

## Background

As cancer treatment becomes more personalized and the use of immunotherapy continues to expand, it is important that patients and family caregivers have access to cutting edge educational and self-care management tools, as well as highly accessible community resources to make informed decisions, reduce cancer-related distress, and get optimal benefit across the continuum of care.

## Purpose

To understand the unique challenges faced by patients undergoing immunotherapy, their caregivers, and the clinical staff who care for them. To ultimately inform the development of a new patient education and empowerment program that will transform the patient experience with immunotherapy.

## Survey Methods

In Spring 2017, the Cancer Support Community (CSC) conducted three needs assessments of patients, caregivers, and health care providers (e.g. oncologists, nurses, social workers) that focused on exploring experiences related to immunotherapy treatment.

The surveys were taken online and on paper at nine oncology practices across the country, between June and October of 2017. The sample was comprised of 122 health care providers (HCPs), 95 patients undergoing immunotherapy treatment, and 45 caregivers.

## Participants

PATIENTS (n=95) AND CAREGIVERS (n=45)		
Age	PATIENTS	CAREGIVERS
Mean Age	67.4	59.5
Gender		
Female	37.6%	79.5%
Race		
White	84.9%	84.6%
Education		
College Degree or Higher	25.0%	17.9%
Employment		
Retired	50.5%	33.3%
Not employed/ Disability/Other	23.7%	15.4%
Full Time	25.8%	51.3%

HEALTHCARE PROFESSIONALS (n=115)	
Professional Role	
Nurse	53.0%
Oncologist	15.7%
Navigator	5.2%
Nurse Practitioner	8.1%
Physician	4.3%
Other*	13.9%
Gender (n=111)	
Female	78.4%
Do you provide care for patients receiving immunotherapy?	
Yes	84.8%

(\* Health care professionals who responded 'other' include patient representatives, lab technicians, and administration personnel.

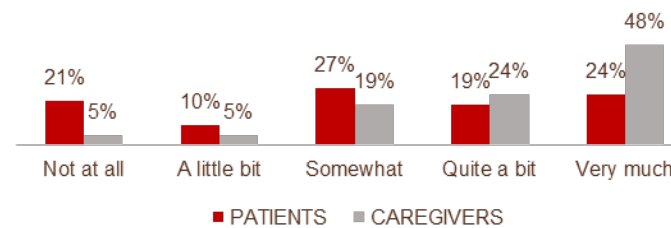
## Results

### Needs of Respondents

- Most patients (52.4%), and nearly 40% (39.3%) of caregivers, reported that understanding how immunotherapy works and managing treatment-related side effects were 'quite a bit' or 'very much' of a problem during immunotherapy treatment.
- Among HCPs, about 40% indicated that understanding how immunotherapy works and managing treatment-related symptoms and side effects are 'quite a bit' challenging for their patients receiving immunotherapy treatment. Also, nearly half (48.7%) of HCPs stated that finding support with issues related to cancer care was also 'quite a bit' challenging for their patients.
- Compared to patients, caregivers reported greater difficulty finding information about immunotherapy (20% vs 25%) as well as managing immunotherapy treatment-related side effects (50% vs 73%).

### Knowledge and Information-Seeking

#### How important is it for you to understand or learn more about immunotherapy?



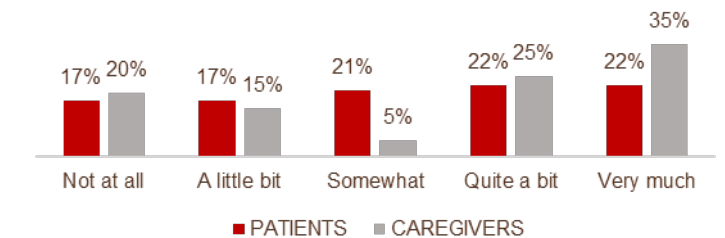
- More than 40% (42.9%) of patients and 70% (71.9%) of caregivers reported that learning about immunotherapy treatment was 'quite a bit' or 'very much' important to them.
- At the same time, 85% of caregivers and 55% of patients stated that understanding how to cope with immunotherapy symptoms and side effects was 'quite a bit' or 'very much' important for them.
- Most (95%) HCPs indicated that it is 'quite a bit' or 'very much' important for patients to understand immunotherapy treatment, how to cope with immunotherapy symptoms and side effects, as well as routine health and wellness management while on immunotherapy treatment.

## Conclusions and Next Steps

These results underscore the importance of developing turnkey resources to help patients and HCPs manage immunotherapy-related side effects, and to empower patients to engage actively in their care. CSC's needs assessments indicate that for both patients and HCPs, treatment-related side effects are top-of-mind. These results have informed the development and implementation of an innovative companion program, *Immunotherapy & Me*, that provides critical care coordination and communication tools to support patients, caregivers, and HCPs. Through this multi-faceted initiative and *Frankly Speaking about Cancer* Immunotherapy programs, CSC strives to impact patient awareness, behavior and attitudes, to ensure that they have the proper tools to actively participate in managing symptoms and side effects to reduce distress across the care continuum.

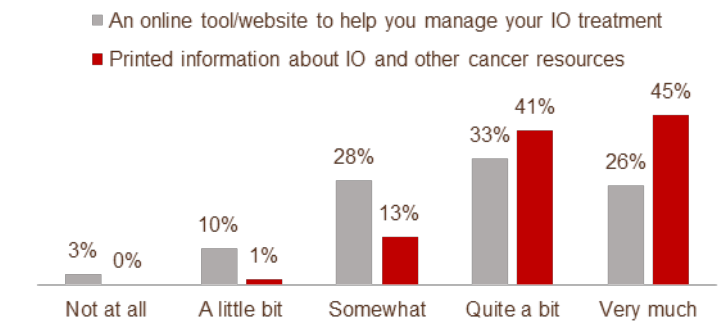
### Resources and Support

#### How helpful would an online tool/website to manage your IO treatment be to you?



- 60% of caregivers and nearly 45% (44%) of patients stated that an online tool/website to manage their immunotherapy (IO) treatment would be 'quite a bit' or 'very much' helpful to them.
- Nearly 30% (29.8%) of patients and 50% (48.2%) of caregivers reported that they would be willing to use an online tool to help manage their, or their loved one's, immunotherapy treatment on a 'weekly' basis.

#### How likely you are to refer your patients to the following resources:



- Almost 90% (86%) of HCPs reported that they were 'quite a bit' or 'very much' likely to refer patients to immunotherapy and cancer-related print materials.
- Nearly 60% (59.3%) stated that they were 'quite a bit' or 'very much' likely to refer their patients to an online tool to help manage their immunotherapy treatment.
- Overall, about 80% (77%) of HCPs rated educational information as 'quite a bit' or 'very much' helpful resources for their patients.

## Acknowledgements:

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[www.cancersupportcommunity.org](http://www.cancersupportcommunity.org)