

# Innovation in Developing Evidence-Based Programs that Identify and Address the Social and Emotional Needs of Cancer Caregivers: Examples of Community-Initiated Research

Buzaglo, J.S.<sup>1</sup>, Kennedy, V.<sup>1</sup>, Longacre, M.<sup>1</sup>, Miller, M.<sup>1</sup>, Taylor, J.<sup>1</sup>, Golant, M<sup>1</sup>.

<sup>1</sup>Cancer Support Community, Philadelphia, PA,



### Background

Patient-powered research networks are informing care for patients in cancer. These networks too often lack a vital voice in patient care – family caregivers. Caregiver-powered networks hold similar potential to improve care for patients but also for the caregivers, or "hidden patients," themselves.

#### Methods

Informed by literature showing that distress is common among caregivers and can negatively impact physical health,<sup>1</sup> the Cancer Support Community (CSC) has developed two methods for accessing caregiver-reported needs and stressors. These include:

- 1) Cancer Experience Registry: Caregivers
- 2) CancerSupportSource-Caregivers

The purpose of this poster is to report on the process of developing both initiatives that involved the active, and ongoing, participation of caregivers and other stakeholders within the caregiving field.

1. Bevans, M & Sternberg, EM. (2014). Caregiving burden, stress, and health effects among family caregivers of adult cancer patients, JAMA, 307(4):398-403.

## CancerSupportSource-Caregivers (CSS-Caregivers)

The goal of CSS-Caregivers is to provide caregivers for persons with cancer a distress screening and referral program. Development of CSS-Caregivers to date has included:

Conducting focus groups with caregivers to identify the specific distress-related concerns and needs so to develop CSS-Caregivers.



Conducting cognitive interviews with caregivers to assess the CSS-Caregivers version developed from the focus group sessions.



Coordinating with CSC affiliates across the U.S to validate CSS-Caregivers among 300 caregivers by October, 2015.

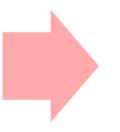
#### Cancer Experience Registry: Caregivers

In 2014, CSC launched Cancer Experience Registry: Caregivers, an online initiative to capture the social and emotional experiences of individuals providing care and support to a person with cancer at any stage of the journey. Caregivers respond to survey questions about the experience of caregiving, including topics such as physical and emotional health, caregiving roles, and the direct and indirect costs of caregiving. These collective findings will drive future programming and policy efforts to benefit caregivers. Caregivers are currently being enrolled in the Registry. Development stages have included:

Assembling a National Advisory Council of diverse experts in caregiving, including caregivers.



Developing cancer caregiving-specific priority areas and survey questions based on feedback from advisors.



Ongoing recruitment via outreach to caregivers through CSC's network and advocacy partners.

### **Preliminary Findings from Registry**

- 76% female (n=45)
- 61% care for a spouse; 24% care for a parent (n=33)
- Caregivers report high levels of distress on the Distress Thermometer (0; not at all -10; extreme distress) (n=35):
  - 40% reported scores of 5 or greater
- 26% reported scores of 7 or above

#### **Next Steps**

- Validation of CSS-Caregivers and dissemination of the program in diverse care contexts.
- Ongoing engagement of caregivers in the Registry via follow-up surveys and interactive programming.
- Ongoing dissemination of Registry findings to diverse audiences to inform programs, research and policy.

#### **Funders**

Onyx Pharmaceuticals: An Amgen Subsidiary; Takeda Oncology; Lilly Oncology; Amgen Oncology