

115TH CONGRESS
1ST SESSION

S. 1530

To amend title XVIII of the Social Security Act to encourage Medicare beneficiaries to voluntarily adopt advance directives guiding the medical care they receive.

IN THE SENATE OF THE UNITED STATES

JULY 11, 2017

Mr. COONS (for himself, Mr. CASSIDY, Mr. BARRASSO, and Mr. BENNET) introduced the following bill; which was read twice and referred to the Committee on Finance

A BILL

To amend title XVIII of the Social Security Act to encourage Medicare beneficiaries to voluntarily adopt advance directives guiding the medical care they receive.

1 *Be it enacted by the Senate and House of Representa-*
2 *tives of the United States of America in Congress assembled,*

3 **SECTION 1. SHORT TITLE.**

4 This Act may be cited as the “Medicare Choices Em-
5 powerment and Protection Act”.

1 **SEC. 2. MEDICARE ADVANCE DIRECTIVE CERTIFICATION**
 2 **PROGRAM.**

3 Part B of title XVIII of the Social Security Act (42
 4 U.S.C. 1395 et seq.) is amended by adding at the end
 5 the following new section:

6 “MEDICARE ADVANCE DIRECTIVE CERTIFICATION
 7 PROGRAM

8 “SEC. 1849. (a) IN GENERAL.—

9 “(1) ESTABLISHMENT OF PROGRAM.—The Sec-
 10 retary shall establish and implement an Advance Di-
 11 rective Certification Program (in this section re-
 12 ferred to as the ‘Program’) under which the Sec-
 13 retary shall encourage eligible beneficiaries to adopt
 14 and maintain certified advance directives to guide
 15 the delivery of health care to such beneficiaries. The
 16 Secretary shall implement the Program not later
 17 than 3 years after the date of enactment of this sec-
 18 tion.

19 “(2) DEFINITIONS.—In this section:

20 “(A) CERTIFIED ADVANCE DIRECTIVE.—
 21 The term ‘certified advance directive’ means
 22 any electronically stored statement by an eligi-
 23 ble beneficiary who—

24 “(i) provides instructions that outline
 25 the kind of medical treatments and care
 26 that such beneficiary would want or not

1 want under particular conditions, and may
2 also include the identification of a health
3 care proxy or legal representative to make
4 medical treatment decisions for the bene-
5 ficiary if the beneficiary becomes unable to
6 make or communicate those decisions;

7 “(ii) is executed in accordance with
8 the law governing advance directives of the
9 State involved; and

10 “(iii) is offered by an entity that has
11 received accreditation from the Secretary
12 under this section.

13 “(B) ELIGIBLE BENEFICIARY.—The term
14 ‘eligible beneficiary’ means an individual en-
15 rolled under this part.

16 “(3) VOLUNTARY.—Participation in the Pro-
17 gram shall be voluntary with respect to the eligible
18 beneficiary and an eligible beneficiary who has reg-
19 istered a certified advance directive under the Pro-
20 gram may terminate such directive at any time.
21 Nothing in this section shall require an eligible bene-
22 ficiary to adopt or maintain a certified advance di-
23 rective.

1 “(4) BEST PRACTICES.—In establishing and im-
2 plementing the Program, the Secretary shall con-
3 sider—

4 “(A) best practices within existing advance
5 directive registry technologies, programs, and
6 systems, including web-based or cloud-based ad-
7 vance directive technologies—

8 “(i) which may utilize time and date
9 stamps, video, or other innovative meas-
10 ures to protect the authenticity, improve
11 the quality, and enhance the security of
12 such directives; and

13 “(ii) which may utilize secure email
14 and messaging technologies and nationally
15 recognized health care information tech-
16 nology standards to improve the accessi-
17 bility and interoperability of such direc-
18 tives; and

19 “(B) best practices for educating bene-
20 ficiaries on means for communicating bene-
21 ficiaries’ authenticated wishes to applicable
22 family members, legal representatives, providers
23 or health care proxies, including the use of
24 email or other mail formats as well as access

1 through mobile devices (as defined by the Sec-
2 retary).

3 “(5) ENROLLMENT AND DISENROLLMENT.—

4 The Secretary shall establish procedures for eligible
5 beneficiaries to enroll and disenroll under the Pro-
6 gram. Such procedures shall ensure that enrollment
7 and disenrollment is available through an online
8 process. The Secretary shall also establish proce-
9 dures to ensure Program participants can update or
10 amend an advance directive in a timely and secure
11 manner.

12 “(6) STATE LAW.—This section shall in no way
13 supercede, abrogate, or otherwise interfere with
14 State law governing advance directives. Under the
15 Program, the Secretary shall establish a process
16 under which the Secretary is required to verify that
17 digital advance directive vendors or other entities
18 providing a digital advance directive participating in
19 the program enable those using their services to
20 complete advance directives that fully comply with
21 the law governing advance directives of the State in-
22 volved.

23 “(7) DISPLAY OF STATUTORY AND ALTER-
24 NATIVE ADVANCE DIRECTIVE FORMS.—Under the
25 Program, the Centers for Medicare & Medicaid Serv-

ices shall provide, through a clearinghouse website, links to statutory and alternative advance directive forms and a State-by-State index to such forms to allow a beneficiary to create, adopt, modify, and terminate an advance directive with any content permitted or required, and in any form authorized by a State, in accordance with the requirements of subparagraphs (C) through (E) of subsection (e)(1) and subsection (e)(2).

“(8) ACCESS IN CASES OF DISPUTE OVER TREATMENT.—Under the Program:

“(A) SPECIAL ACCESS.—The Secretary shall establish a process whereby, with respect to a beneficiary with a certified advance directive, a person described in subparagraph (B) may obtain access to the beneficiary’s advance directive for the purposes of viewing and sharing such advance directive when—

“(i) the provisions of the advance directive have come into force under the applicable State’s law because the beneficiary has become incapable of making health care decisions or under other circumstances provided under State law; and

1 “(ii) at least one person described in
2 subparagraph (B) is questioning or dis-
3 puting the provision, withholding, or with-
4 drawal of medical treatment, food, or
5 fluids with respect to the beneficiary.

6 “(B) INTERESTED INDIVIDUALS.—A per-
7 son described in this subparagraph, with re-
8 spect to a beneficiary, is—

9 “(i) any individual who is a member
10 of any class of persons who, under the ap-
11 plicable State’s law, would potentially be
12 eligible to serve as a health care decision
13 maker for the beneficiary if an advance di-
14 rective had not been executed regardless of
15 whether higher priority for such eligibility
16 would be accorded to another individual or
17 individuals; and

18 “(ii) if the applicable State’s law does
19 not designate persons or classes of persons
20 described in clause (i), any person related
21 within the third degree of consanguinity or
22 affinity to the beneficiary.

23 “(b) REGISTRATION.—

24 “(1) IN GENERAL.—The Secretary shall estab-
25 lish procedures for an eligible beneficiary to register

1 such beneficiary's adoption of a certified advance di-
2 rective under the Program. Such procedures shall
3 ensure that registration is available through an on-
4 line process. The Secretary shall also establish pro-
5 cedures to ensure Program participants can update
6 previously registered information that is no longer
7 accurate and indicate that an advance directive has
8 been terminated.

9 “(2) REQUIRED INFORMATION.—In addition to
10 such other information as the Secretary may deem
11 appropriate, an eligible beneficiary seeking to reg-
12 ister a certified advance directive under the Program
13 shall indicate where the advance directive is main-
14 tained or how it may be accessed.

15 “(3) REGISTRATION PERIODS.—The procedures
16 established under paragraph (1) shall provide that
17 registration under the Program shall occur during—

18 “(A) an eligible beneficiary's initial enroll-
19 ment under an MA plan under part C as de-
20 scribed in paragraph (1) of section 1851(e);
21 and

22 “(B) the annual, coordinated election pe-
23 riod under paragraph (3) of such section.

24 “(4) PRIVACY AND SECURITY.—

1 “(A) IN GENERAL.—The Secretary shall
2 ensure that all aspects of the registration sys-
3 tem comply with the Federal regulations (con-
4 cerning the privacy of individually identifiable
5 health information) promulgated under section
6 264(c) of the Health Insurance Portability and
7 Accountability Act of 1996 subject to the access
8 authorized under subsection (a)(8), in accord-
9 ance with subsection (c)(2)(E).

10 “(B) ACCESS.—The Secretary shall utilize
11 standardized data protections and privacy
12 standards, including the Federal regulations de-
13 scribed in paragraph (1), to ensure that the
14 registration record of an eligible beneficiary can
15 only be accessed by—

16 “(i) the beneficiary, through the proc-
17 ess established under paragraph (1);

18 “(ii) those authorized to access the
19 advance directive under subsection (a)(8)
20 and subsection (c)(2)(E); and

21 “(iii) providers of services and sup-
22 pliers participating under this title,
23 through a process established by the Sec-
24 retary.

25 “(c) ACCREDITATION.—

1 “(1) IN GENERAL.—Under the Program, the
2 Secretary shall—

3 “(A) grant accreditation to advance direc-
4 tive vendors and other entities providing ad-
5 vance directives that meet the accreditation cri-
6 teria established under paragraph (2); and

7 “(B) establish a process whereby advance
8 directive vendors and other entities providing
9 advance directives may obtain accreditation
10 under this subsection.

11 “(2) ACCREDITATION CRITERIA.—The Sec-
12 retary, in consultation with the General Accounting
13 Office, shall establish accreditation criteria for ad-
14 vance directive vendors and other entities providing
15 advance directives that seek to offer advance direc-
16 tives to be certified under the Program. Such cri-
17 teria shall consist of the following:

18 “(A) PROCESS FOR ADOPTING ADVANCE
19 DIRECTIVE.—The advance directive vendor or
20 other entity providing an advance directive shall
21 allow a beneficiary to create, adopt, modify, and
22 terminate an advance directive through an on-
23 line process.

24 “(B) VENDORS.—The advance directive
25 vendor or other entity providing an advance di-

1 rective shall comply with an annual quality re-
 2 view to be conducted by the Secretary.

3 “(C) USE OF STATUTORY AND ALTER-
 4 NATIVE ADVANCE DIRECTIVE FORMS.—The ad-
 5 vance directive vendor or other entity providing
 6 an advance directive shall enable a beneficiary
 7 to access, complete, modify, and adopt any ad-
 8 vance directive applicable to the State indicated
 9 by the beneficiary who is posted as provided
 10 under subparagraphs (C) through (E) of sub-
 11 section (e)(1) and of subsection (e)(2).

12 “(D) ACCESS.—The advance directive ven-
 13 dor or other entity providing an advance direc-
 14 tive shall maintain advance directives in such a
 15 way that—

16 “(i) an eligible beneficiary who has
 17 adopted an advance directive with such
 18 vendor or entity and any family member,
 19 legal representative, or health care proxy
 20 legally designated by such beneficiary has
 21 direct, has near real-time online access to
 22 the beneficiary’s advance directive for pur-
 23 poses of viewing and sharing such advance
 24 directive, including communication of the
 25 advance directive and corresponding bene-

1 ficiary’s wishes using nationally recognized
2 health care information technology data
3 content and data transport standards spec-
4 ified by the Secretary;

5 “(ii) in the case of an eligible bene-
6 ficiary who has adopted an advance direc-
7 tive with such vendor or entity or any fam-
8 ily member, legal representative, or health
9 care proxy legally designated by such bene-
10 ficiary who is unable or unwilling to use
11 the online access under subparagraph (A),
12 such individual is able to obtain a hard
13 copy of the beneficiary’s advance directive
14 for the purposes of viewing and sharing
15 such advance directive; and

16 “(iii) providers of services and sup-
17 pliers participating under this title have
18 near real-time online access to the advance
19 directive of an eligible beneficiary who has
20 adopted an advance directive with such
21 vendor or entity, including communication
22 of the advance directive and corresponding
23 beneficiary’s wishes through secure email
24 and messaging technologies and nationally
25 recognized health care information tech-

1 nology standards specified by the Secretary
2 to improve the accessibility and interoper-
3 ability of such directives.

4 “(E) PRIVACY PROTECTIONS.—

5 “(i) IN GENERAL.—The advance di-
6 rective vendor or other entity providing an
7 advance directive shall comply with the
8 Federal regulations (concerning the privacy
9 of individually identifiable health informa-
10 tion) promulgated under section 264(c) of
11 the Health Insurance Portability and Ac-
12 countability Act of 1996 (42 U.S.C.
13 1320d–2 note), subject to the access au-
14 thorized under subparagraph (D) and sub-
15 section (a)(8).

16 “(ii) ACCESS.—Such vendor or entity
17 shall utilize standardized data protections
18 and privacy standards, including the Fed-
19 eral regulations described in clause (i), to
20 ensure that the content of an eligible bene-
21 ficiary’s advance directive is owned and
22 maintained by the beneficiary and can only
23 be accessed by those authorized to access
24 the advance directive under subparagraph
25 (D) and subsection (a)(8).

1 “(F) SECURITY AND TESTING.—The ad-
2 vance directive vendor or other entity providing
3 an advance directive shall certify that—

4 “(i) all data management and data
5 transfer elements involved in adopting,
6 maintaining, and accessing the advance di-
7 rective have successfully passed rigorous
8 independent testing regarding standards of
9 timeliness, accuracy, and efficiency;

10 “(ii) the data management and data
11 transfer elements involved in adopting,
12 maintaining, and accessing the advance di-
13 rective meet widely accepted industry secu-
14 rity standards; and

15 “(iii) the system that provides access
16 to the advance directive has passed real-
17 time tests simulating a realistic volume of
18 beneficiaries and providers accessing ad-
19 vance directives simultaneously.

20 “(G) CERTIFIED ADVANCE DIRECTIVES.—
21 The advance directive vendor or other entity
22 providing an advance directive shall agree to
23 offer certified advance directives (as defined in
24 subsection (a)(2)(A)).

25 “(H) BENEFICIARY SURVEYS.—

1 “(i) IN GENERAL.—The advance di-
2 rective vendor or other entity providing an
3 advance directive shall agree to administer
4 annual beneficiary surveys on the informa-
5 tion described in clause (ii) and submit the
6 results of such surveys to the Centers for
7 Medicare & Medicaid Services.

8 “(ii) INFORMATION.—The information
9 described in this clause, with respect to an
10 annual beneficiary survey and certified ad-
11 vance directive of a beneficiary, is the fol-
12 lowing:

13 “(I) Whether the beneficiary had
14 to pay any third party for the cre-
15 ation, storage, or retrieval of the cer-
16 tified advance directive.

17 “(II) Whether the beneficiary
18 had a health care encounter or emer-
19 gency that required the location, ac-
20 cess, retrieval, or consultation of the
21 certified advance directive and if so,
22 whether the certified advance directive
23 was accessible in online and in near
24 real-time, as required under this sec-
25 tion.

1 “(III) Whether the certified ad-
2 vance directive was actionable.

3 “(IV) Whether medical personnel
4 followed the certified advance direc-
5 tive.

6 “(d) INCENTIVE.—

7 “(1) IN GENERAL.—The Secretary shall make a
8 one-time payment of the amount specified in para-
9 graph (2) to each eligible beneficiary who adopts a
10 certified advance directive and registers such direc-
11 tive with the Program.

12 “(2) AMOUNT.—

13 “(A) IN GENERAL.—For purposes of para-
14 graph (1), the amount specified in this para-
15 graph is—

16 “(i) for a beneficiary who registers a
17 certified advance directive with the Pro-
18 gram in 2017, \$75; or

19 “(ii) for a beneficiary who registers a
20 certified advance directive with the Pro-
21 gram in a subsequent year, the amount
22 specified in this paragraph for the pre-
23 ceding year increased by the percentage in-
24 crease in the Chained Consumer Price
25 Index for All Urban Consumers (as pub-

lished by the Bureau of Labor Statistics of the Department of Labor) over the preceding year.

“(B) ROUNDING.—If any amount determined under subparagraph (A) is not a multiple of 10 cents, such amount shall be rounded to the nearest multiple of 10 cents.

“(3) FUNDING.—For purposes of carrying out this subsection, the Secretary shall provide for the transfer, from the Federal Supplementary Medical Insurance Trust Fund under section 1841, of such sums as the Secretary determines necessary.

“(4) ADMINISTRATION.—The Secretary shall, through a full notice and comment rulemaking process, establish procedures for—

“(A) making the incentive payment directly to the eligible beneficiary or a personal account maintained by the beneficiary at a financial institution that has been designated by the beneficiary, and ensuring that no other entity receives the payment on the beneficiary’s behalf; and

“(B) ensuring that a beneficiary does not receive an incentive payment under this section more than once.

1 “(e) EDUCATION AND OUTREACH.—

2 “(1) IN GENERAL.—The Secretary shall provide
3 for—

4 “(A) the inclusion of the statement set
5 forth in paragraph (3) in the Medicare and You
6 handbook under section 1804 and on a clear-
7 inghouse website linked to the Internet website
8 of the Centers for Medicare & Medicaid Serv-
9 ices;

10 “(B) the promotion of the benefits of elec-
11 tronic advance directives services, as they be-
12 come available, through the use of mass com-
13 munications and other means;

14 “(C) the inclusion, under the heading
15 ‘Statutory Advance Directive Forms’, of any
16 relevant forms, whether mandatory or optional,
17 specified in the statutes or regulations of the
18 States to be displayed on a clearinghouse
19 website;

20 “(D) the inclusion, under the heading ‘Al-
21 ternative Advance Directive Forms’, on a sepa-
22 rate clearinghouse website, and in accordance
23 with paragraph (2)—

24 “(i) of other advance directive forms
25 submitted to the Secretary by individuals

1 and groups in an electronic format speci-
 2 fied by the Secretary for which the submit-
 3 ting entity includes, for each form sub-
 4 mitted, an opinion by an attorney licensed
 5 to practice in the relevant State dem-
 6 onstrating that the submitted form com-
 7 plies with the law of that State; and

8 “(ii) of the following disclaimer, which
 9 shall be prominently posted on the website:

10 ‘This website includes for your consider-
 11 ation alternative advance directive forms
 12 submitted by individuals or groups reflect-
 13 ing different perspectives on advance
 14 health care decisions which you may wish
 15 to review before completing your own ad-
 16 vance directive.’; and

17 “(E) the inclusion of a user friendly index
 18 on the clearinghouse website by State and, in
 19 the case of the ‘Alternative Advance Directive
 20 Forms’, by the name of the provider, so that a
 21 user may readily access those statutory and al-
 22 ternative forms.

23 “(2) ALTERNATIVE ADVANCE DIRECTIVE
 24 FORMS.—

1 “(A) IN GENERAL.—For purposes of para-
2 graph (1)(D), the following shall apply:

3 “(i) Not later than 60 days after re-
4 ceiving an advance directive form sub-
5 mitted under such paragraph, the Sec-
6 retary shall either post the submitted form
7 on a clearinghouse website or provide to
8 the submitting entity a detailed expla-
9 nation of the basis for the Secretary’s de-
10 termination that the submitted form does
11 not comply with relevant State or Federal
12 law, which determination shall be subject
13 to judicial review under section 702 of title
14 5 of the United States Code; and

15 “(ii) the Secretary shall either remove
16 or refuse to post any submitted form if
17 provided with an official determination by
18 the Attorney General of the applicable
19 State that the form is not in compliance
20 with State law, subject to applicable State
21 law described in subparagraph (B).

22 “(B) STATE LAW DESCRIBED.—For pur-
23 poses of subparagraph (A), State law described
24 in this subparagraph is—

1 “(i) a ruling by a court of the applica-
 2 ble State, or by a Federal court applying
 3 that State’s law, subject to subsequent rul-
 4 ings by a court or courts with authority to
 5 supercede that ruling; or

6 “(ii) a statute or regulation of the ap-
 7 plicable State that provides for a specific
 8 procedure for officially determining wheth-
 9 er particular advance directive forms com-
 10 ply with State law.

11 “(3) STATEMENT.—For purposes of paragraph
 12 (1)(A), the statement included in this paragraph is
 13 the following statement, with appropriate insertions
 14 in the bracketed segments updated at least annually:

15 “WHY YOU MAY WANT TO CONSIDER AN ‘AD-
 16 VANCE DIRECTIVE’ Do you ever worry what would
 17 happen if you became unable to make health care decisions
 18 for yourself because of an illness or injury? Do you hold
 19 certain values and beliefs with respect to your medical
 20 treatment that you would want to be upheld if you were
 21 unable to convey them yourself? That’s what an ‘advance
 22 directive’ is for. You can use it to give directions for your
 23 health care providers and family about your health care
 24 wishes that are to be followed if you are no longer able
 25 to speak for yourself. You can also name someone you

1 trust, like a family member or friend, to give health care
2 directions for you when you can't do so yourself.

3 “You should consider carefully who to choose to
4 speak for you and what directions you want to give to en-
5 sure your representative clearly reflects your own values
6 and treatment preferences. You should not feel pressured
7 to violate your own values and preferences, and you are
8 entitled to implement them without discrimination based
9 on age or degree of disability.

10 “There are many resources to help you.

11 “By choosing the name of a State at [INSERT name
12 of webpage for the index provided in paragraph 4 of this
13 subsection and its URL (and, on the clearinghouse
14 website, include a hyperlink to it)], you can find sample
15 advance directives for that State. You can see any sample
16 or required forms given in State law, as well as others
17 from individuals or groups with different viewpoints on ad-
18 vance health care decisions which you may wish to review
19 before completing your own advance directive.

20 “Below is contact information for the accredited ven-
21 dor in your State who will arrange for your advance direc-
22 tive to be confidentially kept online, where it can be seen
23 by doctors who are treating you so they are made aware
24 of your wishes. You can also give permission to certain
25 other people, like family members or friends, you want to

1 be able to get a copy of your advance directive. If a dis-
2 agreement about your treatment develops, depending on
3 your State’s law certain other people may also be allowed
4 to see it.

5 “This vendor can also help you create an advance di-
6 rective online or with paper documents, if you wish. Online
7 directives allow you to change or cancel one that no longer
8 fits with your wishes in a more timely manner.

9 “[INSERT, name and contact information for cur-
10 rently accredited advance directive vendor (and, on the
11 clearinghouse website, hyperlinks to their website).]

12 “Although any adult who is capable of doing so can
13 use these resources to complete an advance directive at
14 any time, Medicare beneficiaries are particularly encour-
15 aged to do so when enrolling in Medicare or during the
16 annual enrollment period when you can choose among dif-
17 ferent Medicare health insurance alternatives.

18 “In addition, some Medicare Advantage plans or sup-
19 plemental insurance plans may offer a financial incentive
20 or other additional benefits for creating an advance direc-
21 tive online.

22 “By completing an advance directive you can not only
23 make it more likely that your wishes about health care
24 will be known if you are unable to tell them at the time,
25 but also spare family, friends, and doctors the difficulty

1 of trying to figure out what you would have wanted. These
2 are matters of the highest importance that can affect life-
3 or-death decisions, as well as your future comfort and
4 well-being. You are encouraged to think about them care-
5 fully, and give serious consideration to recording your
6 wishes in an advance directive.”.

