

# Kidney Cancer Survivorship Survey

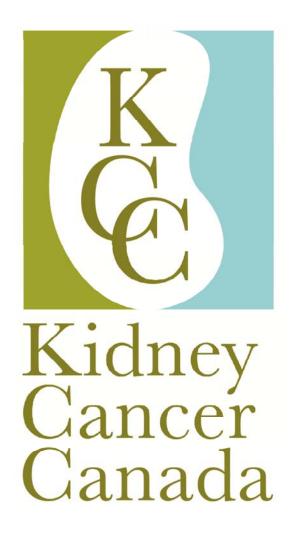
Research demonstrates a disconnect when it comes to early-stage kidney cancer survivorship planning.

Results Summary March 12, 2012



#### Agenda

- Survey Rationale
  - why focus on early stage patients?
- 2. Survey Methodology
  - patients/caregivers and urologists
- 3. Key Findings
- 4. Next Steps



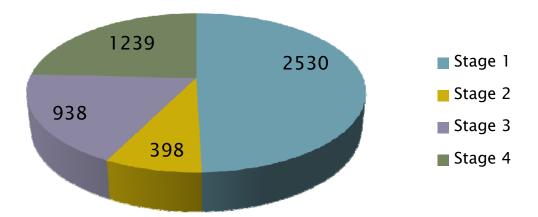
# Survey Rationale



## Why focus on early stage rcc?

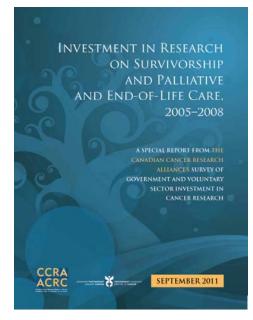
- Approximately 75 per cent of kidney cancer patients in Canada are diagnosed at one of the first three (of four) stages of the disease.
- Some patients will recur with stage four metastatic disease the most serious form; others will face separate health challenges as a result of kidney cancer surgery.

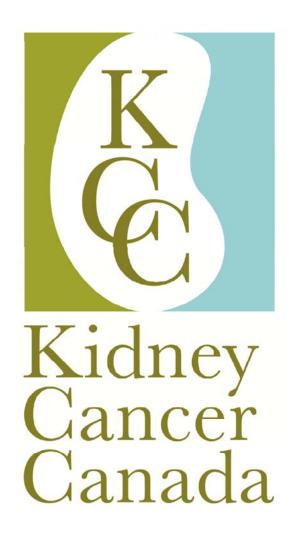
### Estimated Numbers of New Kidney Cancer Patients in Canada by Stage



#### Survey Rationale

- To shed more light on early-stage kidney cancer survivorship. Empower patients and caregivers with information.
- To gain a better understanding of what survivorship information urologists are currently delivering -- and what patients remember hearing.
- To address a gap in survivorship research. A recent Canadian Cancer Research Alliance report demonstrated there has been no investment in survivorship projects related to kidney cancer in Canada.





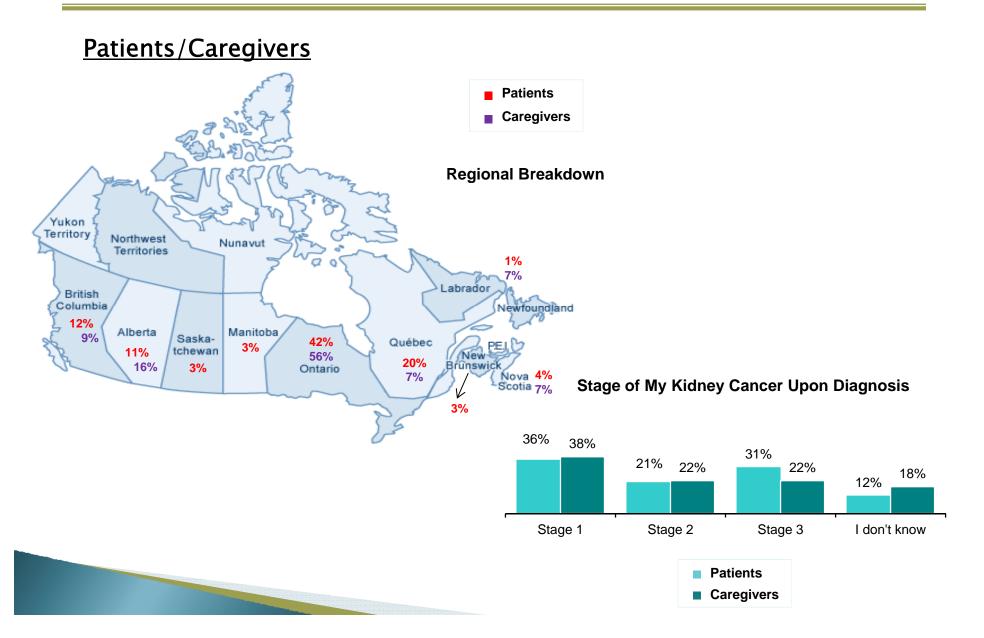
# Survey Methodology



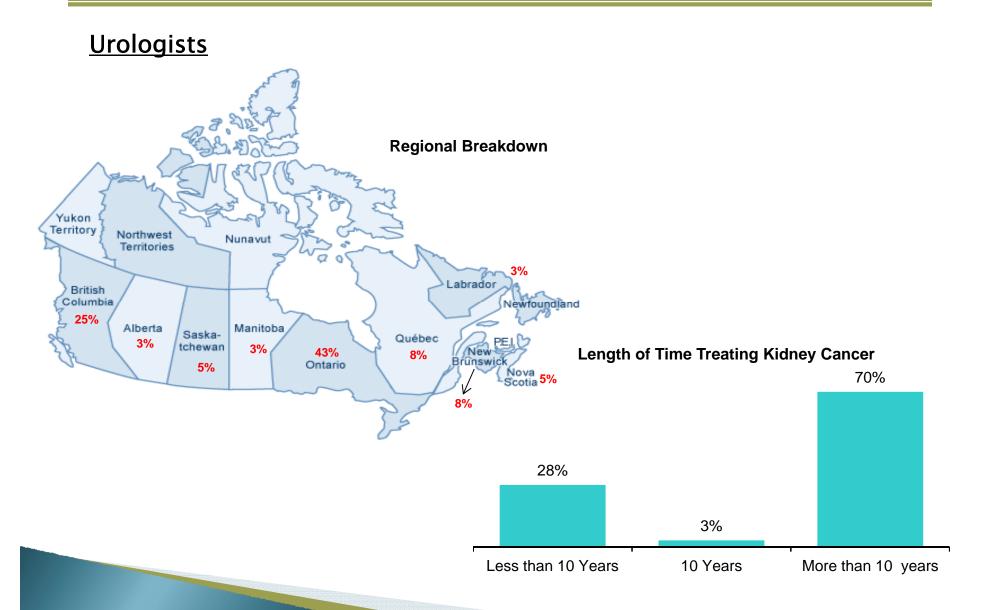
## Survey Methodology

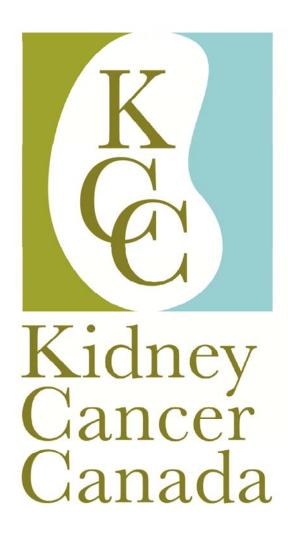
- The survey was commissioned by Kidney Cancer Canada, with arms-length funding from Pfizer Inc., and conducted by Leger Marketing.
- Between November 17, 2011 and December 8, 2011, the survey was completed online with 276 patients and 45 caregivers of kidney cancer patients that have/had been diagnosed at stages one through three. (n=321)
- ▶ 40 urologists were surveyed online from November 17, 2011 to November 24, 2011. (n=40)

#### Respondent Profile



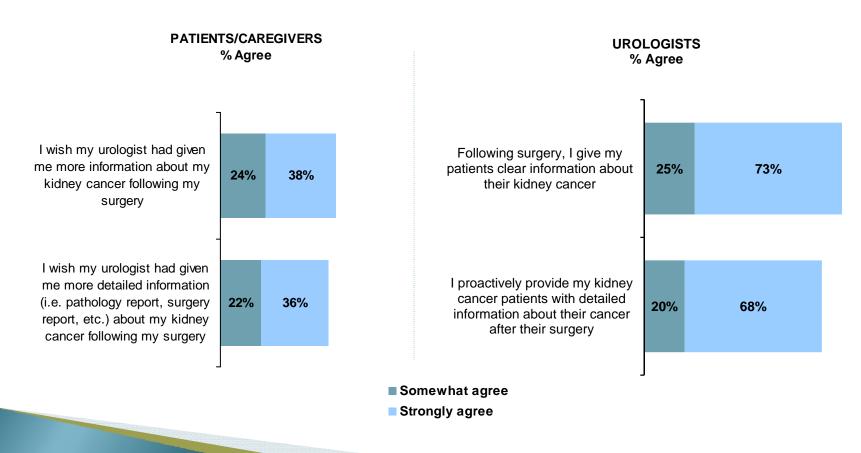
# Respondent Profile



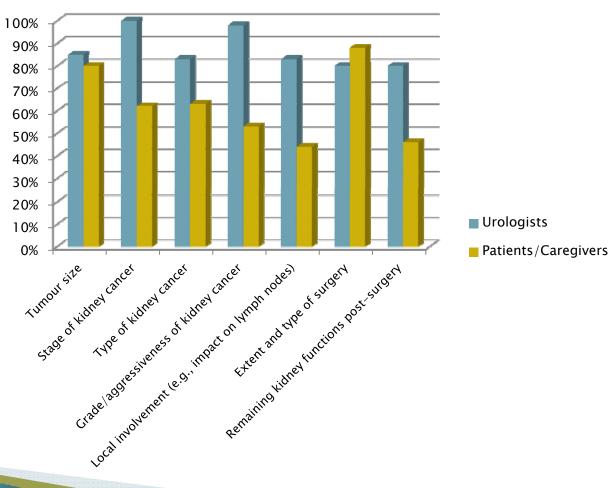




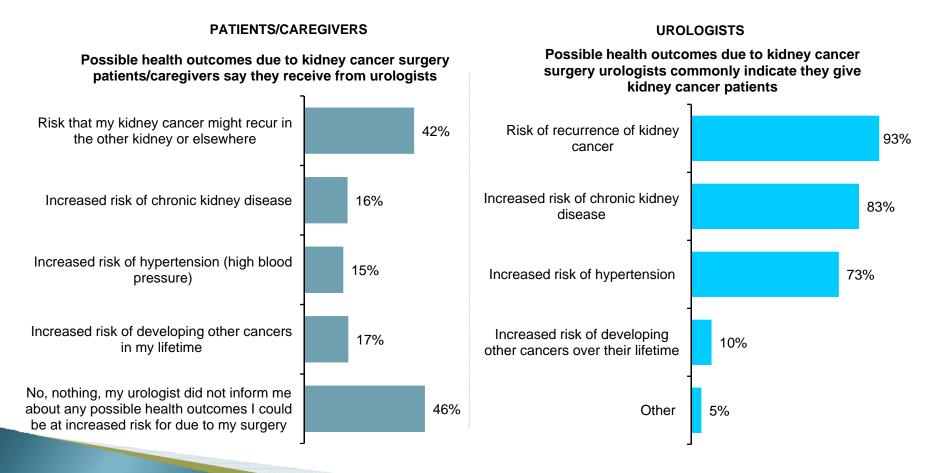
- Most urologists indicate they provide their patients with detailed and clear information about their kidney cancer following surgery
- Patients/caregivers wish their urologist gave them more detailed information (i.e. pathology report, surgery report etc.).



 Urologists and kidney cancer patients/caregivers do not agree on what cancer details and survivorship information are given postsurgery.



There is also a disconnect between urologists and kidney cancer patients/caregivers regarding information given about possible health outcomes due to kidney cancer surgery.

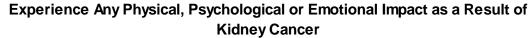


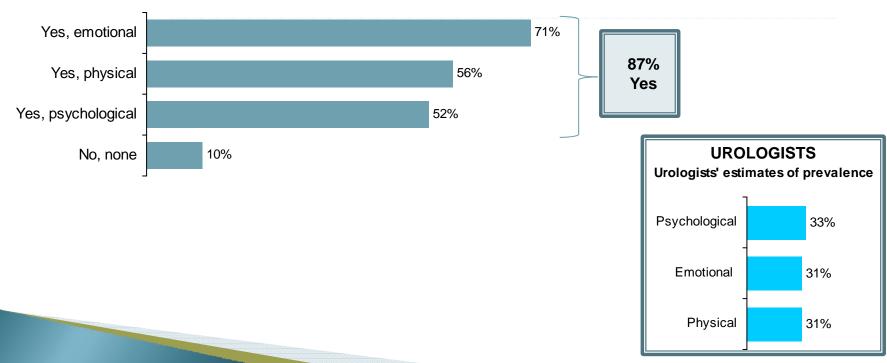
Most urologists and kidney cancer patients/caregivers that indicate they were informed of possible health outcomes admit they did not provide/receive any information in written format.

Possible Health Outcomes Indicated Given In Written Format Post-Surgery	Patients/Caregivers	Urologists
Risk that my kidney cancer might recur in the other kidney or elsewhere	17%	20%
Increased risk of hypertension (high blood pressure)	7%	15%
Increased risk of chronic kidney disease	4%	15%
Increased risk of developing other cancers in my lifetime	7%	
Other	3%	3%
Nothing, my urologist did not provide any of the above information to me in written format	68%	73%

The majority of patients/caregivers admitted to the patient dealing with emotional, physical, and psychological impacts as a result of their experience with kidney cancer. Interestingly, urologists may be underestimating the prevalence of these issues among patients.

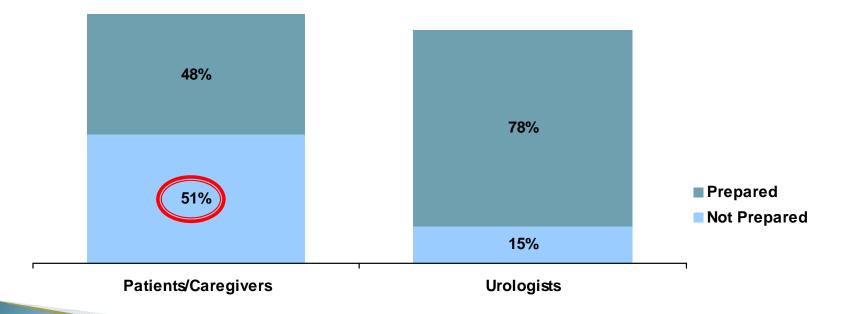
#### PATIENTS/CAREGIVERS



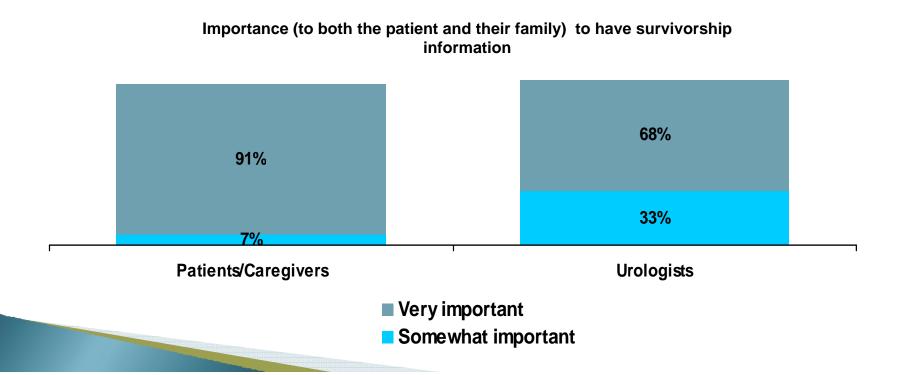


- Half of those affected by kidney cancer say they were not prepared after their surgery/treatment to recognize or deal with any physical, psychological or emotional concerns.
- However, most urologists believe their patients feel prepared postsurgery to recognize or deal with these concerns.

Level of Prepardness Post-Surgery/Treatment to Recoginze or Deal With Any Physical, Psychological or Emotional Concerns

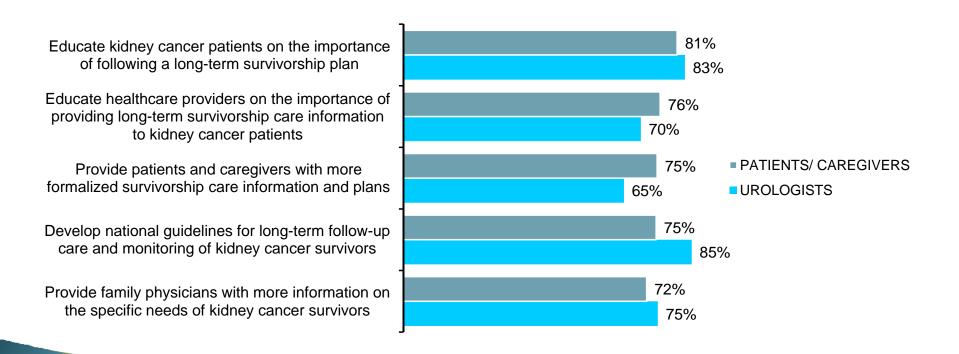


- Virtually all patients/caregivers and urologists agree it is important for those impacted by kidney cancer to receive survivorship information such as:
  - Medications to avoid
  - Specific lifestyle habits to adopt
  - Ways to manage on reduced kidney function



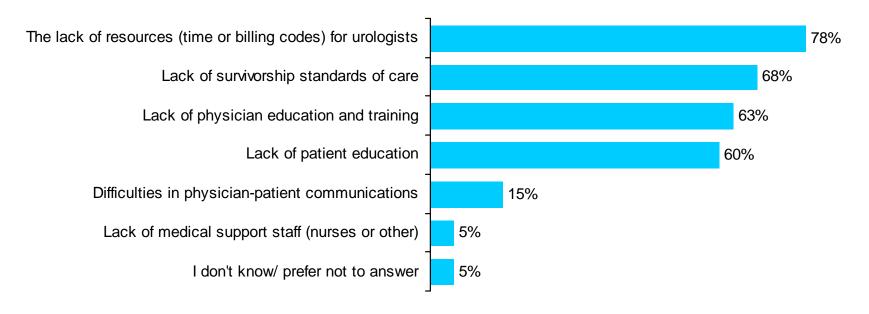
Most kidney cancer patients/caregivers and urologists believe all of the actions below need to happen to ensure optimal survivorship care for kidney cancer patients.

#### **Ensuring Optimal Long Term Survivorship for Kidney Cancer Patients**



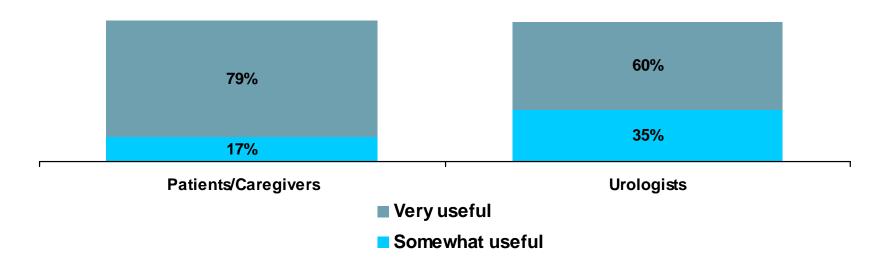
While it is agreed survivorship information is important and that there is a role for urologists to play in educating the patient, urologists identify a number of barriers to providing optimal survivorship care.

#### **Urologists Thoughts On the Barriers To Optimal Survivorship Care**



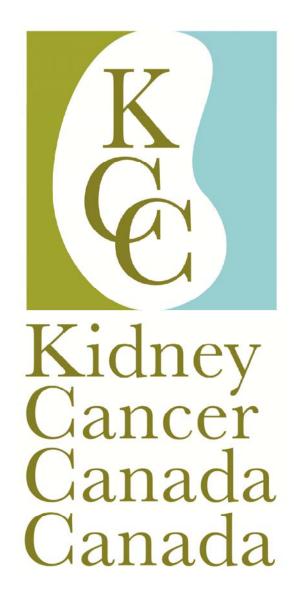
- Kidney cancer patients/caregivers and urologists agree a medicallyendorsed survivorship website would be useful.
- Such a website would allow patients to input information about their kidney cancer treatment and outcomes, and then automatically receive an individualized survivorship care plan.

Usefulness of a Medically Endorsed Website Where Patients Can Automatically Receive an Individualized Survivorship Care Plan



#### Next Steps

- March Campaign for National Kidney Month
  - Media Campaign to raise public awareness across Canada
- Reach to urologists:
  - Poster abstract accepted for CUA (Canadian Urology Association)
    Conference in June 2012
  - Poster abstract submitted to UNC (Urology Nurses of Canada) Sept 2012
  - Journal publication planned for CUAJ
  - Other conference opportunities TBD
- Development of Kidney Cancer Survivorship Care Plans
  - In conjunction with Kidney Cancer Research Network of Canada
  - Ideally a global project with international reach.



# Questions?

Thank you / Merci.

