

# The Kidney Cancer Research Priority-Setting Partnership: Identifying the Top 10 Research Priorities as Defined by Patients, Caregivers, and Expert Clinicians

Jones et al. (2017)  
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## For which topic were research priorities identified?

kidney cancer

## In which location was the research priority setting conducted?

North America - Canada

## Why was it conducted at all?

It is critically important to define disease-specific research priorities to better allocate limited resources. There is growing recognition of the value of involving patients and caregivers, as well as expert clinicians in this process. To our knowledge, this has not been done this way for kidney cancer.

## What was the objective?

to have patients, caregivers, and expert clinicians identify unanswered questions encountered during management of kidney cancer, to agree by consensus on a prioritized list of the top 10 shared unanswered questions and to establish corresponding research priorities

## What was the outcome?

a ranking list of 10 research topics

## How long did the research prioritization take?

June 2014 - March 2015

## Which methods were used to identify research priorities?

JLA method

## How were the priorities for research identified exactly?

Step 1: setting up PS: formation of steering group. Step 2: identifying treatment questions: survey asking: What uncertainties have you faced about the overall management of kidney cancer? Think broadly. You can include uncertainties about diagnosis, prognosis (prediction of how things may develop in the disease), treatment, and anything else. You can include as many uncertainties as you like, 2004 treatment questions identified. Step 3: data processing: questions organized into 10 categories, out-of-scope removed, duplicates combined, resulting in 451 unique questions, check against evidence, resulting in 246 unique uncertainties. Step 4: interim ranking: list of 246 questions circulated to subsample of 10 participants and to steering group, participants were asked to rate each topic, to indicate their top-ranked 20 questions and to comment on wording, steering group then considered ratings and agreed on a shortlist of 29 questions that were taken forward. Step 5: final prioritization: workshop: before workshop participants provided with shortlist of 29 questions and asked to review and rank their own top 10, group discussions with nominal group technique and diamond nine ranking approach, small groups ranked the 29 questions, small groups ranking combined, plenary discussions, new small groups formed to agree on top 15 and top 10, plenary discussion

## Which stakeholders took part?

Patients, caregivers, clinicians. Survey: 255 participants: 135 (59%) patients, including those who had been treated for kidney cancer in the past (n=98), those who were currently on treatment (n=34), and those who were recently diagnosed and currently waiting for surgical treatment (n=4), 60 (27%) clinicians, including urologists (n=25), nurses (n=18), and medical oncologists (n=7), 35 (14%) family caregivers. Interim ranking: subsample of 10 participants and 15-member steering group. Workshop: 23 participants: 10 patients, 2 caregivers, 7 physicians, 2 nurses, 1 psychologist, 1 dietitian plus three facilitators.

## How were stakeholders recruited?

The survey was distributed electronically between September and November 2014. Also, a paper-based survey was distributed. The survey was advertised through the KCC and the KFofC websites and newsletters in both official languages and through social media channels and also distributed by e-blasts to the members of various clinical associations, including the Canadian Urological Association (CUA), Genitourinary Medical Oncologists of Canada (GUMOC), Canadian Association of Nurses in Oncology (CANO), and the Urology Nurses of Canada (UNC).

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Stakeholders not only participated but were also actively involved in the research prioritization process: They were part of a steering group. The steering group consisted of 15 members: 7 patients/caregivers, 7 expert clinicians from across Canada and 1 JLA adviser. The members defined the scope of partnership, developed the protocol, identified potential partners and stakeholders and had oversight of the whole process. The members met at least monthly in