

114TH CONGRESS
1ST SESSION

H. R. 4059

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 HOUSE OF REPRESENTATIVES

NOVEMBER 18, 2015

Mrs. BLACK (for herself, Mr. WELCH, Mr. THOMPSON of California, and Mr. COLLINS of New York) 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

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.

24 “(4) BEST PRACTICES.—In establishing and im-
25 plementing the Program, the Secretary shall con-

1 sider best practices within existing advance directive
2 registry technologies, programs, and systems, includ-
3 ing web-based or cloud-based advance directive tech-
4 nologies, which may utilize time and date stamps,
5 video, or other innovative measures to protect the
6 authenticity, improve the quality, and enhance the
7 security of such directives.

8 “(5) ENROLLMENT AND DISENROLLMENT.—

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

17 “(6) STATE LAW.—This section shall in no way

18 supercede, abrogate, or otherwise interfere with
19 State law governing advance directives. Under the
20 Program, the Secretary shall establish a process
21 under which the Secretary is required to verify that
22 digital advance directive vendors or other entities
23 providing a digital advance directive participating in
24 the program enable those using their services to
25 complete advance directives that fully comply with

1 the law governing advance directives of the State in-
2 volved.

3 “(7) DISPLAY OF STATUTORY AND ALTER-
4 NATIVE ADVANCE DIRECTIVE FORMS.—Under the
5 Program, the Centers for Medicare & Medicaid Serv-
6 ices shall provide, through a clearinghouse website,
7 links to statutory and alternative advance directive
8 forms and a State-by-State index to such forms to
9 allow a beneficiary to create, adopt, modify, and ter-
10 minate an advance directive with any content per-
11 mitted or required, and in any form authorized by
12 a State, in accordance with the requirements of sub-
13 paragraphs (C) through (E) of subsection (e)(1) and
14 subsection (e)(2).

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

17 “(A) SPECIAL ACCESS.—The Secretary
18 shall establish a process whereby, with respect
19 to a beneficiary with a certified advance direc-
20 tive, a person described in subparagraph (B)
21 may obtain access to the beneficiary’s advance
22 directive for the purposes of viewing and shar-
23 ing such advance directive when—

24 “(i) the provisions of the advance di-
25 rective have come into force under the ap-

1 applicable State’s law because the beneficiary
2 has become incapable of making health
3 care decisions or under other cir-
4 cumstances provided under State law; and

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

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

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

22 “(ii) if the applicable State’s law does
23 not designate persons or classes of persons
24 described in clause (i), any person related

1 within the third degree of consanguinity or
2 affinity to the beneficiary.

3 “(b) REGISTRATION.—

4 “(1) IN GENERAL.—The Secretary shall estab-
5 lish procedures for an eligible beneficiary to register
6 such beneficiary’s adoption of a certified advance di-
7 rective under the Program. Such procedures shall
8 ensure that registration is available through an on-
9 line process. The Secretary shall also establish pro-
10 cedures to ensure Program participants can update
11 previously registered information that is no longer
12 accurate and indicate that an advance directive has
13 been terminated.

14 “(2) REQUIRED INFORMATION.—In addition to
15 such other information as the Secretary may deem
16 appropriate, an eligible beneficiary seeking to reg-
17 ister a certified advance directive under the Program
18 shall indicate where the advance directive is main-
19 tained.

20 “(3) REGISTRATION PERIODS.—The procedures
21 established under paragraph (1) shall provide that
22 registration under the Program shall occur during—

23 “(A) an eligible beneficiary’s initial enroll-
24 ment under an MA plan under part C as de-

1 scribed in paragraph (1) of section 1851(e);
2 and

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

5 “(4) PRIVACY AND SECURITY.—

6 “(A) IN GENERAL.—The Secretary shall
7 ensure that all aspects of the registration sys-
8 tem comply with the Federal regulations (con-
9 cerning the privacy of individually identifiable
10 health information) promulgated under section
11 264(c) of the Health Insurance Portability and
12 Accountability Act of 1996 subject to the access
13 authorized under subsection (a)(8) and sub-
14 section (c)(2)(D).

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

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

23 “(ii) those authorized to access the
24 advance directive under subsection (a)(8)
25 and subsection (c)(2)(D); and

1 “(iii) providers of services and sup-
2 pliers participating under this title,
3 through a process established by the Sec-
4 retary.

5 “(c) ACCREDITATION.—

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

8 “(A) grant accreditation to advance direc-
9 tive vendors and other entities providing ad-
10 vance directives that meet the accreditation cri-
11 teria established under paragraph (2); and

12 “(B) establish a process whereby advance
13 directive vendors and other entities providing
14 advance directives may obtain accreditation
15 under this subsection.

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

23 “(A) PROCESS FOR ADOPTING ADVANCE
24 DIRECTIVE.—The advance directive vendor or
25 other entity providing an advance directive shall

1 allow a beneficiary to create, adopt, modify, and
2 terminate an advance directive through an on-
3 line process.

4 “(B) VENDORS.—The advance directive
5 vendor or other entity providing an advance di-
6 rective shall comply with an annual quality re-
7 view to be conducted by the Secretary.

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

17 “(D) ACCESS.—The advance directive ven-
18 dor or other entity providing an advance direc-
19 tive shall maintain advance directives in such a
20 way that—

21 “(i) an eligible beneficiary who has
22 adopted an advance directive with such
23 vendor or entity and any family member,
24 legal representative, or health care proxy
25 legally designated by such beneficiary has

1 direct, near real-time online access to the
2 beneficiary's advance directive for purposes
3 of viewing and sharing such advance direc-
4 tive;

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.

22 “(E) PRIVACY PROTECTIONS.—

23 “(i) IN GENERAL.—The advance di-
24 rective vendor or other entity providing an
25 advance directive shall comply with the

1 Federal regulations (concerning the privacy
2 of individually identifiable health informa-
3 tion) promulgated under section 264(c) of
4 the Health Insurance Portability and Ac-
5 countability Act of 1996 (42 U.S.C.
6 1320d–2 note), subject to the access au-
7 thorized under subparagraph (D) and sub-
8 section (a)(8).

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

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

22 “(i) all data management and data
23 transfer elements involved in adopting,
24 maintaining, and accessing the advance di-
25 rective have successfully passed rigorous

1 independent testing regarding standards of
2 timeliness, accuracy, and efficiency;

3 “(ii) the data management and data
4 transfer elements involved in adopting,
5 maintaining, and accessing the advance di-
6 rective meet widely accepted industry secu-
7 rity standards; and

8 “(iii) the system that provides access
9 to the advance directive has passed real-
10 time tests simulating a realistic volume of
11 beneficiaries and providers accessing ad-
12 vance directives simultaneously.

13 “(G) CERTIFIED ADVANCE DIRECTIVES.—

14 The advance directive vendor or other entity
15 providing an advance directive shall agree to
16 offer certified advance directives (as defined in
17 subsection (a)(2)(A)).

18 “(H) BENEFICIARY SURVEYS.—

19 “(i) IN GENERAL.—The advance di-
20 rective vendor or other entity providing an
21 advance directive shall agree to administer
22 annual beneficiary surveys on the informa-
23 tion described in clause (ii) and submit the
24 results of such surveys to the Centers for
25 Medicare & Medicaid Services.

1 “(ii) INFORMATION.—The information
2 described in this clause, with respect to an
3 annual beneficiary survey and certified ad-
4 vance directive of a beneficiary, is the fol-
5 lowing:

6 “(I) Whether the beneficiary had
7 to pay any third party for the cre-
8 ation, storage, or retrieval of the cer-
9 tified advance directive.

10 “(II) Whether the beneficiary
11 had a health care encounter or emer-
12 gency that required the location, ac-
13 cess, retrieval, or consultation of the
14 certified advance directive and if so,
15 whether the certified advance directive
16 was accessible in online and in near
17 real-time, as required under this sec-
18 tion.

19 “(III) Whether the certified ad-
20 vance directive was actionable.

21 “(IV) Whether medical personnel
22 followed the certified advance direc-
23 tive.

24 “(d) INCENTIVE.—

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

6 “(2) AMOUNT.—

7 “(A) IN GENERAL.—For purposes of para-
8 graph (1), the amount specified in this para-
9 graph is—

10 “(i) for a beneficiary who registers a
11 certified advance directive with the Pro-
12 gram in 2015, \$75; or

13 “(ii) for a beneficiary who registers a
14 certified advance directive with the Pro-
15 gram in a subsequent year, the amount
16 specified in this paragraph for the pre-
17 ceding year increased by the percentage in-
18 crease in the Chained Consumer Price
19 Index for All Urban Consumers (as pub-
20 lished by the Bureau of Labor Statistics of
21 the Department of Labor) over the pre-
22 ceding year.

23 “(B) ROUNDING.—If any amount deter-
24 mined under subparagraph (A) is not a multiple

1 of 10 cents, such amount shall be rounded to
2 the nearest multiple of 10 cents.

3 “(3) ADMINISTRATION.—The Secretary shall,
4 through a full notice and comment rulemaking proc-
5 ess, establish procedures for—

6 “(A) making the incentive payment di-
7 rectly to the eligible beneficiary or a personal
8 account maintained by the beneficiary at a fi-
9 nancial institution that has been designated by
10 the beneficiary, and ensuring that no other enti-
11 ty receives the payment on the beneficiary’s be-
12 half; and

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

16 “(e) EDUCATION AND OUTREACH.—

17 “(1) IN GENERAL.—The Secretary shall provide
18 for—

19 “(A) the inclusion of the statement set
20 forth in paragraph (3) in the Medicare and You
21 handbook under section 1804 and on a clear-
22 inghouse website linked to the Internet website
23 of the Centers for Medicare & Medicaid Serv-
24 ices;

1 “(B) the promotion of the benefits of elec-
2 tronic advance directives services, as they be-
3 come available, through the use of mass com-
4 munications and other means;

5 “(C) the inclusion, under the heading
6 ‘Statutory Advance Directive Forms’, of any
7 relevant forms, whether mandatory or optional,
8 specified in the statutes or regulations of the
9 States to be displayed on a clearinghouse
10 website;

11 “(D) the inclusion, under the heading ‘Al-
12 ternative Advance Directive Forms,’ on a sepa-
13 rate clearinghouse website, and in accordance
14 with paragraph (2)—

15 “(i) of other advance directive forms
16 submitted to the Secretary by individuals
17 and groups in an electronic format speci-
18 fied by the Secretary for which the submit-
19 ting entity includes, for each form sub-
20 mitted, an opinion by an attorney licensed
21 to practice in the relevant State dem-
22 onstrating that the submitted form com-
23 plies with the law of that State; and

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

1 ‘This website includes for your consider-
 2 ation alternative advance directive forms
 3 submitted by individuals or groups reflect-
 4 ing different perspectives on advance
 5 health care decisions which you may wish
 6 to review before completing your own ad-
 7 vance directive.’; and

8 “(E) the inclusion of a user friendly index
 9 on the clearinghouse website by State and, in
 10 the case of the ‘Alternative Advance Directive
 11 Forms’, by the name of the provider, so that a
 12 user may readily access those statutory and al-
 13 ternative forms.

14 “(2) ALTERNATIVE ADVANCE DIRECTIVE
 15 FORMS.—

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

18 “(i) Not later than 60 days after re-
 19 ceiving an advance directive form sub-
 20 mitted under such paragraph, the Sec-
 21 retary shall either post the submitted form
 22 on a clearinghouse website or provide to
 23 the submitting entity a detailed expla-
 24 nation of the basis for the Secretary’s de-
 25 termination that the submitted form does

1 not comply with relevant State or Federal
2 law, which determination shall be subject
3 to judicial review under section 702 of title
4 5 of the United States Code; and

5 “(ii) the Secretary shall either remove
6 or refuse to post any submitted form if
7 provided with an official determination by
8 the Attorney General of the applicable
9 State that the form is not in compliance
10 with State law, subject to applicable State
11 law described in subparagraph (B).

12 “(B) STATE LAW DESCRIBED.—For pur-
13 poses of subparagraph (A), State law described
14 in this subparagraph is—

15 “(i) a ruling by a court of the applica-
16 ble State, or by a Federal court applying
17 that State’s law, subject to subsequent rul-
18 ings by a court or courts with authority to
19 supercede that ruling; or

20 “(ii) a statute or regulation of the ap-
21 plicable State that provides for a specific
22 procedure for officially determining wheth-
23 er particular advance directive forms com-
24 ply with State law.

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

5 “WHY YOU MAY WANT TO CONSIDER AN ‘AD-
6 VANCE DIRECTIVE’ Do you ever worry what would
7 happen if you became unable to make health care decisions
8 for yourself because of an illness or injury? That’s what
9 an ‘advance directive’ is for. You can use it to give direc-
10 tions for your health care providers and family about your
11 health care wishes that are to be followed if you are no
12 longer able to speak for yourself. You can also name some-
13 one you trust, like a family member or friend, to give
14 health care directions for you when you can’t do so your-
15 self.

16 “You should consider carefully who to choose to
17 speak for you and what directions you want to give to en-
18 sure your representative clearly reflects your own values
19 and treatment preferences. You should not feel pressured
20 to violate your own values and preferences, and you are
21 entitled to implement them without discrimination based
22 on age or degree of disability.

23 “There are many resources to help you.

24 “By choosing the name of a state at [INSERT name
25 of webpage for the index provided in paragraph 4 of this

1 subsection and its URL (and, on the clearinghouse
2 website, include a hyperlink to it)], you can find sample
3 advance directives for that state. You can see any sample
4 or required forms given in state law, as well as others from
5 individuals or groups with different viewpoints on advance
6 health care decisions which you may wish to review before
7 completing your own advance directive.

8 “Below is contact information for accredited vendors
9 who will arrange for your advance directive to be confiden-
10 tially kept online, where it can be seen by doctors who
11 are treating you so they are made aware of your wishes.
12 You can also give permission to certain other people, like
13 family members or friends, you want to be able to get a
14 copy of your advance directive. If a disagreement about
15 your treatment develops, depending on your state’s law
16 certain other people may also be allowed to see it.

17 “These vendors can also help you create an advance
18 directive online or with paper documents, if you wish. On-
19 line directives allow you to change or cancel one that no
20 longer fits with your wishes in a more timely manner.

21 “[INSERT, in alphabetical order, the names and
22 contact information for currently accredited advance di-
23 rective vendors (and, on the clearinghouse website,
24 hyperlinks to their websites).]

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

7 “In addition, some Medicare Advantage plans or sup-
8 plemental insurance plans may offer a financial incentive
9 or other additional benefits for creating an advance direc-
10 tive online.

11 “By completing an advance directive you can not only
12 make it more likely that your wishes about health care
13 will be known if you are unable to tell them at the time,
14 but also spare family, friends, and doctors the difficulty
15 of trying to figure out what you would have wanted. These
16 are matters of the highest importance that can affect life-
17 or-death decisions, as well as your future comfort and
18 well-being. You are encouraged to think about them care-
19 fully, and give serious consideration to recording your
20 wishes in an advance directive.”.

