

## Appendix: Cancer Survivorship Survey for GU Cancer Specialists in Canada (Survey questions)

### Cancer Survivorship Survey for GU Cancer Specialists in Canada

Survivorship is of key and timely importance as the number of cancer survivors increases and individuals move beyond their initial diagnosis and seek improved quality of life. The total number of GU cancer survivors exceeds that of any other cancer group and includes all age groups. In an attempt to better understand how we approach key survivorship issues in this population, our group of uro-, medical and radiation oncologists at the University of Toronto and Princess Margaret Hospital have developed this short survey. We intend to publish and present the results at national speciality meetings in the near future.

#### Do you treat genitourinary (GU) cancers?

Please note, that in order to be eligible to complete this survey, you must treat GU cancers. If you do not treat GU cancers you will be directed out of the survey.

|                          |     |
|--------------------------|-----|
| <input type="checkbox"/> | Yes |
| <input type="checkbox"/> | No  |

#### DEMOGRAPHIC INFORMATION

##### What is your specialty?

|                          |                    |
|--------------------------|--------------------|
| <input type="checkbox"/> | Medical Oncology   |
| <input type="checkbox"/> | Urology            |
| <input type="checkbox"/> | Radiation Oncology |

##### How long have you been treating GU cancers, in years?

|                          |                                     |
|--------------------------|-------------------------------------|
| <input type="checkbox"/> | 1                                   |
| <input type="checkbox"/> | 2                                   |
| <input type="checkbox"/> | 3                                   |
| <input type="checkbox"/> | 4                                   |
| <input type="checkbox"/> | 5                                   |
| <input type="checkbox"/> | 6                                   |
| <input type="checkbox"/> | 7                                   |
| <input type="checkbox"/> | 8                                   |
| <input type="checkbox"/> | 9                                   |
| <input type="checkbox"/> | 10                                  |
| <input type="checkbox"/> | ... 9 additional choices hidden ... |
| <input type="checkbox"/> | 21                                  |
| <input type="checkbox"/> | 22                                  |
| <input type="checkbox"/> | 23                                  |
| <input type="checkbox"/> | 24                                  |
| <input type="checkbox"/> | 25                                  |
| <input type="checkbox"/> | 26                                  |
| <input type="checkbox"/> | 27                                  |
| <input type="checkbox"/> | 28                                  |
| <input type="checkbox"/> | 29                                  |
| <input type="checkbox"/> | 30 or more                          |

##### Did you have special training in GU oncology?

|                          |     |
|--------------------------|-----|
| <input type="checkbox"/> | Yes |
| <input type="checkbox"/> | No  |

##### Where is your practice based?

|                          |                                |
|--------------------------|--------------------------------|
| <input type="checkbox"/> | Community hospital             |
| <input type="checkbox"/> | University affiliated hospital |
| <input type="checkbox"/> | Both                           |
| <input type="checkbox"/> | Neither                        |

##### Are you affiliated with a provincial cancer centre program?

|                          |     |
|--------------------------|-----|
| <input type="checkbox"/> | Yes |
| <input type="checkbox"/> | No  |

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In what province do you practice?

|                          |                         |
|--------------------------|-------------------------|
| <input type="checkbox"/> | Alberta                 |
| <input type="checkbox"/> | British Columbia        |
| <input type="checkbox"/> | Manitoba                |
| <input type="checkbox"/> | New Brunswick           |
| <input type="checkbox"/> | Newfoundland & Labrador |
| <input type="checkbox"/> | Northwest Territories   |
| <input type="checkbox"/> | Nova Scotia             |
| <input type="checkbox"/> | Nunavut                 |
| <input type="checkbox"/> | Ontario                 |
| <input type="checkbox"/> | Prince Edward Island    |
| <input type="checkbox"/> | Quebec                  |
| <input type="checkbox"/> | Saskatchewan            |
| <input type="checkbox"/> | Yukon                   |

Have you attended a course, conference and/or a workshop on survivorship in cancer care?

|                          |     |
|--------------------------|-----|
| <input type="checkbox"/> | Yes |
| <input type="checkbox"/> | No  |

### POST TREATMENT CARE PRACTICES

Which best describes your approach to post treatment follow up care of your patients with GU cancer?

|                          |                                                                                    |
|--------------------------|------------------------------------------------------------------------------------|
| <input type="checkbox"/> | Continue specialist follow up care indefinitely EXCLUDING the general practitioner |
| <input type="checkbox"/> | Share follow up care with the primary care practitioner indefinitely               |
| <input type="checkbox"/> | Discharge follow up care at some point to the primary care practitioner            |
| <input type="checkbox"/> | Discharge follow up care at some point to a nurse practitioner                     |
| <input type="checkbox"/> | Discharge to survivorship program (e.g. After Cancer Treatment Transition clinic)  |
| <input type="checkbox"/> | None of the above, please specify: _____                                           |

If you share follow up with the primary care practitioner, do you provide a written plan guiding follow up practices?

|                          |           |
|--------------------------|-----------|
| <input type="checkbox"/> | Never     |
| <input type="checkbox"/> | Rarely    |
| <input type="checkbox"/> | Sometimes |
| <input type="checkbox"/> | Often     |
| <input type="checkbox"/> | Always    |

If you provide a written plan, what components do you include?

Select all that apply.

|                          |                                                                                           |
|--------------------------|-------------------------------------------------------------------------------------------|
| <input type="checkbox"/> | Summary of cancer status including diagnosis and stage                                    |
| <input type="checkbox"/> | Summary of treatment given including toxicities experienced                               |
| <input type="checkbox"/> | Expected persistent and late effects of therapy                                           |
| <input type="checkbox"/> | Surveillance guidelines for identifying recurrent disease/2nd primary and/or late effects |
| <input type="checkbox"/> | Lifestyle recommendations                                                                 |

### SURVIVORSHIP CARE IMPLEMENTATION

Please rate to what extent the following items pose a barrier to meeting the post treatment care (survivorship) needs of your GU cancer patients (survivors).

**Lack of physician knowledge of cancer survivorship issues and recommended surveillance practices.**

|                          |                     |
|--------------------------|---------------------|
| <input type="checkbox"/> | Never a barrier     |
| <input type="checkbox"/> | Rarely a barrier    |
| <input type="checkbox"/> | Sometimes a barrier |
| <input type="checkbox"/> | Often a barrier     |
| <input type="checkbox"/> | Always a barrier    |

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### Lack of patient engagement or adherence to recommendations

|                          |                     |
|--------------------------|---------------------|
| <input type="checkbox"/> | Never a barrier     |
| <input type="checkbox"/> | Rarely a barrier    |
| <input type="checkbox"/> | Sometimes a barrier |
| <input type="checkbox"/> | Often a barrier     |
| <input type="checkbox"/> | Always a barrier    |

Below is a list of services that should be offered to cancer survivors. Please indicate how accessible these services are to patients in your practice.

### Information and education about potential late effects due to cancer treatment for patients

|                          |                          |
|--------------------------|--------------------------|
| <input type="checkbox"/> | Very accessible          |
| <input type="checkbox"/> | Accessible               |
| <input type="checkbox"/> | Moderately accessible    |
| <input type="checkbox"/> | Difficult to access      |
| <input type="checkbox"/> | Very difficult to access |

### Opportunities to interact with other survivors

|                          |                          |
|--------------------------|--------------------------|
| <input type="checkbox"/> | Very accessible          |
| <input type="checkbox"/> | Accessible               |
| <input type="checkbox"/> | Moderately accessible    |
| <input type="checkbox"/> | Difficult to access      |
| <input type="checkbox"/> | Very difficult to access |

### Psychosocial support

|                          |                          |
|--------------------------|--------------------------|
| <input type="checkbox"/> | Very accessible          |
| <input type="checkbox"/> | Accessible               |
| <input type="checkbox"/> | Moderately accessible    |
| <input type="checkbox"/> | Difficult to access      |
| <input type="checkbox"/> | Very difficult to access |

### Pain and symptom management programs

|                          |                          |
|--------------------------|--------------------------|
| <input type="checkbox"/> | Very accessible          |
| <input type="checkbox"/> | Accessible               |
| <input type="checkbox"/> | Moderately accessible    |
| <input type="checkbox"/> | Difficult to access      |
| <input type="checkbox"/> | Very difficult to access |

### Access to cancer rehabilitation programs

|                          |                          |
|--------------------------|--------------------------|
| <input type="checkbox"/> | Very accessible          |
| <input type="checkbox"/> | Accessible               |
| <input type="checkbox"/> | Moderately accessible    |
| <input type="checkbox"/> | Difficult to access      |
| <input type="checkbox"/> | Very difficult to access |

### Fertility counselling and resources

|                          |                          |
|--------------------------|--------------------------|
| <input type="checkbox"/> | Very accessible          |
| <input type="checkbox"/> | Accessible               |
| <input type="checkbox"/> | Moderately accessible    |
| <input type="checkbox"/> | Difficult to access      |
| <input type="checkbox"/> | Very difficult to access |

### Genetic counselling

|                          |                          |
|--------------------------|--------------------------|
| <input type="checkbox"/> | Very accessible          |
| <input type="checkbox"/> | Accessible               |
| <input type="checkbox"/> | Moderately accessible    |
| <input type="checkbox"/> | Difficult to access      |
| <input type="checkbox"/> | Very difficult to access |

**Appendix: Cancer Survivorship Survey for GU Cancer Specialists in Canada (Survey questions) (cont'd)****PERSPECTIVES ON PATIENT ADVOCACY GROUPS**

How often do you refer patients to the GU patient advocacy groups listed below?

**Bladder Cancer Canada**

|                          |           |
|--------------------------|-----------|
| <input type="checkbox"/> | Never     |
| <input type="checkbox"/> | Seldom    |
| <input type="checkbox"/> | Sometimes |
| <input type="checkbox"/> | Often     |
| <input type="checkbox"/> | Always    |

**Kidney Cancer Canada**

|                          |           |
|--------------------------|-----------|
| <input type="checkbox"/> | Never     |
| <input type="checkbox"/> | Seldom    |
| <input type="checkbox"/> | Sometimes |
| <input type="checkbox"/> | Often     |
| <input type="checkbox"/> | Always    |

**Prostate Cancer Canada**

|                          |           |
|--------------------------|-----------|
| <input type="checkbox"/> | Never     |
| <input type="checkbox"/> | Seldom    |
| <input type="checkbox"/> | Sometimes |
| <input type="checkbox"/> | Often     |
| <input type="checkbox"/> | Always    |

**Canadian Testicular Cancer Association**

|                          |           |
|--------------------------|-----------|
| <input type="checkbox"/> | Never     |
| <input type="checkbox"/> | Seldom    |
| <input type="checkbox"/> | Sometimes |
| <input type="checkbox"/> | Often     |
| <input type="checkbox"/> | Always    |

**In January 2011, a group of GU clinicians and advocacy groups met to explore ways to collaboratively enhance survivorship care. The list below is what has been proposed as initiatives by the group. Select the three initiatives that you believe are the most important.**

|                          |                                                                                                                                   |
|--------------------------|-----------------------------------------------------------------------------------------------------------------------------------|
| <input type="checkbox"/> | A pamphlet that describes all relevant cancer groups, community supports.                                                         |
| <input type="checkbox"/> | A website that describes all relevant cancer advocacy groups, community supports and their services.                              |
| <input type="checkbox"/> | Learning opportunities to educate health care professionals on the function and credibility of patient advocacy groups.           |
| <input type="checkbox"/> | Regular networking opportunities for patient advocacy groups to interact with health care professionals (ie. annual meeting).     |
| <input type="checkbox"/> | Involvement of patient advocacy groups in the planning and conduct of survivorship research (including clinical trials)           |
| <input type="checkbox"/> | Learning opportunities to provide advocacy groups with skills to effectively collaborate with health care professionals.          |
| <input type="checkbox"/> | A council of representatives from each site-specific advocacy group including the national cancer agencies.                       |
| <input type="checkbox"/> | A communications office to facilitate communication and knowledge exchange between advocacy groups and health care professionals. |