

## 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. Bevens, 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:



## 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:



## 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