

## A-Engrossed

# Senate Bill 215

Ordered by the Senate April 18  
Including Senate Amendments dated April 18

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### SUMMARY

The following summary is not prepared by the sponsors of the measure and is not a part of the body thereof subject to consideration by the Legislative Assembly. It is an editor's brief statement of the essential features of the measure.

Directs Oregon Health Authority to establish and operate statewide database for collection and dissemination of orders for rare disease emergency response medical treatment for purpose of ensuring safe treatment of individuals with rare diseases in emergency situations. **For purpose of collecting and disseminating orders, provides that authority may use existing electronic database that emergency departments use to exchange information.** Creates Oregon ORDER Database Advisory Committee to advise authority on establishment, operation and evaluation of database.

### 1 A BILL FOR AN ACT

2 Relating to emergency response medical treatment necessary to treat a rare disease.

3 **Be It Enacted by the People of the State of Oregon:**

4       **SECTION 1. Definitions.** As used in sections 1 to 8 of this 2017 Act:

5       (1) “Authorized user” means a person authorized by the Oregon Health Authority to  
6 provide information to or receive information from the database established under section 2  
7 of this 2017 Act.

8       (2) “Emergency response medical treatment” means an emergency medical procedure,  
9 the emergency administration of a pharmaceutical or medical device or any other emergency  
10 medical intervention that is necessary to prevent medical complications and maintain life.

11       (3) “Nurse practitioner” has the meaning given that term in ORS 678.010.

12       (4) “ORDER” means an order for rare disease emergency response medical treatment  
13 that is necessary to treat a rare disease and that has been signed by a physician, nurse  
14 practitioner or physician assistant.

15       (5) “Physician” has the meaning given that term in ORS 677.010.

16       (6) “Physician assistant” has the meaning given that term in ORS 677.495.

17       (7) “Rare disease” means a disease, disorder, allergy or mental health condition that, in  
18 the professional judgment of a physician, nurse practitioner or physician assistant, is rare  
19 and may require emergency response medical treatment.

20       **SECTION 2. Establishment of database; rules.** (1) The Oregon Health Authority shall es-  
21 tablish and operate a statewide database for the collection and dissemination of orders for  
22 rare disease emergency response medical treatment to ensure the safe treatment of indi-  
23 viduals with rare diseases in emergency situations. For the purpose of collecting and dis-  
24 seminating orders under this subsection, the authority may use an existing electronic

NOTE: Matter in **boldfaced** type in an amended section is new; matter [*italic and bracketed*] is existing law to be omitted.  
New sections are in **boldfaced** type.

1 database that emergency departments use to exchange information, provided that the au-  
2 thority determines that the electronic database is an effective means of collecting and dis-  
3 seminating the orders. The database must be available for use by emergency medical service  
4 providers, hospitals, urgent care centers and the State Police.

5 (2) The authority shall adopt rules for the database established under subsection (1) of  
6 this section, including rules that:

7 (a) Require the submission of the following documents to the database, unless the patient  
8 has requested to opt out of the database:

9 (A) A copy of each ORDER;

10 (B) A copy of each revised ORDER; and

11 (C) Notice of each revocation of an ORDER;

12 (b) Prescribe the manner for submitting information to the database;

13 (c) Require the release of information from the database to authorized users;

14 (d) Provide notice by the database to authorized users of the receipt, revision or revo-  
15 cation of an ORDER; and

16 (e) Establish procedures to protect the accuracy and confidentiality of information sub-  
17 mitted to or released from the database.

18 (3) The authority may permit qualified researchers to access information kept in the  
19 database established under subsection (1) of this section. If the authority permits qualified  
20 researchers to access information under this subsection, the authority shall adopt rules  
21 governing that access, including rules that:

22 (a) Create a process by which a qualified researcher may request the access;

23 (b) Specify the types of information that may be accessed; and

24 (c) Establish the manner in which a qualified researcher must protect accessed infor-  
25 mation.

26 (4) The authority may contract with a private or public entity to establish or maintain  
27 the database established under subsection (1) of this section. A contract entered into under  
28 this subsection is exempt from the requirements of ORS chapters 279A, 279B and 279C.

29 **SECTION 3. Oregon Health Authority not required to perform certain acts.** Nothing in  
30 sections 1 to 8 of this 2017 Act requires the Oregon Health Authority to:

31 (1) Prescribe the form or content of an ORDER;

32 (2) Disseminate forms to be used for an ORDER;

33 (3) Educate the public about ORDERS; or

34 (4) Train health care professionals about ORDERS.

35 **SECTION 4. ORDER not required; revocation.** (1) Nothing in sections 1 to 8 of this 2017  
36 Act requires:

37 (a) An individual to have an ORDER; or

38 (b) A health care professional to authorize or execute an ORDER.

39 (2) An ORDER may be revoked at any time.

40 **SECTION 5. Oregon ORDER Database Advisory Committee; members; meetings; term.**

41 (1) There is established within the Oregon Health Authority the Oregon ORDER Database  
42 Advisory Committee to advise the authority on the establishment, operation and evaluation  
43 of the database established under section 2 of this 2017 Act.

44 (2) The members of the committee shall be appointed by the Director of the Oregon  
45 Health Authority and shall include, at a minimum:

1       (a) A health care professional who has experience in ORDER issues;  
2       (b) A physician who is a supervising physician, as defined in ORS 682.025, for emergency  
3 medical services providers, and who has experience in ORDER issues;

4       (c) A representative from the hospital community who has experience in ORDER issues;  
5       (d) A representative from the rare disease and disorder community who has experience  
6 in ORDER issues;

7       (e) A representative from a rare disease or disorder patient group who has experience in  
8 ORDER issues;

9       (f) An emergency medical services provider actively involved in providing emergency  
10 medical services; and

11      (g) Two members of the public who have an active interest in emergency response med-  
12 ical treatment situations, at least one of whom represents the interests of minorities.

13      (3) The Director of the Emergency Medical Services and Trauma Systems Program  
14 within the Oregon Health Authority, or a designee of the director, shall serve as a voting ex  
15 officio member of the committee.

16      (4) The Director of the Oregon Health Authority may appoint additional members to the  
17 committee.

18      (5) The committee shall meet at least four times per year, at times and places specified  
19 by the Director of the Oregon Health Authority.

20      (6) Except for the member described in subsection (3) of this section, a member of the  
21 committee shall serve a term of two years. Before the expiration of the term of a member,  
22 the Director of the Oregon Health Authority shall appoint a successor whose term begins  
23 on January 2 next following. A member is eligible for reappointment. If there is a vacancy  
24 for any cause, the Director of the Oregon Health Authority shall make an appointment to  
25 become immediately effective for the unexpired term.

26      (7) The Director of the Oregon Health Authority, or a designee of the director, shall  
27 consult with the committee in drafting rules on the establishment, operation and evaluation  
28 of the database established under section 2 of this 2017 Act.

29      SECTION 6. Confidentiality. Except as provided in section 2 of this 2017 Act, all infor-  
30 mation kept in the database established under section 2 of this 2017 Act that identifies or  
31 that could be used to identify a patient, health care professional or health care facility is  
32 confidential and not subject to civil or administrative subpoena or to discovery in a civil or  
33 administrative action.

34      SECTION 7. Immunity from liability. Any person reporting information to, or acting in  
35 good faith on information released from, the database established under section 2 of this 2017  
36 Act is immune from any civil or criminal liability that might otherwise be incurred or im-  
37 posed with respect to the reporting of, or the acting on, the information.

38      SECTION 8. Short title. Sections 1 to 8 of this 2017 Act shall be known and may be cited  
39 as the Oregon ORDER Database Act.

40      SECTION 9. Initial term of membership for Oregon ORDER Database Advisory Commit-  
41 tee. Notwithstanding the term of office specified in section 5 of this 2017 Act, of the members  
42 described in section 5 (2) of this 2017 Act who are first appointed to the Oregon ORDER  
43 Database Advisory Committee:

44       (1) Four shall serve for terms ending January 1, 2019.

45       (2) The remaining members shall serve for terms ending January 1, 2020.

1        **SECTION 10. Captions.** The section captions used in this 2017 Act are provided only for  
2        the convenience of the reader and do not become part of the statutory law of this state or  
3        express any legislative intent in the enactment of this 2017 Act.  
4        \_\_\_\_\_