



2005 Market Street, Suite 1700
Philadelphia, PA 19103-7077

215.575.9050 Phone
215.575.4939 Fax

901 E Street NW, 10th Floor
Washington, DC 20004

202.552.2000 Phone
202.552.2299 Fax

www.pewtrusts.org

June 22, 2016

The Honorable Phil Roe, M.D.
United States House of Representatives
407 Cannon House Office Building
Washington, DC 20515

The Honorable Earl Blumenauer
United States House of Representatives
1111 Longworth House Office Building
Washington, DC 20515

Dear Representatives Roe and Blumenauer:

The Pew Charitable Trusts is pleased to offer strong support for the *Personalize Your Care Act 2.0*. The bill recognizes that Americans often do not receive care near the end of life that reflects their values, goals, and preferences. This bipartisan legislation would help people make informed decisions about their treatment and improve the documentation of these preferences across care settings. The effect of this legislation would be to improve the quality of care and reduce the strain on families who are often left unsure of a patient's wishes.

The Pew Charitable Trusts is an independent, non-profit research and public policy organization. Pew's project on improving end-of-life care advances policies that help people receive high-quality health care as they near the end of their lives.

The *Personalize Your Care Act 2.0* enhances federal policy around advanced illness and end-of-life care in a number of important ways. Pew encourages the development of innovative models of care designed to address the needs of people with serious and advanced illness and this bill would direct the Department of Health & Human Services to undertake a demonstration focused on advanced illness management. Currently, there are few demonstration programs that explore pioneering ideas for the delivery of palliative and end-of-life care and we commend this legislation for addressing that gap.

The bill would also make available grants for Physician Orders for Life Sustaining Treatment (POLST) programs, which translate a patient's goals for care near the end of his or her life into medical orders. The research shows that use of POLST increases the likelihood that the site of death will correspond with a person's stated preferences. We support federal funding that would expand the use of state POLST programs through consumer and physician outreach and education. Such grants are seen by experts as the best way to expand and improve the quality of POLST programs for this singular type of advance care planning document. Sustainability and support of new and innovative efforts is critical for the continued ability of POLST to reach more seriously ill patients and their families.

Advance care planning is a vital element of ensuring that individuals receive the care they desire when they are no longer able to speak for themselves. However, an advance care plan is of

limited use if it cannot be easily located within an electronic health record (EHR), particularly as individuals change health care facilities. We strongly endorse the provision that would require the Secretary of Health and Human Services to establish standards for qualified electronic health records to display patients' advance directives and POLST forms in electronic health records. Providers must be able to access this information across sites of care in order to ensure that they understand patient preferences and deliver patient-centered care.

Another key provision in the *Personalize Your Care Act 2.0* prioritizes the development of quality measures for care near the end of life; the lack of such measures is a significant barrier to improving this care. We strongly endorse the bill's language to develop measures that assess the extent to which care was concordant with patient goals, values, and preference.

We appreciate your leadership on advancing palliative and end-of-life care and we look forward to working with you to help advance this important legislative initiative.

Sincerely,

A handwritten signature in blue ink, appearing to read "Lee Goldberg". The signature is fluid and cursive, written in a professional style.

Lee Goldberg
Director, Project on Improving End of Life Care
The Pew Charitable Trusts