Real World Evidence for decision-making in the Canadian Context
How patients can play a constructive role in working with other stakeholders

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Disclosure

• I have no actual or potential conflict of interest in relation to this topic or presentation
The CAPCA Drug Funding Sustainability Initiative, through the Cancer Drug Implementation Advisory Committee (CDIAC) has the mandate to address 4 “opportunities” to strengthen the pan-Canadian Oncology Drug System.
Cancer Drug Implementation Advisory Committee (CDIAC)

• Seek clinical expert opinion about conditions/criteria for funding
• Considers affordability and budget impact
• Looks at trade-offs and choices between and among therapeutic options to inform implementation

Where is Real World Evidence?
CAPCA consultation re: Drug Funding Sustainability Initiative

A question that was highlighted by CAPCA about RWE was:

*Are the provincial and federal governments prepared to invest in the resources required for data collection and data sharing infrastructure?*
Case Study:
Canadian Kidney Cancer information system (CKCis)

- A web-based national registry supporting the development of clinical and basic research in kidney cancer across Canada.
- Contains retrospective and prospective de-identified patient data collected from consented patients.
- 15 Cdn centres actively accrue patients capturing over 80% of Cdn patients.
- Flexible database platform that can integrate different data needs
- Information input into CKCis is used to carry out many research studies.
Canadian Kidney Cancer information system (CKCis)

• Supported by Kidney Cancer Canada, CKCis has now been in operation for about 6 years with 8000+ patients enrolled and their data being collected.

• CKCis is now central to the activities of the Kidney Cancer Research Network of Canada (KCRNC).

• The data has matured enough to inform the publication of many manuscripts and, recently, was used to provide RWE to inform reimbursement decision-making.
pCORDER Provincial Advisory Group: Request for Advice

PAG submitted in April 2017 a RFA for the Final Recommendation of axitinib which was originally posted on March 2013

*Is there evidence to fund axitinib as an alternative to everolimus for the second-line treatment of metastatic clear cell renal carcinoma?*

Kidney Cancer Canada was invited to provide input on the RFA. We requested that CKCis investigators make as a research priority the RFA question.
Analysis/Results

• CKCis identified a study cohort of patients who were pretreated with either sunitinib or pazopanib.

• Axitinib was given second line in 108 patients while everolimus was used in 229 patients.

• Time to treatment failure (TTF) was found to be longer in the axitinib group while Overall Survival (OS) was similar in both groups.
Conclusion of CKCis Investigators: “Axitinib should be considered an option for all patients in Canada post 1stL VEGF-Targeted Therapy without the limitations of the existing pCODR recommendation”.

pCODR Clinical Guidance Panel Conclusions: “The Clinical Guidance Panel is of the opinion that there is appropriate real world evidence and expert judgment to justify axitinib as an equal alternative to everolimus in the second line setting.”
In the Absence of a National Framework, or Provincial or Federal Funding....... 

Many patient groups and clinician networks are building patient registries:

• Bladder Cancer Canada has partnered with clinicians to build the **Canadian Bladder Cancer Information System** (CBCIS)

• Myeloma Canada and the Myeloma Canada Research Network are building the **Canadian Multiple Myeloma Database**

• The Brain Tumour Foundation of Canada is fundraising and building the **Canadian Brain Tumour Registry**

• Lung Cancer Canada is in the early stages of planning a Canadian Lung Cancer Registry.
Beyond the DIY approach, what more can patients do?

- Need to advocate for provincial and federal governments to invest in the resources required for data collection and data sharing infrastructure.

- Need to push for pilot projects to investigate an *Adaptive Pathways* approach where conditional approval is granted based on early data with evidence collection through real-life use.