

Comments on PCORI's Proposed National Priorities for Research and Draft Research Agenda (2012)

LIVESTRONG applauds PCORI's meaningful public engagement and thorough process of developing draft priorities. We have a substantial nationwide constituency of patients, survivors, caregivers, professionals, and other cancer stakeholders. Given our broad reach and representation, we appreciate the opportunity to help shape the research priorities and agenda developed by PCORI's board and staff.

Focus on Patients and Cancer

With patients and survivors at the center of our mission, we support efforts to improve research information and advances that facilitate individual decision-making and healthcare outcomes. While we understand the preference not to focus on a particular disease, we offer the following recommendations based on our experience as a cancer organization. Due to its significant burden across myriad subsets of the US population, cancer can be a useful framework in planning a research strategy.

We echo the recommendations of panelists at the public meeting February 27th that "patients" at times be segmented into the following research groups for better understanding of unique circumstances:

- Those at risk for disease (including people diagnosed with specific precursors – e.g. HBP, BRCA)
- Those living with disease (and currently managing their illness or multiple conditions)
- Those having been treated for a disease (and experiencing or at risk for after-effects)

Assessment of Prevention, Diagnosis, and Treatment Options

We encourage PCORI to support studies that assess patient access to and participation in clinical trials, especially for diseases (including some cancers) with low survival rates and with an emphasis on underserved populations. Often, involvement in research studies yields the best treatment options for such conditions yet patient engagement is limited. In addition, PCORI-funded studies related to this proposed research priority on treatment and as well as those addressing communication should track how patients – particularly those representing underserved populations – are informed of clinical trials, how they are engaged in the development and implementation of protocols, and how they utilize both interim and final results to make decisions regarding their own healthcare and with what outcome.

Improving Healthcare Systems; Communication and Dissemination Research

We implore PCORI to use care planning models that have been demonstrated as useful for coordinating cancer care and equipping patients with information for joint decision-making. Ideally, PCORI's agenda

could explore how such models are employed across chronic conditions, including in populations with multiple diseases (i.e. comorbidity), and how implementing care plans affects patient outcomes, from diagnosis through treatment and beyond. We support PCORI's emphasis on allied health professionals and research that studies how successful patient navigation models can be better integrated into community and hospital healthcare delivery systems as well as how patient navigation can be applied across the disease continuum, from research and prevention through diagnosis, treatment, and support.

We stress the importance of innovation and aligning PCORI research priorities with consumer-engagement objectives of the Office of the National Coordinator for Health Information Technology. We appreciate the proposal to study how implementation of electronic health records affects patient communication, and urge PCORI also to research how personal health records and more patient-centered platforms can help improve patient or caregiver education as well as clinical decision-making.

Addressing Disparities

We remind PCORI that, among the groupings for proposed study, such as race, ethnicity, gender, geographic location, and socioeconomic status, it is important to delineate underserved age groups with historically poor outcomes, especially adolescents and young adults (AYAs). This group has unique needs distinct from children and older adults, and research should highlight special circumstances often related to age transitions such as how AYAs are included in treatment decision-making, balancing their level of understanding with limited involvement in healthcare consent, as well as how their engagement changes through the life course as they become of legal age during treatment or patient follow-up visits.

Accelerating PCOR and Methodological Research

We support proposals to expand understanding of patient-centered outcomes and related research methodology and encourage PCORI's agenda to foster collaboration both within and across research institutions. Sharing data across studies should enhance information and outcomes for patient subjects.

LIVESTRONG is available for consultation on the proposed PCORI strategy. Below is further information on the ongoing patient-centered research initiatives from which we have drawn our recommendations.

LIVESTRONG Survivor Survey: <http://livestrong.org/pdfs/3-0/LSSurvivorSurveyReport>

LIVESTRONG Survivorship Centers of Excellence: http://livestrong.org/pdfs/3-0/COEreport_FINAL

Essential Elements of Survivorship Care: <http://livestrong.org/pdfs/3-0/EssentialElementsBrief>

LIVESTRONG Electronic Health Information Survey: http://livestrong.org/pdfs/3-0/EHI_Report

LIVESTRONG Patient Navigation: http://livestrong.org/pdfs/3-0/LSNavigationReport_FINAL