I

114TH CONGRESS
2D SESSION

H. R. 5555

To amend titles XVIII and XIX of the Social Security Act to improve end-of-life care and advanced illness management.

IN THE HOUSE OF REPRESENTATIVES

JUNE 22, 2016

Mr. BLUMENAUER (for himself and Mr. ROE of Tennessee) introduced the following bill; which was referred to the Committee on Energy and Commerce, and in addition to the Committee on Ways and Means, for a period to be subsequently determined by the Speaker, in each case for consideration of such provisions as fall within the jurisdiction of the committee concerned

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A BILL

To amend titles XVIII and XIX of the Social Security Act to improve end-of-life care and advanced illness management.

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 2.0''.

(b) FINDINGS.—Congress finds the following:

(1) All individuals should be afforded the opportunity to fully participate in decisions related to their health care.

(2) Care near the end of life should be person- and family-oriented and evidence-based.

(3) To ensure high-quality, person-centered care near the end of life, care must align with an individual's goals, values, and stated preferences.

(4) Advance care planning plays a valuable role in achieving quality care by informing providers and family members of an individual's treatment preferences.

(5) All clinicians who care for people with advanced serious illness should demonstrate competence in basic advance care planning and palliative care, including communication skills, inter-professional collaboration, and symptom management.

(6) More should be done 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 how to communicate with people with developmental, psychiatric, speech, and sensory disabilities.

(7) Including completed advance care planning documents within a patient's electronic health record can increase the likelihood these documents are kept current and available at the right place at the right time.

(8) A decade of research has demonstrated that physician orders for life-sustaining treatment effectively convey patient preferences and guide medical personnel toward medical treatment aligned with patient wishes.

(9) Patients, caregivers, families, and health professionals would benefit from an authoritative, validated list of core components to the delivery high-quality end-of-life care.

(10) Palliative care, hospice, and various care models that integrate health care and supportive services provide high-quality end-of-life care and reduce the use of avoidable hospital- and institution-based services that the patient does not want.

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

SEC. 2. ADVANCED ILLNESS MANAGEMENT AND CHOICES CARE MODEL DEMONSTRATION PROGRAM.

(a) IN GENERAL.—The Secretary of Health and Human Services (in this section referred to as the ''Secretary'') shall establish a 3-year demonstration program (in this section referred to as the ''demonstration program'') to test the use of advanced illness management and early use of palliative care under the Medicare program. The Secretary may extend the program to a duration of 4 or 5 years, as determined necessary by the Secretary in coordination with the Centers for Medicare and Medicaid Innovation.

(b) DEMONSTRATION PROGRAM DESIGN.—Under the demonstration program the Secretary shall establish a capitated payment for the payment of advanced illness management services and the early use of palliative care consistent with the following:

(1) The services and care are furnished to individuals who—

(A) reside at home or in an institutional setting;

(B) have a documented medical prognosis that the individual's life expectancy is 24 months or less; and

(C) have the need for assistance with two or more activities of daily living or meet such other criteria as the Secretary may specify.

(2) The services and care are furnished concurrently with the receipt of services related to the treatment of the individual's condition with respect to which a diagnosis of terminal illness has been made.

(3) The services and care include at least hospice care (as defined in section 1861(dd)(1) of the Social Security Act), a functional assessment of the individual and of the family caregiver (as appropriate), in-home services and supports, 24-hour, 7-day-a-week emergency supports, care coordination and communication across settings and providers, and such other palliative care services as the Secretary deems necessary.

(4) The services and care are furnished by an interdisciplinary team that includes primary care providers, palliative medicine specialists, palliative nurses, social workers, chaplains, pharmacists, dieticians, physical therapists, occupational therapists,

psychotherapists, and such others as the Secretary deems necessary and appropriate.

(c) TIMELY IMPLEMENTATION.—The Secretary of Health and Human Services shall implement a capitated payment model for the payment of advanced illness management services under subsection (a) not later than 2 years after the date of the enactment of this Act.

SEC. 3. GRANTS FOR PROGRAMS FOR ORDERS FOR LIFE-SUSTAINING TREATMENT AND SIMILAR PROVIDER OR MEDICAL ORDERS.

(a) IN GENERAL.—The Secretary of Health and Human Services shall make grants to eligible entities for the purpose of developing, expanding, and enhancing programs for orders for life-sustaining treatment (as defined in subsection (c)(2)).

(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;

(2) expanding an existing program for orders regarding life-sustaining treatment to serve more pa-

tients or enhance the quality of services, including educational services for patients and patients' families, training of health care professionals, or establishing an orders for life-sustaining treatment registry; and

(3) technical assistance and professional training.

(c) 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 ''program for orders for life-sustaining treatment'' means a program that, regardless of its name—

(A) implements a clinical process designed to facilitate shared, informed medical decision-making and communication between health care professionals and patients with serious, progressive illness or frailty and results in a set of

medical orders that are substantially consistent with the national standard and that—

(i) are portable and honored across care settings; and

(ii) address key medical decisions consistent with the patient's goals of care; and

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

(3) The term ''Secretary'' means the Secretary of Health and Human Services.

(d) AUTHORIZATION OF APPROPRIATIONS.—To carry out this section, there are authorized to be appropriated $35,000,000 for the 5-fiscal-year period beginning with fiscal year 2017, to remain available until expended.

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

(a) IN GENERAL.—Notwithstanding section 3004(b)(3) of the Public Health Service Act (42 U.S.C. 300jj–14(b)(3)), not later than 4 years after the date of the enactment of this Act, 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 organizing patient communications with health care providers about care goals and to provide one-click access to 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 order for life-sustaining treatment (described in section 3(c)(2)(A)), as applicable.

(3) Documentation of advance care planning discussion between the patient and the provider.

(b) TREATMENT OF STANDARDS.—A standard adopted under subsection (a) 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) GAO STUDY ON HEALTH CARE DECISIONMAKING LAWS AND BARRIERS TO THE USE OF ADVANCE DIRECTIVES.—

(1) STUDY.—The Comptroller General of the United States shall conduct a study that examines the use, portability, and electronic storage of advance directives and that identifies barriers towards adopting, using, and following advance directives in the clinical setting. Such examination shall include issues that remain unresolved after the Stage 3 Meaningful Use final rule, including barriers and solutions to finding and accessing advance care planning documents, best practices for alerting eligible providers to the presence of an advance care plan, and best practices for transmitting advance care plans across sites of care.

(2) REPORT.—Not later than 1 year after the date of the enactment of this Act, the Comptroller General shall submit to Congress a report on the study conducted under paragraph (1) and shall include in the report such recommendations regarding improving advance health care planning as the Comptroller General deems appropriate.

SEC. 6. APPLICATION OF QUALITY MEASURES UNDER MEDICARE RELATING TO END-OF-LIFE CARE.

(a) INCORPORATING END-OF-LIFE CARE SUBDOMAINS WITHIN QUALITY DOMAINS UNDER MEDICARE PHYSICIAN FEE SCHEDULE.—Section 1848(s)(1) of the

Social Security Act (42 U.S.C. 1395w–4(s)(1)) is amended by adding at the end the following new subparagraph:

"(G) END-OF-LIFE SUBDOMAINS RELATING TO QUALITY DOMAINS.—Within one or more appropriate quality domains, the Secretary shall establish subdomains relating to end-of-life care, including subdomains relating to each of the following:

"(i) The process of eliciting and documenting goals, preferences, and values of the patient (and, where relevant and appropriate, family caregiver) regarding end-of-life care from the patient or from a legally authorized representative, including the articulation of goals that accurately reflect how the patient wants to live.

"(ii) The effectiveness, patient-centeredness (and, where relevant, family caregiver-centeredness), and accuracy of end-of-life care plans, including documentation of individual goals, preferences, and values.

"(iii) Agreement and consistency with respect to end-of-life care among—

''(I) patient's goals, values, and preferences;

''(II) any documented care plan; and

''(III) the care delivered.''.

(b) INCORPORATING QUALITY MEASURES ON END-OF-LIFE CARE FOR POST-ACUTE CARE (PAC).—Section 1899B of the Social Security Act (42 U.S.C. 1395lll) is amended—

(1) in subsection (a)(2)(E)(i)—

(A) by striking ''and'' at the end of subclause (IV);

(B) by striking the period at the end of subclause (V) and inserting ''; and''; and

(C) by adding at the end the following new subclause:

''(VI) with respect to the domain described in subsection (c)(1)(F) (relating to end-of-life care)—

''(aa) for PAC providers described in clauses (ii), (iii), and (iv) of paragraph (2)(A), October 1, 2018; and

''(bb) for PAC providers described in clauses (i) of such

paragraph, January 1, 2019.''; and

(2) in subsection (c)(1), by adding at the end the following new subparagraph:

''(F) The effectiveness, patient-centeredness (and, where relevant, family caregiver-centeredness), and accuracy of end-of-life care plans and communications relating to such plans, including—

''(i) documentation of a patient's goals, preferences, and values; and

''(ii) agreement and consistency with respect to end-of-life care among—

''(I) patient's goals, values, and preferences;

''(II) any documented care plan; and

''(III) the care delivered.''.

SEC. 7. ANNUAL REPORT ON MEDICARE DECEDENTS.

The Secretary of Health and Human Services shall issue for each fiscal year (beginning no later than fiscal year 2018) an annual report that analyzes the circumstances of Medicare beneficiaries who died during the fiscal year covered by such report. Such analysis shall include at least the following with respect to such decedents:

(1) Information on the care or payor settings (such as under part A or part C of Medicare) at the time of death.

(2) Information on the demographic characteristics of such decedents.

(3) Information on the geographic distribution of such decedents.

(4) An evaluation of the Medicare claims data for such decedents for services furnished in the last year of life, including an analysis of the setting of care for decedents who had more than one chronic illness at the time of death.

(5) Such other information as the Secretary deems appropriate.

SEC. 8. GRANTS TO INCREASE PUBLIC AWARENESS OF ADVANCE CARE PLANNING.

(a) IN GENERAL.—The Secretary of Health and Human Services shall award grants to increase public awareness of advance care planning. Such grants shall be awarded under such terms and conditions as the Secretary shall specify.

(b) TYPES OF GRANTS.—Grants under this section may provide for the development of—

(1) decision support tools and instructional materials for individuals, family caregivers, and health

care providers that include the importance of planning for treatment decisions, discussing values and goals related to catastrophic injury or illness, and completing an advance directive; and

(2) materials for individuals that presents the importance of articulating goals of care, understanding disease diagnosis and prognosis, evaluating treatment options, and developing a plan of care, and documenting the treatment plan.

(c) AUTHORIZATION OF APPROPRIATIONS.—There are authorized to be appropriated to carry out this section for the 5-fiscal-year period beginning with fiscal year 2017 $20,000,000, to remain available until expended.

SEC. 9. ADVANCE CARE PLANNING AND PALLIATIVE CARE EDUCATION AND TRAINING.

(a) IN GENERAL.—The Secretary of Health and Human Services shall award grants to eligible entities to develop and implement programs and initiatives to train and educate individuals to provide advance care planning, advance illness care, hospice care, and palliative care in hospital, hospice, home, community, and long-term care settings.

(b) ELIGIBLE ENTITIES.—For purposes of this section, eligible entities may be a medical school, a nursing

school, a health care system, non-profit organization, or other entity the Secretary deems appropriate.

(c) USE OF FUNDS.—Funding under grants awarded under this section shall be used—

(1) to provide training and continuing education to individuals who will provide advance care planning services or palliative care in the hospital, hospice, home, community, and long-term care settings; and

(2) to develop curricula or teaching materials related to advance care planning or palliative care in such settings.

(d) AUTHORIZATION OF APPROPRIATIONS.—There are authorized to be appropriated to carry out this section for the 5-fiscal-year period beginning with fiscal year 2017 $20,000,000, to remain available until expended.

SEC. 10. ADVANCE CARE PLANNING ADVISORY COUNCIL.

(a) ESTABLISHMENT.—Not later than 180 days after the date of the enactment of this Act, the Secretary of Health and Human Services (in this section referred to as the ''Secretary'') shall establish within the Office of the Secretary an advisory committee to be known as the Advance Care Planning Advisory Council (in this section referred to as the ''Council'').

(b) DUTIES.—

(1) MISSION.—The Council shall advise the Secretary regarding the compilation, development, and dissemination of resources for individuals facing advanced and terminal illness.

(2) RESPONSIBILITIES.—Responsibilities of the council include the following:

(A) Ensuring that resources provided contain non-biased information about the range of options available to individuals with advance and terminal illness, including information about conventional, curative treatments, palliative care, and hospice care.

(B) Developing strategies for increasing public understanding about advanced illness and the important role advance care planning can play in documenting an individual's wishes for medical care for loved ones in the event that individual cannot communicate the individual's his or her wishes.

(C) Compiling information for dissemination regarding existing advance care planning models including POLST, MOLST, advance directives, and healthcare proxies.

(D) Promoting interagency coordination and minimizing overlap regarding advance care

planning, including opportunities to coordinate efforts between the Federal agencies and external stakeholders.

(E) Identifying and evaluating cross-cutting issues such as perinatal end-of-life care and advance care planning access issues.

(c) MEMBERSHIP.—

(1) IN GENERAL.—The Council shall be composed of up to 15 members appointed by the Secretary from among qualified individuals who are not officers or employees of the Federal Government.

(2) GROUPS.—The members of the Council shall include the following:

(A) At least 3 members with clinical training and an expertise in advanced illness or end-of-life care.

(B) At least 3 members from patient and family advocacy groups.

(C) At least 3 members from religious or spiritual organizations.

(D) Other members from interested stakeholder groups with a proven expertise in chronic, advanced, and end-of-life care.

(d) APPLICABILITY OF FACA.—The Council shall be treated as an advisory committee subject to the Federal Advisory Committee Act (5 U.S.C. App.).

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