H. R. 113TH CONGRESS
1ST SESSION

To amend the Social Security Act to provide for coverage of voluntary advance care planning consultation under Medicare and Medicaid, and for other purposes.

IN THE HOUSE OF REPRESENTATIVES

Mr. BLUMENAUER introduced the following bill; which was referred to the Committee on

A BILL

To amend the Social Security Act to provide for coverage of voluntary advance care planning consultation under Medicare and Medicaid, and for other purposes.

Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled,

SECTION 1. SHORT TITLE; FINDINGS; TABLE OF CONTENTS.

(a) SHORT TITLE.—This Act may be cited as the “Personalize Your Care Act of 2013”.

(b) FINDINGS.—Congress finds the following:

(1) All individuals should be afforded the opportunity to fully participate in decisions related to
their health care or the care of a person for whom they are the proxy or surrogate.

(2) Every individual’s values and goals should be identified, understood, and respected. Particular attention should be paid to populations which have not regularly had the opportunity to express their choices or preferences.

(3) Advance care planning plays a valuable role in achieving quality care by informing physicians and family members of an individual’s treatment preferences should he or she become unable to direct care.

(4) Early advance care planning is ideal because a person’s ability to make decisions may diminish over time and the person may suddenly lose the capability to participate in their health care decisions.

(5) Advance directives (such as living wills and durable powers of attorney for health care) must be prepared while individuals have the capacity to complete them and only apply to future medical circumstances when decisionmaking capacity is lost. An individual can change or revoke an advance directive at any time.
(6) Physician orders for life-sustaining treatment complement advance directives by providing a process to focus patients’ values, goals, and preferences on current medical circumstances and to translate them into visible and portable medical orders applicable across care settings. A patient (or proxy or surrogate) can change or revoke a physician order for life-sustaining treatment at any time.

(7) Advance care planning should be routinely conducted in community and clinical practices. Care plans should be periodically revisited to reflect a person’s changes in values and perceptions at different stages and circumstances of life. This shared decisionmaking and collaborative planning between the patient (or proxy or surrogate) and the clinician of their choice will lead to more person-centered, culturally appropriate care.

(8) Effective, respectful, and culturally competent advance care planning requires recognition that both overtreatment and undertreatment may be concerns of individuals contemplating future care.

(9) More should be done within local health systems to establish specific policies and programs to assist people with sensory, mental, and other disabilities in order to maximize the degree to which they...
are active participants in the decisions related to their health care, including training health care providers to be aware of augmentative communication devices and how to communicate with people with developmental, psychiatric, speech, and sensory disabilities.

(10) Studies funded by the Agency for Healthcare Research and Quality have shown that individuals who talked with their families or physicians about their preferences for care had less fear and anxiety, felt they had more ability to influence and direct their medical care, believed that their physicians had a better understanding of their wishes, and indicated a greater understanding and comfort level than they had before the discussion. Patients who had advance planning discussions with their physicians continued to discuss and talk about these concerns with their families. Such discussions enabled patients and families to reconcile any differences about care and could help the family and physician come to agreement if they should need to make decisions for the patient.

(11) A decade of research has demonstrated that physician orders for life-sustaining treatment effectively convey patient preferences and guide med-
ical personnel toward medical treatment aligned with patient wishes. Programs for these orders have developed locally on a statewide or communitywide basis and have different program names, forms, and policies, but all follow the principle of patient-centered care.

(12) According to research published in the Archives of Internal Medicine, between 65 and 76 percent of physicians whose patients had an advance directive were not aware that it existed.

(13) Including completed advance care planning documents within a patient’s electronic health record can increase the likelihood these documents are kept up-to-date and available at the right place at the right time.

(e) TABLE OF CONTENTS.—The table of contents of this Act is as follows:

Sec. 1. Short title; findings; table of contents.
Sec. 2. Voluntary advance care planning consultation coverage under Medicare and Medicaid.
Sec. 4. Advance care planning standards for electronic health records.
Sec. 5. Portability of advance directives.

SEC. 2. VOLUNTARY ADVANCE CARE PLANNING CONSULTATION COVERAGE UNDER MEDICARE AND MEDICAID.

(a) MEDICARE.—
I N GENERAL.—Section 1861 of the Social Security Act (42 U.S.C. 1395x) is amended—

(A) in subsection (s)(2)—

(i) by striking “and” at the end of subparagraph (EE);

(ii) by adding “and” at the end of subparagraph (FF); and

(iii) by adding at the end the following new subparagraph:

“(GG) voluntary advance care planning consultation (as defined in subsection (iii)(1));”;

and

(B) by adding at the end the following new subsection:

“Voluntary Advance Care Planning Consultation

“(iii)(1) Subject to paragraphs (3) and (4), the term ‘voluntary advance care planning consultation’ means an optional consultation between the individual and a practitioner described in paragraph (2) regarding advance care planning. Such consultation may include the following, as specified by the Secretary:

“(A) An explanation by the practitioner of advance care planning and the uses of advance directives.
“(B) An explanation by the practitioner of the role and responsibilities of a proxy or surrogate.

“(C) An explanation by the practitioner of the services and supports available under this title during chronic and serious illness, including palliative care, home care, long-term care, and hospice care.

“(D) An explanation by the practitioner of physician orders for life-sustaining treatment or similar orders in States where such orders or similar orders exist.

“(E) Facilitation by the practitioner of shared decisionmaking with the patient (or proxy or surrogate) which may include—

“(i) use of decision aids and patient support tools;

“(ii) the provision of patient-centered, easy-to-understand information about advance care planning or disease-specific care planning; and

“(iii) the incorporation of patient preferences and values into the medical plan, an advance directive, and a physician order for life-sustaining treatment as appropriate.
“(2) A practitioner described in this paragraph is a physician (as defined in subsection (r)(1)), nurse practitioner, or physician assistant.

“(3) Payment may not be made under this title for a voluntary advance care planning consultation furnished more often than once every 5 years unless there is a significant change in the health, health-related condition, or care setting of the individual.

“(4) For purposes of this section, the term ‘physician order for life-sustaining treatment’ means, with respect to an individual, an actionable medical order relating to the treatment of that individual that effectively communicates the individual’s preferences regarding life-sustaining treatment, is in a form that is sanctioned or approved under State law or regulation or is widely recognized by health care providers in the State, and permits it to be followed by health care professionals across the continuum of care. Such an order may be changed or revoked by the individual (or proxy or surrogate) at any time.”.

(2) CONSTRUCTION.—The voluntary advance care planning consultation described in section 1861(iii) of the Social Security Act, as added by paragraph (1), shall be completely optional. Nothing in this section shall—
(A) require an individual to complete an advance directive or a physician order for life-sustaining treatment;

(B) require an individual to consent to restrictions on the amount, duration, or scope of medical benefits an individual is entitled to receive under this title; or

(C) violate the Assisted Suicide Funding Restriction Act of 1997 (Public Law 105–12) by encouraging the promotion of suicide or assisted suicide.

(3) PAYMENT.—Section 1848(j)(3) of such Act (42 U.S.C. 1395w–4(j)(3)) is amended by inserting “(2)(GG),” before “(3),”.

(4) FREQUENCY LIMITATION.—Section 1862(a) of such Act (42 U.S.C. 1395y(a)) is amended—

(A) in paragraph (1)—

(i) in subparagraph (O), by striking “and” at the end;

(ii) in subparagraph (P) by striking the semicolon at the end and inserting “, and”; and

(iii) by adding at the end the following new subparagraph:
“(Q) in the case of voluntary advance care planning consultations (as defined in paragraph (1) of section 1861(iii)), which are performed more frequently than is covered under such section;”; and

(B) in paragraph (7), by striking “or (P)” and inserting “(P), or (Q)”.

(5) **Effective Date.**—The amendments made by this subsection shall apply to consultations furnished on or after January 1, 2014.

(b) **Medicaid.—**

(1) **Mandatory Benefit.**—Section 1902(a)(10)(A) of the Social Security Act (42 U.S.C. 1396a(a)(10)(A)) is amended, in the matter preceding clause (i), by striking “and (28)” and inserting “, (28), and (29)”.

(2) **Medical Assistance.**—Section 1905(a) of such Act (42 U.S.C. 1396d(a)) is amended—

(A) by striking “and” at the end of paragraph (28);

(B) by redesignating paragraph (29) as paragraph (30); and

(C) by inserting after paragraph (28) the following new paragraph:
“(29) voluntary advance care planning consultation (as defined in section 1861(iii)(1)); and”.

c) Definition of Advance Directive Under Medicare and Medicaid.—

(1) Medicare.—Section 1866(f)(3) of the Social Security Act (42 U.S.C. 1395ee(f)(3)) is amended by striking “means” and all that follows and inserting the following: “means a living will, medical directive, health care power of attorney, durable power of attorney for health care, advance health care directive, health care directive, or other statement that is recorded and completed in a manner recognized under State law by an individual with capacity to make health care decisions and that indicates the individual’s wishes regarding medical treatment in the event of future incapacity of the individual to make health care decisions.”.

(2) Medicaid.—Section 1902(w)(4) of such Act (42 U.S.C. 1396a(w)(4)) is amended by striking “means” and all that follows and inserting the following: “means a living will, medical directive, health care power of attorney, durable power of attorney for health care, advance health care directive, health care directive, or other statement that is recorded and completed in a manner recognized under
State law by an individual with capacity to make health care decisions and that indicates the individual’s wishes regarding medical treatment in the event of future incapacity of the individual to make health care decisions.”.

(d) Effective Date.—The amendments made by this section take effect on January 1, 2014.

SEC. 3. GRANTS FOR PROGRAMS FOR PHYSICIAN ORDERS FOR LIFE-SUSTAINING TREATMENT.

(a) In General.—The Secretary of Health and Human Services shall make grants to eligible entities for the purpose of—

   (1) establishing statewide programs for physician orders for life-sustaining treatment; or

   (2) expanding or enhancing existing programs for physician orders for life-sustaining treatment.

(b) Authorized Activities.—Activities funded through a grant under this section for an area may include—

   (1) developing such a program for the area that includes hospitals, home care, hospice, long-term care, community and assisted living residences, skilled nursing facilities, and emergency medical services within a State; and
(2) expanding an existing program for physician orders regarding life-sustaining treatment to serve more patients or enhance the quality of services, including educational services for patients and patients’ families, training of health care professionals, or establishing a physician orders for life-sustaining treatment registry.

(c) DISTRIBUTION OF FUNDS.—In funding grants under this section, the Secretary shall ensure that, of the funds appropriated to carry out this section for each fiscal year—

(1) at least one-half are used for establishing new programs for physician orders regarding life-sustaining treatment; and

(2) remaining funds are to be used for expanding or enhancing existing programs for physician orders regarding life-sustaining treatment.

(d) DEFINITIONS.—In this section:

(1) The term “eligible entity” includes—

(A) an academic medical center, a medical school, a State health department, a State medical association, a multistate task force, a hospital, or a health system capable of administering a program for physician orders regarding life-sustaining treatment for a State; or
(B) any other health care agency or entity as the Secretary determines appropriate.

(2) The term “physician order for life-sustaining treatment” has the meaning given such term in section 1861(iii)(4) of the Social Security Act, as added by section 2.

(3) The term “program for physician orders for life-sustaining treatment” means a program that—

(A) supports the active use of physician orders for life-sustaining treatment in the State; and

(B) is guided by a coalition of stakeholders that includes patient advocacy groups and representatives from across the continuum of health care services, such as disability rights advocates, senior advocates, emergency medical services, long-term care, medical associations, hospitals, home health, hospice, the State agency responsible for senior and disability services, and the State department of health.

(4) The term “Secretary” means the Secretary of Health and Human Services.

(e) AUTHORIZATION OF APPROPRIATIONS.—To carry out this section, there are authorized to be appropriated
such sums as may be necessary for each of the fiscal years 2014 through 2019.

SEC. 4. ADVANCE CARE PLANNING STANDARDS FOR ELECTRONIC HEALTH RECORDS.

Notwithstanding section 3004(b)(3) of the Public Health Service Act (42 U.S.C. 300jj–14(b)(3)), not later than January 1, 2015, the Secretary of Health and Human Services shall adopt, by rule, standards for a qualified electronic health record (as defined in section 3000(13) of such Act (42 U.S.C. 300jj(13)), with respect to patient communications with a health care provider about values and goals of care, to adequately display the following:

(1) The patient’s current advance directive (as defined in section 1866(f)(3) of the Social Security Act (42 U.S.C. 1395cc(f)(3)), as applicable.

(2) The patient’s current physician order for life-sustaining treatment (as defined in section 1861(iii)(4) of the Social Security Act (42 U.S.C. 1395x(iii)(4)), as applicable.

A standard adopted under this section shall be treated as a standard adopted under section 3004 of the Public Health Service Act (42 U.S.C. 300jj–14) for purposes of certifying qualified electronic health records pursuant to
section 3001(c)(5) of such Act (42 U.S.C. 300jj–11(c)(5)).

SEC. 5. PORTABILITY OF ADVANCE DIRECTIVES.

(a) IN GENERAL.—Section 1866(f) of the Social Security Act (42 U.S.C. 1395cc(f)) is amended by adding at the end the following new paragraph:

“(5)(A) An advance directive validly executed outside the State in which such directive is presented must be given effect by a provider of services or organization to the same extent as an advance directive validly executed under the law of the State in which it is presented.

“(B) In the absence of knowledge to the contrary, a physician or other health care provider or organization may presume that a written advance health care directive or similar instrument, regardless of where executed, is valid.

“(C) In the absence of a validly executed advance directive, any authentic expression of a person’s wishes with respect to health care shall be honored.

“(D) The provisions of this paragraph shall preempt any State law on advance directive portability to the extent such law is inconsistent with such provisions. Nothing in the paragraph shall be construed to authorize the administration of health care treatment otherwise prohibited by the laws of the State in which the directive is presented.”.
(b) MEDICAID.—Section 1902(w) of the Social Security Act (42 U.S.C. 1396a(w)) is amended by adding at the end the following new paragraph:

“(6)(A) An advance directive validly executed outside the State in which such directive is presented must be given effect by a provider or organization to the same extent as an advance directive validly executed under the law of the State in which it is presented.

“(B) In the absence of knowledge to the contrary, a physician, other health care provider, or organization may presume that a written advance health care directive or similar instrument, regardless of where executed, is valid.

“(C) In the absence of a validly executed advance directive, any authentic expression of a person’s wishes with respect to health care shall be honored.

“(D) The provisions of this paragraph shall preempt any State law on advance directive portability to the extent such law is inconsistent with such provisions. Nothing in the paragraph shall be construed to authorize the administration of health care treatment otherwise prohibited by the laws of the State in which the directive is presented.”.