent (sunitinib) and Avastin (bevacizumab) come off patent. Generics are legal and active copies of branded drug produced by a pharmaceutical company only after patent expiry. They have the same medical profile as original drug and therapeutic equivalence, but different shape, taste, and packaging, and are 60-70% cheaper. Generic sunitinib will become available later this year. Biosimilars are biologically derived products (vaccines, hormones, CAR-T cell) and are 20-30% cheaper than brand. They go through extensive regulatory checks, and only one cancer type needs to be tested. Bevacizumab has been approved for 6 cancers in combination with interferon alpha. Countries that currently don't have expensive biologics, might now be able to purchase them. The panel recommended informing patients about generics/biosimilars, and no switching to enable tracking of medication use and side effects.

Day 3

Capacity building 2

Unmet needs of long-term survivors (5+ years); adherence, psychosocial, late-term effects

Moderator: Berit Eberhardt (DE)

Speaker: Dr Sara J MacLennan (UK)

Dr MacLennan talked about the unmet needs of long-term cancer survivors, including the physical demands of treatment and side effects, information needs, support, psychological needs, quality of life etc. Patients need to adapt during/after treatment and deal with things such as pain related to surgery, changes in employment, fear of recurrence and dying, disease-related anxiety, fatigue etc. They need more knowledge about changes over time, confidence in other people, and personalised care plans for cancer survivorship. She suggested patient groups learn from other cancer groups of long-term survivors, use decision aids to maximise decision-making, and encourage support for financial issues, anxiety, and relationships.

Standards of excellence for patient organisations

Moderator: Markus Wartenberg (DE)

Panel: Lauren Pretorius (ZA) and Vandana Gupta (IN)

This panel discussion focused on the standards of excellence that are important for any organisation. Non-profit organisations work hard for patients/carers and need trust and support from stakeholders and the public. Standards of excellence are rules, regulations, recommendations, and directions that form organisational governance. The aim is to raise levels of accountability, transparency, effectiveness, and quality related to stages of organisational development. Standards need to be transparent/ethical, effective, high quality, maintain external relationships, sustainable, manage risk etc. Mr Wartenberg outlined the requirements for good standards of excellence in an organisation, including a strategic plan, corporate identity, data protection, insurance etc.

Ms Pretorius spoke about the characteristics embodied in governance, the elements of governance, financial accountability, policy, and basic good governance principles.

Ms Gupta spoke about the development of best practices in V-Care, which is now 25 years old with 70 volunteers, including working with doctors and pharmaceutical employees for patient information sheets and access to drugs, respectively.

Management of toxicities in the era of combination therapies, more toxic oral therapies, immune-related side effects

Moderator: Rose Woodward (UK)

Speakers: Robin Martinez (USA) and Dr Lewis Au (UK)

From her vast experience with cancer patients on Smart Patients, Ms Martinez gave the patient perspective on the management of toxicities to immunotherapy and combination therapy. She highlighted the most serious side effects seen with immunotherapies and best practices for the management of these side effects. She recommended that immune-related side effects should be reported immediately, and patients should wear a medical alert bracelet. Best practice is to be seen at the treating facility, if possible, and to double-check treatment information.

Dr Au gave the clinical perspective on the management of drug toxicities and mentioned that quality and length of life are the patient's main concerns. He spoke about the incidence of toxicities in clinical trials versus the real world and the unpredictable nature and longevity of immunotherapy and combination side effects. Education of healthcare professionals and access to specialist care is needed for the management of toxicities.

Levels of evidence: RCTs, RWE, guidelines, case studies, anecdotes and fake news

Moderator: Bernardo Carvalho (PT)

Speakers: Dr Lorenzo Marconi (PT) and Jan Geissler (DE)

Dr Marconi spoke about the different levels of evidence available to clinicians, in particular, evidence from randomised controlled trials, real world evidence, systematic reviews and guidelines. He mentioned that evidence alone is never sufficient to make the best clinical decisions, decisions must be consistent with the values and preferences of the patient, and involvement of patients in the development of guidelines is fundamental to their quality.

Mr Geissler spoke about the gold standard for clinical evidence being randomised controlled double-blind trials and compared this to pseudoscience and evidence available for complimentary/alternative medicines. He recommended that evidence-based advocacy needs to interpret existing evidence and identify pseudoscience. Patient groups need to advocate with trustworthy scientific evidence. Patients should be involved with the generation of new evidence and patient perspective included in trial design.

Closing remarks

Speakers: Dr Rachel Giles (NL) and Bernardo Carvalho (PT)

Dr Giles and Mr Carvalho thanked everyone for their active participation in the meeting, especially Julia Black for her organisational skills. Dr Giles then presented the first Special Award for Patient Organisations to Professor Xiao Nong Zou from the Cancer Foundation of China in recognition of their impressive work around World Kidney Cancer Day 2018. Finally, Dr Giles thanked Portugal for hosting this event and wished everyone a safe journey home.

Prepared by Dr Sharon Deveson Kell, freelance medical writer.