



## **WHAT ARE THE TOP TEN RESEARCH PRIORITIES IN KIDNEY CANCER?**

### **CITIZEN INVOLVEMENT IN KIDNEY CANCER RESEARCH PRIORITIZATION**

On February 5, 2015, a group of volunteers (survivors and caregivers) from Kidney Cancer Canada had the distinct privilege of participating in a unique and innovative process to help shape the future of kidney cancer research in Canada. This was a unique experience for us all — and truly innovative for setting research priorities according to real citizen/stakeholder input. As those most affected and most in need of research outcomes, we have found our way to the decision-making table thanks to the Kidney Cancer Research Network of Canada.

The process we followed was a methodology from the [James Lind Alliance](#) in the UK that seeks to put the patient/caregiver in the very centre of research prioritization – to ensure that researchers will focus on finding answers to questions that will make the most difference to people with kidney cancer. Our understanding is that this is the first time the JLA process has ever been used in cancer of any type.

#### **Background – The Survey**

Some of you will remember a survey that we asked patients/survivors/caregivers to complete. In total, 225 surveys were completed from 135 patients, 35 caregivers, and 60 healthcare professionals. The survey sought to identify areas of “uncertainty” in kidney cancer treatment or care. In total, 2004 uncertainties (potential projects) were identified. (Other surveys for other diseases had yielded a few hundred... this was certainly a flag that MUCH WORK needs to be done in kidney cancer!)

From this list a steering committee worked to group items and eliminate any for which research is already well established. From 2004 items, they reduced this list to 246 priorities, and then with input from others, down to 29. Our job on Friday Feb 5<sup>th</sup> was to examine the final 29 and agree upon the top 10. How hard could that be?



The group who met to battle it out included nurses, oncologists, survivors, caregivers and facilitators and observers from across Canada. We all came to the meeting having already ranked the top 29 ourselves, but were assured by facilitator Dr. Andreas Laupacis that “your top 10 will not be the final top 10” – this was to be an exercise in listening, respecting different perspectives, and

finding common ground.

Over the course of the day we worked to understand why some individuals and groups had ranked something very high while others had ranked the very same item so low. How were we interpreting the research area differently? Some items shifted a great deal as participants shared where they thought research was needed.

You’ll see from the list below that we ranked three items as equal Number One priorities – each of these items has a very compelling case for more research and so we felt no need to rank within that three. You might think of great research topics that aren’t listed here – chances are that they WERE in the top 29 – they were all great topics and we have ranked items from 11-29 to come back to.

### **What’s Next?**

The [Kidney Cancer Research Network of Canada](#) (KCRNC) will now be seeking research funding for specific projects that address the top 10. Together with the KCRNC, Kidney Cancer Canada is committed to supporting research in priority areas that are important to us all.

Here are the top 10 Priorities for Kidney Cancer Research. Please help us fund this important work ahead! All of our donations designated for Research go to

support these initiatives. Kidney Cancer Canada is pleased to issue a charitable receipt — we are for the patients, by the patients. To donate, click [here](#).

Thank you. Comments, feedback welcome as always!

Deb Maskens  
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### **TOP TEN RESEARCH UNCERTAINTIES IN KIDNEY CANCER**

- 1. What are the treatment options for patients with advanced non-clear cell renal cell carcinoma (kidney cancer)?**
- 1. Are there measurable, biological indicators (biomarkers) that can be used to predict the response to a treatment?**
- 1. Are there measurable, biological indicators (biomarkers) for the detection of kidney cancer?**
- 4. Can we develop better therapies that use the immune system to fight cancer (immunotherapies) including biomarkers, immune markers of patient, tumour characteristics and response?**
- 5. What indicators can be used to predict the development and progression of metastatic kidney cancer?**

- 6. How can psychological, emotional and social support be best given to patients and their families?**
  
- 7. Can decision making tools be developed that help both patients and healthcare providers to make treatment decisions in advanced/metastatic disease?**
  
- 8. What is the role and criteria for using biopsy in the management of kidney cancer?**
  
- 9. What is the impact of regional funding and access to treatment on outcomes of kidney cancer patients?**
  
- 10. What causes kidney cancer (including risk factors and dietary causes)?**