

1 AN ACT relating to the Kentucky statewide health data utility.

2 *Be it enacted by the General Assembly of the Commonwealth of Kentucky:*

3 ➔SECTION 1. A NEW SECTION OF KRS CHAPTER 7 IS CREATED TO
4 READ AS FOLLOWS:

5 *(1) The Kentucky statewide health data utility is established in Sections 1 to 9 of this*
6 *Act to effectuate the following purposes:*

7 *(a) Create a seamless, transparent, and secure approach to health information*
8 *sharing and exchange among broad health care and health care*
9 *coordination settings that:*

10 *1. Uses health information technology to support health-related*
11 *functions, including without limitation:*

12 *a. A patient's health care experience;*

13 *b. The overall health of the population; and*

14 *c. Health care quality and value;*

15 *2. Improves patient outcomes and the overall health and well-being of*
16 *Kentucky residents by:*

17 *a. Creating administrative efficiencies in health care delivery; and*

18 *b. Preventing health care errors;*

19 *3. Identifies opportunities for savings while improving health outcomes;*

20 *4. Informs state health care planning;*

21 *5. Improves the accessibility, adequacy, and affordability of health care*
22 *and health coverage through the review and dissemination of data;*

23 *6. Evaluates the effectiveness of health care programs and services to*
24 *improve patient outcomes; and*

25 *7. Supports the development of quality improvement initiatives;*

26 *(b) Operate and govern a statewide health data utility that:*

27 *1. Represents the interests and meets the needs of:*

- 1 a. Patients;
- 2 b. The health care sector; and
- 3 c. The General Assembly;
- 4 2. Ensures the integrity, privacy, and security of personal health
- 5 information and other proprietary information related to the collection
- 6 and release of data;
- 7 3. Promotes best practices for health information sharing and exchange;
- 8 4. Provides data to authorized recipients, as allowed by law; and
- 9 5. Makes meaningful and relevant information available to the public;
- 10 (c) Ensure the creation of clear data governance, privacy, and security policies
- 11 to facilitate the sharing and exchange of health information through the
- 12 statewide health data utility;
- 13 (d) Demonstrate a commitment to respecting personal privacy by establishing
- 14 protocols and standards that:
- 15 1. Ensure compliance with all applicable state and federal data privacy
- 16 and security laws relating to the collection, storage, and release of
- 17 data; and
- 18 2. Allow an opt-out for patients who choose not to share their personal
- 19 data;
- 20 (e) Promote a policy of health information sharing and exchange that follows
- 21 the patient and improves the health of Kentucky residents; and
- 22 (f) Establish a duty for health care professionals, health facilities, health care
- 23 payers, and other persons that deliver, administer, or coordinate health care
- 24 to share and exchange information for the purpose of optimizing patient
- 25 and population health, as allowed by law.
- 26 (2) Sections 1 to 9 of this Act shall not be construed to create a health benefit
- 27 network or other type of health insurance network.

1 ➔SECTION 2. A NEW SECTION OF KRS CHAPTER 7 IS CREATED TO
2 READ AS FOLLOWS:

3 *As used in Sections 1 to 9 of this Act:*

4 *(1) "Authorized recipient" means a person that is provided access to health*
5 *information in the statewide health data utility, which may include any of the*
6 *following:*

7 *(a) The General Assembly;*

8 *(b) The Commission;*

9 *(c) Any committee, task force, office, division, or entity of the General*
10 *Assembly or Commission;*

11 *(d) Health care professionals;*

12 *(e) Health facilities;*

13 *(f) Health care payers;*

14 *(g) Health care purchasers;*

15 *(h) Patients;*

16 *(i) Members of academia engaged in health-related research;*

17 *(j) The public; and*

18 *(k) Any other persons designated by the Commission in an administrative*
19 *regulation promulgated in accordance with KRS Chapter 13A;*

20 *(2) "Commission" means the Legislative Research Commission created in KRS*
21 *7.090;*

22 *(3) "Electronic longitudinal health record" means an electronic collection of health*
23 *information about the health status of an individual that:*

24 *(a) Is compiled over time;*

25 *(b) May be derived from multiple sources; and*

26 *(c) Includes the individual's:*

27 *1. Clinical data;*

- 1 2. Health care claims data;
- 2 3. Social referrals; and
- 3 4. Designated public health data, including but not limited to
- 4 immunizations and laboratory data;
- 5 (4) "Federally-qualified health center" has the same meaning as in 42 U.S.C. sec.
- 6 1396d, as amended;
- 7 (5) "Health care claims data" means data relating to claims made for the payment or
- 8 reimbursement of the following types of health care services:
- 9 (a) Medical and hospital, which includes without limitation surgical, mental
- 10 health, substance use disorder, nursing, habilitative and rehabilitative, and
- 11 laboratory;
- 12 (b) Dental;
- 13 (c) Pharmacy; and
- 14 (d) Any other health care services designated by the Commission by
- 15 administrative regulation promulgated in accordance with KRS Chapter
- 16 13A;
- 17 (6) "Health care payer" means any of the following, to the extent the person, plan,
- 18 or program makes payments or reimbursements for, or administers the payment
- 19 or reimbursement of, health care services:
- 20 (a) Medicare;
- 21 (b) Medicaid;
- 22 (c) The Kentucky Children's Health Insurance Program;
- 23 (d) Any state or local government health plan or program regulated, created, or
- 24 authorized under Kentucky law, including without limitation:
- 25 1. Any plan or program offered or administered under KRS Chapter 205;
- 26 and
- 27 2. Any governmental plan, as defined in 29 U.S.C. sec. 1002, including

- 1 any plan offered to the Public Employee Health Insurance Program
2 for public employees under KRS 18A.225 or 18A.2254;
- 3 (e) Any federal health plan or program that provides coverage in Kentucky for
4 health care services;
- 5 (f) Any insurers or administrators offering or administering a plan or program
6 identified in paragraph (d) or (e) of this subsection;
- 7 (g) Any federal, state, or local government cabinet, agency, department, entity,
8 or official that provides, or contracts with a third-party administrator to
9 administer, a plan or program identified in paragraph (d) or (e) of this
10 subsection;
- 11 (h) Workers' compensation insurers, including governmental and
12 nongovernmental workers' compensation self-insurers and self-insured
13 groups;
- 14 (i) Insurers, self-insurers, and self-insured groups, including governmental
15 and nongovernmental self-insured employers, self-insured health plans, and
16 self-insured employer-organized associations, that provide:
- 17 1. Coverage for health care services;
18 2. Health care benefits; or
19 3. Any kind of insurance regulated under KRS Chapter 304;
- 20 (j) Health maintenance organizations;
- 21 (k) Limited health service organizations;
- 22 (l) Provider-sponsored integrated health delivery networks;
- 23 (m) Nonprofit hospital, medical-surgical, dental, and health service
24 corporations;
- 25 (n) Administrators, as defined in KRS 304.9-051;
- 26 (o) Pharmacy benefit managers;
- 27 (p) Any other third-party payor that is subject to regulation under the insurance

1 laws of this state; and

2 (q) Any vendor or contractor of a person, plan, or program listed in this
3 subsection;

4 (7) "Health care professional":

5 (a) Means any individual who is licensed, certified, or otherwise authorized
6 under the laws of this state to administer or provide health care services in
7 the:

8 1. Ordinary course of business; or

9 2. Practice of a profession; and

10 (b) Includes:

11 1. Pharmacists; and

12 2. Home medical equipment and services providers;

13 (8) "Health care purchaser":

14 (a) Means an entity that purchases, or arranges the purchase of, coverage for
15 health care services or health care benefits for a defined population; and

16 (b) Includes without limitation employers, labor unions, associations, and
17 governmental health benefit programs;

18 (9) "Health facility":

19 (a) Has the same meaning as in KRS 216B.015; and

20 (b) Includes a:

21 1. Pharmacy;

22 2. Medical laboratory;

23 3. Facility that provide habilitative and rehabilitative services, including
24 without limitation physical, occupational, and speech therapy services;

25 4. Federally-qualified health center; and

26 5. Public health agency;

27 (10) "Health information":

1 (a) Means any information, including genetic information, whether oral or
2 recorded in any form or medium, that:

3 1. Is created or received by a participant; and

4 2. Relates to the:

5 a. Past, present, or future physical or mental health or condition of
6 an individual;

7 b. Provision of health care to an individual; or

8 c. Past, present, or future payment or reimbursement for the
9 provision of health care to an individual; and

10 (b) Includes the following:

11 1. Health information as defined in 45 C.F.R. sec. 160.103, as amended,
12 that is created or received by a participant;

13 2. Health care claims data; and

14 3. Actions taken by a participant in the participant's capacity as a public
15 health authority under HIPAA or as required or permitted under other
16 federal or state law relating to public health activities;

17 (11) "Health information technology":

18 (a) Means the application of information processing, involving computer
19 hardware and software, to electronically store, retrieve, share, and use
20 health information; and

21 (b) Includes the creation of the following electronic records, functions, and
22 tools:

23 1. Electronic longitudinal health records;

24 2. Personal health records through which an individual or any other
25 person authorized by the individual can maintain and manage the
26 individual's health information;

27 3. Health records that are:

- 1 a. Used by health care professionals to electronically document,
 2 monitor, and manage health care delivery within a care delivery
 3 organization;
- 4 b. The legal record of a patient's encounter with the care delivery
 5 organization; and
- 6 c. Owned by the care delivery organization;
- 7 4. Diagnostic and treatment services records, including records of the
 8 prescribing and dispensing of medication;
- 9 5. Decision support functions to assist health care professionals in
 10 making clinical decisions by providing electronic alerts and reminders
 11 to:
- 12 a. Improve compliance with best practices;
- 13 b. Promote regular screenings; or
- 14 c. Promote other preventive practices to facilitate diagnosis and
 15 treatments; and
- 16 6. Tools to allow for the collection, analysis, and reporting of
 17 information or data on:
- 18 a. Adverse health events;
- 19 b. The quality and efficiency of health care;
- 20 c. Patient satisfaction; and
- 21 d. Other performance measures related to health care;
- 22 (12) "HIPAA" means the federal Health Insurance Portability and Accountability Act
 23 of 1996, Pub. L. No. 104-191, as amended, and any related federal regulations, as
 24 amended;
- 25 (13) "Interoperability":
- 26 (a) Means the ability of two (2) or more persons, systems, or components to
 27 exchange, and use exchanged, information or data in an accurate, effective,

1 secure, and consistent manner; and

2 (b) Includes without limitation the:

3 1. Capacity to connect to a network for the purpose of exchanging
4 information or data with other users;

5 2. Ability of a connected, authenticated user to demonstrate appropriate
6 permissions to participate in an instant transaction over a network;
7 and

8 3. Capacity of a connected, authenticated user to access, transmit,
9 receive, and exchange usable information with other users;

10 (14) "Kentucky statewide health data utility" or "statewide health data utility" means
11 the statewide health data utility established in Sections 1 to 9 of this Act;

12 (15) "Participant" means any of the following:

13 (a) A health facility;

14 (b) A health care payer;

15 (c) An entity engaged in the sharing of community information or social
16 determinants of health; and

17 (d) A person that is not required under state or federal law to comply with
18 Section 8 of this Act, but otherwise elects to submit health information to
19 the Kentucky statewide health data utility;

20 (16) "Person" includes:

21 (a) A natural person;

22 (b) Any type or form of corporation, company, partnership, proprietorship,
23 association, plan, program, or other legal entity; and

24 (c) A government, governmental subdivision or agency, or other body politic;
25 and

26 (17) "Public health agency" means an entity that is governed by or contractually
27 responsible to a local health department, the cabinet, or a state agency to provide

1 services focused on the health status of population groups and their
2 environments.

3 ➔SECTION 3. A NEW SECTION OF KRS CHAPTER 7 IS CREATED TO
4 READ AS FOLLOWS:

5 (1) The Kentucky statewide health data utility fund is hereby established as a
6 restricted fund in the State Treasury.

7 (2) The following shall be deposited into the fund:

8 (a) All grants, gifts, and funds received or raised under Section 4 of this Act;

9 (b) Any fees charged to authorized recipients for access to data in the statewide
10 health data utility;

11 (c) Any penalties collected under Section 9 of this Act; and

12 (d) Any appropriations made to the fund by the General Assembly.

13 (3) Notwithstanding KRS 45.229, moneys in the fund not expended at the close of a
14 fiscal year shall not lapse but shall be carried forward to the next fiscal year.

15 (4) Moneys in the fund shall be available to the Commission, who may use or direct
16 the use of the moneys in the development, implementation, operation, and
17 maintenance of the Kentucky statewide health data utility.

18 ➔SECTION 4. A NEW SECTION OF KRS CHAPTER 7 IS CREATED TO
19 READ AS FOLLOWS:

20 (1) The Kentucky statewide health data utility shall, to the extent elected under
21 subsection (2) of this section, be developed, implemented, operated, and
22 maintained in accordance with Sections 1 to 9 of this Act.

23 (2) The Commission may elect to carry out one (1) or more duties in subsection (1) of
24 this section.

25 (3) If the Commission elects to carry out one (1) or more duties in subsection (1) of
26 this section, the Commission:

27 (a) May seek and accept grants or gifts, or raise funds, from any available

1 source, public or private, to support the development, implementation,
2 operation, and maintenance of the statewide health data utility;

3 (b) May establish agreements:

4 1. For voluntary reporting of health information from participants that
5 are not subject to the mandatory reporting requirements under Section
6 8 of this Act; and

7 2. With the federal Centers for Medicare and Medicaid Services to obtain
8 Medicare health care claims data and other health information;

9 (c) May establish the following:

10 1. Agreements with health data utilities in other states, including all-
11 payer claims databases, to establish a single application for access to
12 data by authorized recipients across multiple states; and

13 2. Agreements with state and federal agencies and other health data
14 utilities and health databases to share and receive health information
15 or other data, including confidential and proprietary information or
16 data, if:

17 a. The recipient agrees in a written or electronic record to maintain
18 any confidential or proprietary status afforded to the information
19 or data; and

20 b. The information or data is shared or received in a manner that
21 does not violate any applicable laws;

22 (d) Shall ensure the statewide health data utility is operated in compliance with
23 all state and federal law, including without limitation:

24 1. HIPAA; and

25 2. 42 U.S.C. sec. 290dd-2, as amended, and any related federal
26 regulations, as amended, including without limitation 42 C.F.R. pt. 2;

27 (e) Shall promulgate administrative regulations in accordance with KRS

1 Chapter 13A to establish policies and procedures that are necessary to carry
2 out any function elected by the Commission, which shall include
3 establishing:

4 1. a. Subject to subdivision b. of this subparagraph:

5 i. Health information sharing and submission requirements
6 for one (1) or more participants; and

7 ii. The reporting format, and frequency of submissions, for
8 health information submitted by participants to the
9 commission.

10 b. The requirements established under this subparagraph shall
11 comply with:

12 i. Interoperability guidance published by the federal Centers
13 for Medicare and Medicaid Services; and

14 ii. All applicable federal and state data privacy and security
15 laws, including without limitation HIPAA.

16 2. Subject to Section 9 of the Act, the schedule of penalties for any
17 participant that fails to comply with the mandatory reporting
18 requirements under Section 8 of this Act;

19 3. A list of authorized recipients;

20 4. a. Subject to subdivision b. of this subparagraph, the data elements
21 that will be available to each authorized recipient.

22 b. Data shall not be made available to an authorized recipient
23 unless the data:

24 i. Complies with all applicable federal and state data privacy
25 and security laws, including without limitation HIPAA;
26 and

27 ii. Cannot be used to identify an individual, unless identifying

1 information about an individual is otherwise required to
 2 carry out a purpose set forth in subsection (2)(b)2.b. or c.
 3 of Section 5 of this Act; and

4 5. Any fees that may be charged to authorized recipients for access to
 5 data in the statewide health data utility, except a fee shall not be
 6 charged to or required of the General Assembly, the Commission, or a
 7 committee, task force, office, division, or other entity of the General
 8 Assembly or Commission; and

9 (f) May contract with one (1) or more vendors or third parties, which may be
 10 public or private persons, to:

11 1. Operate or govern, in whole or in part, the statewide health data utility
 12 in accordance with Sections 1 to 9 of this Act; and

13 2. For any expertise, service, or function that is necessary to assist the
 14 commission in carrying out the Commission's duties under Sections 1
 15 to 9 of this Act.

16 ➔SECTION 5. A NEW SECTION OF KRS CHAPTER 7 IS CREATED TO
 17 READ AS FOLLOWS:

18 (1) As used in this section:

19 (a) "All-payer claims database" means a database that systematically collects
 20 health care claims data from health care payers;

21 (b) "Community information exchange":

22 1. Means an ecosystem comprised of multidisciplinary network partners
 23 that use standardized technical language, a resource database, and an
 24 integrated technology platform to deliver:

25 a. Enhanced community care planning; and

26 b. Tools to enable partners to integrate data from multiple sources
 27 and make bi-directional referrals to create shared longitudinal

1 records; and

2 2. Includes any system that:

3 a. Stores an individual's personal identifiable information in a
4 database that is shared by a network of one (1) or more health
5 facilities, health care professionals, health care payers, public
6 agencies, or community-based organizations for referral
7 purposes; and

8 b. Encompasses data sets containing personal referral information
9 captured and stored in a database for use by public and private
10 entities, including community-based organizations, to provide
11 services, update referral activity, and close the loop on a referral
12 by updating downstream systems;

13 (c) "Health care information exchange" means the movement and exchange
14 among and between health facilities and health care professionals of health
15 information electronically across organizations within a state, region,
16 community, or hospital system; and

17 (d) "Prescription information exchange" means the movement and exchange
18 among and between health facilities and health care professionals of health
19 information consisting of all medications dispensed by a pharmacy and
20 other related information electronically across organizations within a state,
21 region, community, or hospital system.

22 (2) At the election of the Commission as provided under Section 4 of this Act, the
23 Kentucky statewide health data utility may:

24 (a) Be the sole statewide network for the sharing and exchange of health
25 information;

26 (b) Utilize health information technology to:

27 1. Aggregate health information received from participants; and

- 1 2. Provide access, in a form and manner that ensures the privacy and
2 security of personal health information as required under federal and
3 state law, including without limitation HIPAA, to health information
4 in the statewide health data utility to authorized recipients for one (1)
5 or more of the following purposes:
- 6 a. Collecting and analyzing data to inform the authorized recipients
7 as to health care access, utilization, cost, safety, and quality in
8 Kentucky;
- 9 b. Enabling any health care professional or health facility to
10 evaluate and monitor care and treatment of patients;
- 11 c. Enabling any patient to access, through a technology enabled
12 interface, the patient's electronic longitudinal health record; and
- 13 d. Making information about health care services available to the
14 public, which may include allowing consumers to draw
15 meaningful comparisons between health facilities, health care
16 payers, and other health care professionals as relevant data is
17 available; and
- 18 (c) Contain one (1) or more of the following:
- 19 1. A health care information exchange;
- 20 2. A pharmacy information exchange;
- 21 3. An all-payer claims database;
- 22 4. A community information exchange; and
- 23 5. Other referential sources, including without limitation public health
24 data and self-generated data.
- 25 (3) (a) The information and data acquired by or contained in the statewide health
26 data utility shall not be subject to disclosure under KRS 61.870 to 61.884.
- 27 (b) This subsection shall not be construed to limit or prohibit the public release

1 of aggregated, deidentified information, reports, analyses, or dashboards by
2 the statewide health data utility in accordance with Sections 1 to 9 of this
3 Act.

4 ➔SECTION 6. A NEW SECTION OF KRS CHAPTER 7 IS CREATED TO
5 READ AS FOLLOWS:

6 (1) If the Commission elects to implement and operate one (1) or more functions of
7 the statewide health data utility either directly or through a vendor or third party
8 as provided in subsection (3)(f) of Section 4 of this Act, the Commission:

9 (a) Shall ensure that the statewide health data utility:

10 1. a. Complies with established national standards regarding data
11 accuracy and quality that shall include periodically conducting,
12 or contracting to conduct, audits of health information submitted
13 to the statewide health data utility to corroborate:

14 i. Compliance with Section 8 of this Act; and

15 ii. The accuracy, completeness, and timeliness of the
16 information.

17 b. Any audits conducted under this subparagraph shall, to the
18 extent practicable, be coordinated with other audits or
19 examinations performed by other state or federal agencies or
20 health utilities or databases;

21 2. Protects the:

22 a. Privacy of patients; and

23 b. Security and confidentiality of health information;

24 3. Facilitates and supports the secure, electronic exchange of health
25 information; and

26 4. Promotes interoperability;

27 5. Has a disaster recovery mechanism that allows access to health

1 information in the event of a disaster, a use of ransomware, a
2 cyberattack, or another emergency scenario;

3 6. Increases the accuracy, completeness, and uniformity of health
4 information; and

5 7. Allows a patient to opt out from including the patient's electronic
6 longitudinal health record in the statewide health data utility, except
7 an opt-out under this subparagraph shall not prevent the statewide
8 health data utility from including the patient's deidentified or
9 aggregated health care claims data or encounter data for the purpose
10 of population health monitoring, public health reporting, academic
11 research, or policy analysis, if the data cannot reasonably be used to
12 reidentify the patient;

13 (b) May provide a mechanism for participants without electronic health
14 information to provide health information to the statewide health data
15 utility;

16 (c) Shall use sound business and data governance practices consistent with the
17 goals of:

18 1. Public accountability;

19 2. Transparency; and

20 3. Improving health outcomes;

21 (d) Shall report to the Attorney General any finding made, or information
22 received, by the Commission that:

23 1. Relates to a person who is required to comply with Section 8 of this
24 Act; and

25 2. Indicates that the person referenced in subparagraph 1. of this
26 paragraph has, or may have, materially failed or willfully refused to
27 comply with Section 8 of this Act;

1 (e) Shall ensure that health information is accessible to authorized recipients in
2 a manner that:

3 1. For health information that is provided for the purpose of collecting
4 and analyzing data, allows for comparisons of:

5 a. Geographic, demographic, and economic factors; and

6 b. Institutional size; and

7 2. For health information that is provided to patients and the public, is
8 consumer friendly;

9 (f) For data that is made available to authorized recipients, shall establish a
10 process for requesting and accessing the data that:

11 1. Complies with subsection (3)(e)4. and 5. of Section 4 of this Act; and

12 2. May include requiring authorized recipients to enter into additional
13 data service agreements or memoranda of understanding prior to
14 accessing or using health information in the statewide health data
15 utility;

16 (g) Shall prohibit any person, including an authorized recipient, from accessing
17 or using health information in the statewide health data utility for any of
18 the following purposes:

19 1. To obtain or disclose trade secrets;

20 2. To reidentify or attempt to reidentify an individual's data or
21 information;

22 3. To distribute the data or information for a commercial purpose;

23 4. To take any action in violation of applicable data privacy or security
24 laws; or

25 5. For any purpose not authorized by the Commission;

26 (h) Shall require all authorized recipients to agree in a written or electronic
27 record to comply with paragraph (g) of this subsection prior to accessing or

- 1 using health information in the statewide health data utility; and
- 2 (i) Shall conduct a risk assessment and prepare a mitigation remediation plan
- 3 that:
- 4 1. Assesses risks to an individual's right to privacy within the statewide
- 5 health data utility where the individual does not possess immediate
- 6 control over the individual's information;
- 7 2. Recommends alternatives to both mitigate the risks and achieve the
- 8 stated objectives of the statewide health data utility; and
- 9 3. Identifies those individuals within the Commission who shall be
- 10 directly accountable for:
- 11 a. The assessment and plan;
- 12 b. The statewide health data utility at the time the assessment and
- 13 plan are conducted and prepared; and
- 14 c. The implementation of any approved alternatives and mitigations
- 15 as a result of the assessment and plan.

16 ➔SECTION 7. A NEW SECTION OF KRS CHAPTER 7 IS CREATED TO

17 READ AS FOLLOWS:

- 18 (1) There is hereby established the Kentucky Health Information Technology
- 19 Advisory Board, whose duties shall be to:
- 20 (a) Recommend policies and procedures for the sharing of health information
- 21 by participants under Sections 1 to 9 of this Act, including the submission of
- 22 health information by participants to the Commission;
- 23 (b) Actively promote improved health data utility governance practices across
- 24 the state;
- 25 (c) Identify pivotal health data utility governance roles and responsibilities
- 26 between government agencies and the private sector, as permitted by
- 27 applicable federal and state law;

1 (d) Provide advice on the Commission's data control, governance, and privacy
2 practices in compliance with federal and state information privacy and
3 security policies and laws;

4 (e) Provide advice on the Commission's privacy policies, related procedures,
5 and processes to operationalize policy-driven controls and effective risk
6 management methodologies, using industry standards; and

7 (f) Advise on, review, and make recommendations for:

8 1. The data elements that will be available to authorized recipients,
9 including specific strategies for ensuring the accessibility of data
10 related to health care access, utilization, cost, safety, and quality;

11 2. The process for authorized recipients to access and request data; and

12 3. Any other matters submitted to the board by the Commission.

13 (2) The board shall consist of:

14 (a) The following voting members:

15 1. Two (2) members of the House of Representatives, who shall be
16 appointed by the Speaker of the House of Representatives;

17 2. Two (2) members of the Senate, who shall be appointed by the
18 President of the Senate;

19 3. Two (2) appointed officials or employees of the Cabinet for Health and
20 Family Services, who shall be appointed by the secretary of the
21 Cabinet for Health and Family Services;

22 4. The Attorney General, or a designee of the Attorney General;

23 5. One (1) representative from the Kentucky Hospital Association;

24 6. One (1) representative from the Kentucky Medical Association;

25 7. One (1) representative from the Kentucky Pharmacists Association;

26 8. One (1) representative from the Kentucky Primary Care Association;

27 and

- 1 9. Two (2) at-large members, who shall be appointed by the Commission;
 2 and
 3 (b) A designee of the Commission as a nonvoting ex officio member, who shall
 4 serve as chair of the board.
- 5 (3) The members listed in subsection (2)(a) of this of this subsection:
 6 (a) Shall serve a term of four (4) years; and
 7 (b) May be reappointed.
- 8 (4) (a) The board shall meet upon the call of the chair.
 9 (b) A majority of the voting members shall constitute a quorum to do business.
 10 (c) Actions of the board shall require a:
 11 1. Quorum; and
 12 2. Majority of the voting members present.
 13 (d) A member shall be permitted to participate and vote in board business
 14 through distance communication technology.
- 15 (5) The board shall be a budget unit of the Commission, which shall:
 16 (a) Pay the board's necessary operating expenses; and
 17 (b) Furnish all office space, personnel, equipment, supplies, and technical or
 18 administrative services required by the board in the performance of the
 19 functions established in this section.
- 20 (6) Members of the board shall not receive compensation from the Commission for
 21 the member's service on the board, but shall receive actual and necessary travel
 22 expenses associated with attending meetings in accordance with state
 23 administrative regulations relating to travel reimbursement.

24 ➔SECTION 8. A NEW SECTION OF KRS CHAPTER 7 IS CREATED TO
 25 READ AS FOLLOWS:

- 26 (1) To the extent permitted under federal law:
 27 (a) A participant shall comply with all health information sharing and

1 submission requirements established for the participant by the Commission
 2 in administrative regulations promulgated in accordance with Section 4 of
 3 this Act; and

4 (b) Any person not required to comply with paragraph (a) of this subsection
 5 under state or federal law may elect to voluntarily submit health
 6 information to the Kentucky statewide health data utility.

7 (2) A person that is required to comply with subsection (1)(a) of this section shall
 8 enter into an agreement with the Commission to submit health information to the
 9 statewide health data utility not later than the last of the following to occur:

10 (a) Three (3) months after the relevant exchange or database within the
 11 statewide health data utility becomes operational; or

12 (b) The date the person begins to do business, operate, or otherwise engage in
 13 activity that requires compliance with subsection (1)(a) of this section.

14 ➔SECTION 9. A NEW SECTION OF KRS CHAPTER 7 IS CREATED TO
 15 READ AS FOLLOWS:

16 (1) (a) The Attorney General shall enforce the mandatory reporting requirements
 17 in Section 8 of this Act.

18 (b) In carrying out the duties under paragraph (a) of this subsection, the
 19 Attorney General:

20 1. Shall have the authority to receive complaints and conduct
 21 investigations, which includes:

22 a. Receiving sworn statements; and

23 b. Issuing subpoenas to compel the:

24 i. Attendance and testimony of witnesses; and

25 ii. Production of records and other documents;

26 2. May enter an order assessing a civil penalty in accordance with this
 27 section;

- 1 3. Shall have the power to invoke the aid of the courts through
2 injunction or other proper process to:
- 3 a. Enjoin any existing or threatened violation of Section 8 of this
4 Act; or
- 5 b. Enforce any proper order entered under this section; and
- 6 4. Shall provide a right to an administrative hearing in accordance with
7 KRS Chapter 13B prior to the entry of a final order assessing a civil
8 penalty under this section, except that if a person fails to request an
9 administrative hearing within twenty (20) days of the date of service of
10 any notice of intent to assess a civil penalty under this section, the
11 Attorney General may enter a final order assessing the civil penalty
12 without conducting a hearing.
- 13 (2) (a) Subject to paragraphs (b), (c), and (d) of this subsection, the Commission
14 shall promulgate an administrative regulation designating a schedule of
15 penalties, not to exceed one thousand dollars (\$1,000) per day, for any
16 participant that fails to comply with a mandatory reporting requirement for
17 that person under Section 8 of this Act.
- 18 (b) Local government, state, and federal agencies or entities shall not be subject
19 to or assessed a civil penalty under this section.
- 20 (c) The Attorney General shall promulgate an administrative regulation
21 designating the process for notice, hearing, and collection of any penalty
22 assessed under section.
- 23 (d) The Attorney General may, upon terms and conditions that are determined
24 by the Attorney General to be in the public interest, remit or mitigate any
25 penalty assessed under section.
- 26 (3) Any penalties collected by the Attorney General under this section shall be
27 deposited into the Kentucky statewide health data utility fund established in

1 **Section 3 of this Act.**

2 ➔Section 10. KRS 194A.030 is amended to read as follows:

3 The cabinet consists of the following major organizational units, which are hereby
4 created:

5 (1) Office of the Secretary. Within the Office of the Secretary, there shall be an Office
6 of Legal Services, an Office of Inspector General, an Office of Public Affairs, an
7 Office of Human Resource Management, an Office of Finance and Budget, an
8 Office of Legislative and Regulatory Affairs, an Office of Administrative Services,
9 an Office of Application Technology Services, an Office of Data Analytics, and an
10 Office of Medical Cannabis as follows:

11 (a) The Office of Legal Services shall provide legal advice and assistance to all
12 units of the cabinet in any legal action in which it may be involved. The
13 Office of Legal Services shall employ all attorneys of the cabinet who serve
14 the cabinet in the capacity of attorney, giving legal advice and opinions
15 concerning the operation of all programs in the cabinet. The Office of Legal
16 Services shall be headed by a general counsel who shall be appointed by the
17 secretary with the approval of the Governor under KRS 12.050 and 12.210.
18 The general counsel shall be the chief legal advisor to the secretary and shall
19 be directly responsible to the secretary. The Attorney General, on the request
20 of the secretary, may designate the general counsel as an assistant attorney
21 general under the provisions of KRS 15.105;

22 (b) The Office of Inspector General shall be headed by an inspector general who
23 shall be appointed by the secretary with the approval of the Governor. The
24 inspector general shall be directly responsible to the secretary. The Office of
25 Inspector General shall be responsible for:

26 1. The conduct of audits and investigations for detecting the perpetration of
27 fraud or abuse of any program by any client, or by any vendor of

- 1 services with whom the cabinet has contracted; and the conduct of
2 special investigations requested by the secretary, commissioners, or
3 office heads of the cabinet into matters related to the cabinet or its
4 programs;
- 5 2. Licensing and regulatory functions as the secretary may delegate;
- 6 3. Review of health facilities participating in transplant programs, as
7 determined by the secretary, for the purpose of determining any
8 violations of KRS 311.1911 to 311.1959, 311.1961, and 311.1963;
- 9 4. The duties, responsibilities, and authority pertaining to the certificate of
10 need functions and the licensure appeals functions, pursuant to KRS
11 Chapter 216B;
- 12 5. The notification and forwarding of any information relevant to possible
13 criminal violations to the appropriate prosecuting authority;
- 14 6. The oversight of the operations of the Kentucky Health Information
15 Exchange *in accordance with Section 11 of this Act*; and
- 16 7. The support and guidance to health care providers related to telehealth
17 services, including the development of policy, standards, resources, and
18 education to expand telehealth services across the Commonwealth;
- 19 (c) The Office of Public Affairs shall be headed by an executive director
20 appointed by the secretary with the approval of the Governor in accordance
21 with KRS 12.050. The office shall provide information to the public and news
22 media about the programs, services, and initiatives of the cabinet;
- 23 (d) The Office of Human Resource Management shall be headed by an executive
24 director appointed by the secretary with the approval of the Governor in
25 accordance with KRS 12.050. The office shall coordinate, oversee, and
26 execute all personnel, training, and management functions of the cabinet. The
27 office shall focus on the oversight, development, and implementation of

- 1 quality improvement services; curriculum development and delivery of
2 instruction to staff; the administration, management, and oversight of training
3 operations; health, safety, and compliance training; and equal employment
4 opportunity compliance functions;
- 5 (e) The Office of Finance and Budget shall be headed by an executive director
6 appointed by the secretary with the approval of the Governor in accordance
7 with KRS 12.050. The office shall provide central review and oversight of
8 budget, contract, and cabinet finances. The office shall provide coordination,
9 assistance, and support to program departments and independent review and
10 analysis on behalf of the secretary;
- 11 (f) The Office of Legislative and Regulatory Affairs shall be headed by an
12 executive director appointed by the secretary with the approval of the
13 Governor in accordance with KRS 12.050. The office shall provide central
14 review and oversight of legislation, policy, and administrative regulations.
15 The office shall provide coordination, assistance, and support to program
16 departments and independent review and analysis on behalf of the secretary;
- 17 (g) The Office of Administrative Services shall be headed by an executive
18 director appointed by the secretary with the approval of the Governor in
19 accordance with KRS 12.050. The office shall provide central review and
20 oversight of procurement, general accounting including grant monitoring, and
21 facility management. The office shall provide coordination, assistance, and
22 support to program departments and independent review and analysis on
23 behalf of the secretary;
- 24 (h) The Office of Application Technology Services shall be headed by an
25 executive director appointed by the secretary with the approval of the
26 Governor in accordance with KRS 12.050. The office shall provide
27 application technology services including central review and oversight. The

- 1 office shall provide coordination, assistance, and support to program
2 departments and independent review and analysis on behalf of the secretary;
- 3 (i) The Office of Data Analytics shall be headed by an executive director who
4 shall be appointed by the secretary with the approval of the Governor under
5 KRS 12.050 and shall identify and innovate strategic initiatives to inform
6 public policy initiatives and provide opportunities for improved health
7 outcomes for all Kentuckians through data analytics. The office shall provide
8 leadership in the redesign of the health care delivery system using electronic
9 information technology to improve patient care and reduce medical errors and
10 duplicative services; and
- 11 (j) The Office of Medical Cannabis shall be headed by an executive director
12 appointed by the Governor in accordance with KRS 12.040 and shall
13 implement, operate, oversee, and regulate the medicinal cannabis program.
14 The office shall be composed of the Division of Enforcement and Compliance
15 and the Division of Licensure and Access. Each division in the office shall be
16 headed by a director appointed by the secretary with the approval of the
17 Governor in accordance with KRS 12.050.
- 18 (2) Department for Medicaid Services. The Department for Medicaid Services shall
19 serve as the single state agency in the Commonwealth to administer Title XIX of
20 the Federal Social Security Act. The Department for Medicaid Services shall be
21 headed by a commissioner for Medicaid services, who shall be appointed by the
22 secretary with the approval of the Governor under KRS 12.050. The commissioner
23 for Medicaid services shall be a person who by experience and training in
24 administration and management is qualified to perform the duties of this office. The
25 commissioner for Medicaid services shall exercise authority over the Department
26 for Medicaid Services under the direction of the secretary and shall only fulfill
27 those responsibilities as delegated by the secretary;

1 (3) Department for Public Health. The Department for Public Health shall develop and
2 operate all programs of the cabinet that provide health services and all programs for
3 assessing the health status of the population for the promotion of health and the
4 prevention of disease, injury, disability, and premature death. This shall include but
5 not be limited to oversight of the Division of Women's Health and the Office for
6 Children with Special Health Care Needs. The duties, responsibilities, and authority
7 set out in KRS 200.460 to 200.490 shall be performed by the Department for Public
8 Health. The Department for Public Health shall advocate for the rights of children
9 with disabilities and, to the extent that funds are available, shall ensure the
10 administration of services for children with disabilities as are deemed appropriate
11 by this office pursuant to Title V of the Social Security Act. The Department for
12 Public Health may promulgate administrative regulations under KRS Chapter 13A
13 as may be necessary to implement and administer its responsibilities. The Office for
14 Children with Special Health Care Needs may be headed by an executive director
15 appointed by the secretary with the approval of the Governor in accordance with
16 KRS 12.050. The Department for Public Health shall be headed by a commissioner
17 for public health who shall be appointed by the secretary with the approval of the
18 Governor under KRS 12.050. The commissioner for public health shall be a duly
19 licensed physician who by experience and training in administration and
20 management is qualified to perform the duties of this office. The commissioner
21 shall advise the head of each major organizational unit enumerated in this section
22 on policies, plans, and programs relating to all matters of public health, including
23 any actions necessary to safeguard the health of the citizens of the Commonwealth.
24 The commissioner shall serve as chief medical officer of the Commonwealth. The
25 commissioner for public health shall exercise authority over the Department for
26 Public Health under the direction of the secretary and shall only fulfill those
27 responsibilities as delegated by the secretary;

- 1 (4) Department for Behavioral Health, Developmental and Intellectual Disabilities. The
2 Department for Behavioral Health, Developmental and Intellectual Disabilities shall
3 develop and administer programs for the prevention of mental illness, intellectual
4 disabilities, brain injury, developmental disabilities, and substance use disorders
5 and shall develop and administer an array of services and support for the treatment,
6 habilitation, and rehabilitation of persons who have a mental illness or emotional
7 disability, or who have an intellectual disability, brain injury, developmental
8 disability, or a substance use disorder. The Department for Behavioral Health,
9 Developmental and Intellectual Disabilities shall be headed by a commissioner for
10 behavioral health, developmental and intellectual disabilities who shall be
11 appointed by the secretary with the approval of the Governor under KRS 12.050.
12 The commissioner for behavioral health, developmental and intellectual disabilities
13 shall be by training and experience in administration and management qualified to
14 perform the duties of the office. The commissioner for behavioral health,
15 developmental and intellectual disabilities shall exercise authority over the
16 department under the direction of the secretary, and shall only fulfill those
17 responsibilities as delegated by the secretary;
- 18 (5) Department for Family Resource Centers and Volunteer Services. The Department
19 for Family Resource Centers and Volunteer Services shall streamline the various
20 responsibilities associated with the human services programs for which the cabinet
21 is responsible. This shall include, but not be limited to, oversight of the Division of
22 Family Resource and Youth Services Centers and Serve Kentucky. The Department
23 for Family Resource Centers and Volunteer Services shall be headed by a
24 commissioner who shall be appointed by the secretary with the approval of the
25 Governor under KRS 12.050. The commissioner for family resource centers and
26 volunteer services shall be by training and experience in administration and
27 management qualified to perform the duties of the office, shall exercise authority

1 over the department under the direction of the secretary, and shall only fulfill those
2 responsibilities as delegated by the secretary;

3 (6) Department for Community Based Services. The Department for Community Based
4 Services shall administer and be responsible for child and adult protection,
5 guardianship services, violence prevention resources, foster care and adoption,
6 permanency, and services to enhance family self-sufficiency, including child care,
7 social services, public assistance, and family support. The department shall be
8 headed by a commissioner appointed by the secretary with the approval of the
9 Governor in accordance with KRS 12.050; and

10 (7) Department for Aging and Independent Living. The Department for Aging and
11 Independent Living shall serve as the state unit as designated by the Administration
12 on Aging Services under the Older Americans Act and shall have responsibility for
13 administration of the federal community support services, in-home services, meals,
14 family and caregiver support services, elder rights and legal assistance, senior
15 community services employment program, the state health insurance assistance
16 program, state home and community based services including home care,
17 Alzheimer's respite services and the personal care attendant program, certifications
18 of assisted living facilities, and the state Council on Alzheimer's Disease and other
19 related disorders. The department shall also administer the Long-Term Care
20 Ombudsman Program and the Medicaid Home and Community Based Waivers
21 Participant Directed Services Option (PDS) Program. The department shall serve as
22 the information and assistance center for aging and disability services and
23 administer multiple federal grants and other state initiatives. The department shall
24 be headed by a commissioner appointed by the secretary with the approval of the
25 Governor in accordance with KRS 12.050.

26 ➔Section 11. KRS 194A.103 is amended to read as follows:

27 (1) (a) The Division of Kentucky Health Information Exchange is hereby created in

1 the Office of Inspector General.

2 **(b)** The division shall:

3 **1. Continue to operate and support the Kentucky Health Information**
 4 **Exchange until the functions of the exchange are operated within the**
 5 **Kentucky statewide health data utility established in Sections 1 to 9 of**
 6 **this Act; and**

7 **2. Cooperate with, support, and provide assistance to the Legislative**
 8 **Research Commission in the implementation of the health care**
 9 **information exchange and the prescription information exchange**
 10 **within the Kentucky statewide health data utility established in**
 11 **Sections 1 to 9 of this Act**~~[provide leadership in the redesign of the~~
 12 ~~health care delivery system using electronic information technology as a~~
 13 ~~means to improve patient care and reduce medical errors and duplicative~~
 14 ~~services].~~

15 (2) The Office of Inspector General shall promulgate administrative regulations in
 16 accordance with KRS Chapter 13A to implement the provisions of this section.

17 ➔Section 12. KRS 194A.095 is amended to read as follows:

18 (1) There is created in the Cabinet for Health and Family Services a Division of
 19 Women's Health for the purpose of:

20 (a) Serving as a repository for data and information affecting women's physical
 21 and mental health issues;

22 (b) Analyzing and communicating trends in women's health issues and mental
 23 health;

24 (c) Recommending to the cabinet~~[for Health and Family Services]~~ data elements
 25 affecting women's physical and mental health. The division shall advise and
 26 direct which data elements should be collected, analyzed, and reported in a
 27 timely manner under **the Kentucky statewide health data utility established**

1 *in Sections 1 to 9 of this Act or, to the extent the statewide health data utility*
 2 *is not yet operational or accessible, under* KRS 216.2920 to 216.2929;

3 (d) Cooperating and collaborating with the cabinet~~[for Health and Family~~
 4 ~~Services]~~ in receiving and disseminating through all forms of media,
 5 including the internet, relevant aggregate data findings *that affect women and*
 6 *are collected from the Kentucky statewide health data utility established in*
 7 *Sections 1 to 9 of this Act or, to the extent the statewide health data utility is*
 8 *not yet operational or accessible,* under KRS 216.2920 to 216.2929~~[which~~
 9 ~~affect women]~~; and

10 (e) Planning, developing, and administering a Women's Health Resource Center
 11 within the cabinet~~[for Health and Family Services]~~ to focus on targeted
 12 preventive care and comprehensive health education.

13 (2) The division may accept gifts, grants, and bequests in support of its mission and
 14 duties specified in~~[subsection (1) of]~~ this section. All money received shall be
 15 administered by the cabinet, which shall administer these funds through appropriate
 16 trust and agency accounts.

17 ➔Section 13. KRS 205.640 is amended to read as follows:

18 (1) The commissioner of Medicaid services shall adopt a disproportionate share
 19 program consistent with the requirements of Title XIX of the Social Security Act
 20 which shall include to the extent possible, but not limited to, the provisions of this
 21 section.

22 (2) The Medical Assistance Revolving Trust Fund (MART) shall be established in the
 23 State Treasury and all provider tax revenues collected pursuant to KRS 142.301 to
 24 142.363 shall be deposited in the State Treasury and transferred on a quarterly basis
 25 to the Department for Medicaid Services for use as specified in this section. All
 26 investment earnings of the fund shall be credited to the fund. Provider tax revenues
 27 collected in accordance with KRS 142.301 to 142.363 may be used to fund the

1 provisions of Sections 1 to 9 of this Act or KRS 216.2920 to 216.2929 and to
2 supplement the medical assistance-related general fund appropriations for fiscal
3 year 1994 and subsequent fiscal years. Notwithstanding the provisions of KRS
4 48.500 and 48.600, the MART fund shall be exempt from any state budget
5 reduction acts.

6 (3) (a) Beginning in state fiscal year 2000-2001 and continuing annually thereafter,
7 provider tax revenues and state and federal matching funds shall be used to
8 fund the disproportionate share program established by administrative
9 regulations promulgated by the Cabinet for Health and Family Services.
10 Disproportionate share funds shall be divided into three (3) pools for
11 distribution as follows:

12 1. An acute care pool, composed of critical access hospitals,
13 comprehensive physical rehabilitation hospitals, long-term acute
14 hospitals, and acute care hospitals that do not qualify as a university
15 hospital, shall receive an initial and a final allocation determined by
16 subtracting from the state's total DSH allotment:

17 a. The allocation required in subparagraph 2. of this paragraph for
18 the psychiatric pool; and

19 b. The initial or final, as applicable, DSH payments to be made to
20 hospitals in the university pool in subparagraph 3. of this
21 paragraph;

22 2. A psychiatric pool, composed of private psychiatric hospitals and state
23 mental hospitals, shall receive the percentage allowable by federal law
24 pursuant to 42 U.S.C. sec. 1396r-4(h), up to nineteen and eight-
25 hundredths percent (19.08%) of the total disproportionate share funds,
26 with the allocation between each respective group of hospitals
27 established by the biennial budget; except, however, that the allocation

- 1 to state mental hospitals shall not exceed ninety-two and three-tenths
2 percent (92.3%) of the total allotment to the psychiatric pool. If there are
3 remaining funds within the psychiatric pool after all private psychiatric
4 hospitals reach their hospital-specific DSH limit, state mental hospitals
5 may exceed the ninety-two and three-tenths percent (92.3%) limit but
6 may not exceed their hospital-specific DSH limit;
- 7 3. A university hospital pool, composed of university hospitals, shall
8 receive thirty-seven percent (37%) of the state's DSH allotment; except,
9 however, that initial and final DSH payments to university hospitals
10 shall be determined according to paragraph (e) of this subsection and not
11 exceed the pool's overall allotment;
- 12 4. If there are any remaining disproportionate share funds from the
13 psychiatric pool, fifty-four percent (54%) of those funds shall be
14 distributed to the acute care pool and forty-six percent (46%) shall be
15 distributed to the university pool. If the university hospitals are unable to
16 absorb additional DSH payment dollars, remaining funds shall be
17 distributed to the acute care pool; and
- 18 5. If, in any year, university hospitals fail to provide state matching funds
19 necessary to secure federal financial participation for the funds allocated
20 to university hospitals under this subsection, the portion of the funding
21 allocation that is not matched by university hospitals shall be made
22 available to the acute care pool.
- 23 (b) The MART fund shall be used to compensate acute care hospitals, private
24 psychiatric hospitals, state mental hospitals, critical access hospitals,
25 comprehensive physical rehabilitation hospitals, long-term acute care
26 hospitals, and university hospitals participating in the disproportionate share
27 program for uncompensated care costs.

- 1 (c) An individual hospital shall receive distributions if the hospital meets the
2 requirements of the disproportionate share program pursuant to 42 U.S.C. sec.
3 1396r-4.
- 4 (d) 1. An individual hospital shall not receive an initial DSH payment unless
5 the hospital submits a Medicaid DSH survey by the deadline established
6 by subsection (8)(a) of this section, unless the deadline has been
7 extended by the commissioner of the department. Extension requests
8 shall be received at least ten (10) days prior to the deadline. Extensions
9 shall be limited to rare circumstances which prevent the hospital from
10 meeting the deadline despite due diligence. Extensions shall be granted
11 for no more than thirty (30) calendar days from the original due date for
12 the Medicaid DSH survey. Failure to submit a DSH survey in a timely
13 manner or other required information for receipt of an initial DSH
14 payment shall result in an individual hospital's final DSH payment being
15 reduced by twenty percent (20%).
- 16 2. A hospital newly enrolled in the Medicaid program, which does not
17 have at least six (6) months of cost report information necessary to
18 calculate an initial DSH payment, may submit a limited DSH survey for
19 the purpose of determining if the hospital is eligible to receive an initial
20 DSH payment.
- 21 (e) Distributions shall be made as follows:
- 22 1. For state fiscal year 2018-2019, the department shall use the examined
23 state fiscal year 2014-2015 DSH survey to calculate an initial DSH
24 payment. Providers who did not receive a DSH payment for state fiscal
25 year 2014-2015 shall be eligible to submit data for the purpose of the
26 2019 payment, subject to limited review. For state fiscal year 2019-
27 2020, and each year thereafter, the department shall use the Medicaid

1 DSH survey covering the hospital's fiscal year ending in the calendar
2 year preceding July 1 of the applicable state fiscal year to calculate an
3 initial DSH payment. Using the surveys submitted in accordance with
4 this subsection, payments shall be made as follows:

5 a. Each university hospital in the university pool shall receive an
6 initial DSH payment equal to one hundred percent (100%) of the
7 hospital's total uncompensated care costs if the total initial DSH
8 payments to all hospitals in the university pool do not exceed the
9 maximum allotment to the university pool as set forth in
10 subsection (3)(a) of this section. If the total uncompensated care
11 costs for the pool exceed the pool's maximum allotment, the initial
12 uncompensated care factor for university hospitals shall be
13 determined by calculating the percentage of each hospital's total
14 uncompensated care costs toward the sum of the total
15 uncompensated care costs of all hospitals in the university pool,
16 and each hospital's initial DSH payment shall be calculated by
17 multiplying the hospital's initial uncompensated care factor by the
18 total funds allocated to the university hospital pool;

19 b. For each private psychiatric and state mental hospital in the
20 psychiatric pool, the department shall calculate an initial
21 uncompensated care factor. The initial uncompensated care factor
22 for a private psychiatric or state mental hospital shall be
23 determined by calculating the percentage of each hospital's total
24 uncompensated care costs toward the sum of the total
25 uncompensated care costs for all private psychiatric or state mental
26 hospitals in the psychiatric pool, as appropriate. Each hospital's
27 initial DSH payment shall be calculated by multiplying the

1 hospital's initial uncompensated care factor by the total funds
2 allocated to private psychiatric or state mental hospitals in the
3 psychiatric pool, as appropriate. No individual hospital's initial
4 DSH payment shall exceed the hospital's hospital-specific DSH
5 limit;

6 c. For each hospital in the acute care pool, the department shall make
7 an initial determination of whether the acute care hospital qualifies
8 as an essential hospital and calculate an initial uncompensated care
9 factor for each hospital. The initial uncompensated care factor for
10 each hospital in the acute care pool shall be determined by
11 calculating the percentage of each hospital's total uncompensated
12 care costs toward the sum of the total uncompensated care costs
13 for all hospitals in the acute care pool except that the initial
14 uncompensated care factor for an essential hospital shall be
15 calculated using two hundred percent (200%) of the hospital's total
16 uncompensated care costs. Each hospital's initial DSH payment
17 shall be calculated by multiplying the hospital's initial
18 uncompensated care factor by the total funds allocated to the acute
19 care pool. No individual hospital's initial DSH payment shall
20 exceed the hospital's hospital-specific DSH limit;

21 d. For any hospital that is newly enrolled in the Medicaid program
22 and lacks at least six (6) months of cost report information, the
23 department shall calculate a proxy amount for the hospital's
24 uncompensated care costs. A newly enrolled hospital's
25 uncompensated care costs proxy amount shall be determined by
26 first dividing the total uncompensated care costs for all non-newly
27 enrolled hospitals in the appropriate pool by the total number of

- 1 hospital beds, excluding swing beds, reported on the Medicaid cost
2 reports by those hospitals and then multiplying the resulting
3 uncompensated care cost per bed by the new hospital's total
4 number of hospital beds, excluding swing beds. Any
5 uncompensated care costs proxy amounts calculated for newly
6 enrolled hospitals shall be used in the determination of initial
7 uncompensated care factors for all other hospitals in the
8 appropriate pool;
- 9 e. The department may make adjustments to a Medicaid DSH survey
10 filed by a hospital to correct information that is incomplete or
11 inaccurate as determined by limited review. If the department
12 makes adjustments to a hospital's Medicaid DSH survey, the
13 department shall provide written notice to the hospital;
- 14 f. If a hospital has a negative uncompensated care cost, its
15 uncompensated care costs shall be excluded from the calculation
16 of any uncompensated care costs proxy amount for newly enrolled
17 hospitals and uncompensated care factors for the appropriate pool;
- 18 g. By September 30 of each year, the department shall calculate an
19 initial DSH payment pursuant to subparagraph 1. of this paragraph
20 and shall notify each hospital of their calculation. The notice shall,
21 at minimum, contain the following for each hospital:
- 22 i. Uninsured uncompensated care costs;
- 23 ii. Total uncompensated care costs;
- 24 iii. The status of the MIUR and LIUR calculations;
- 25 iv. The uncompensated care factor; and
- 26 v. The estimated initial annual payment amount;
- 27 h. Hospitals shall notify the department by October 31 of any

- 1 adjustments in the department's initial calculations;
- 2 i. The department shall make any necessary adjustments and shall
3 issue an initial DSH payment to each hospital in one (1) lump-sum
4 payment on or before November 30, for the disproportionate share
5 funds available during the corresponding federal fiscal year. If the
6 federal disproportionate share allotment for the Commonwealth
7 has not been published through the Federal Register by November
8 15, the department may pay a portion but no less than ninety
9 percent (90%) of the expected annual payment prior to the
10 publication of the annual federal allotment. If a partial initial
11 payment is made, the remaining amount shall be paid within sixty
12 (60) days after the date upon which notice of the Commonwealth's
13 federal allotment is published through the Federal Register; and
- 14 j. An initial DSH payment shall not be subject to appeal;
- 15 2. a. Each hospital's total initial DSH payment shall be reconciled to a
16 final DSH payment using the examined Medicaid DSH surveys
17 and shall correspond to the applicable state fiscal year DSH
18 payment year.
- 19 b. Using the surveys submitted in accordance with subsection (8)(a)
20 of this section, the department shall make a final determination of
21 whether an acute care hospital qualifies as a MIUR or as a LIUR
22 hospital. Any qualifying hospital will be deemed an essential
23 hospital. Critical access hospital status will also be confirmed to
24 make a final determination of essential hospital status.
- 25 c. The department shall calculate a final DSH payment as follows:
- 26 i. Each university hospital shall receive a final DSH payment
27 equal to one hundred percent (100%) of the hospital's total

1 uncompensated costs so long as the total final DSH
2 payments to all university hospitals do not exceed the
3 maximum allotment to the university pool as set forth in
4 subsection (3)(a) of this section. If total uncompensated care
5 cost for the pool exceeds the pool's maximum allotment, the
6 final uncompensated care factor for university hospitals shall
7 be determined by calculating the percentage of each
8 hospital's total uncompensated care costs toward the sum of
9 the total uncompensated care costs for all hospitals within
10 the university pool. In this event, each hospital's final DSH
11 payment shall be calculated by multiplying the hospital's
12 uncompensated care factor by the total fund allocated to the
13 hospitals within the respective pool under subsection (3)(a)
14 of this section;

15 ii. For hospitals in the acute care pool and the psychiatric pool,
16 the department shall recalculate each hospital's
17 uncompensated care factor using examined data. The final
18 uncompensated care factor for each hospital that qualifies as
19 an essential hospital shall be computed using two hundred
20 percent (200%) of the hospital's total uncompensated care
21 costs using examined data;

22 iii. If a hospital has a negative uncompensated care cost, their
23 uncompensated care cost will be excluded in the calculation
24 of uncompensated care factors; and

25 iv. The department shall compare each hospital's initial DSH
26 payment with the hospital's final DSH payment and with the
27 hospital's hospital-specific DSH limit to determine if any

- 1 underpayment or an overpayment exists.
- 2 d. By September 30 of the fourth year following the year in which an
- 3 initial DSH payment is made, the department shall provide each
- 4 hospital with a final DSH reconciliation report which, at a
- 5 minimum, shall indicate the following:
- 6 i. A hospital's final MIUR and LIUR status;
- 7 ii. Final uncompensated care factor and underlying data;
- 8 iii. Final DSH payment; and
- 9 iv. If applicable, the amount of any overpayment to be paid to
- 10 the department and the due date for repayment.
- 11 e. If an overpayment is identified, repayment shall be made by
- 12 January 31 of the following year, which is five (5) years following
- 13 the year in which an initial DSH payment is made.
- 14 f. Hospitals shall notify the department by October 31 of any
- 15 corrections to the department's calculations.
- 16 g. If a hospital's initial DSH payment was less than the hospital's
- 17 final DSH payment, the department shall pay the hospital the
- 18 amount of the difference. Final DSH payments shall be issued by
- 19 the department within sixty (60) days of the due date for the
- 20 repayment of funds from hospitals with a DSH overpayment. If all
- 21 repayments have not yet been received by the due date, the
- 22 department shall distribute the funds collected as of the due date,
- 23 and shall issue additional payments on a timely basis upon
- 24 collection of all remaining outstanding overpayments.
- 25 h. Any funds remaining after the reconciliation process shall be
- 26 redistributed pursuant to subparagraph 3. of this paragraph; and
- 27 3. Disproportionate share payments remaining after reconciling each

1 hospital's initial DSH payment with the hospital's final DSH payment
2 shall be distributed to other hospitals in the acute care pool, university
3 pool, or to private psychiatric hospitals in the psychiatric pool as
4 follows:

- 5 a. Funds shall first be distributed to all hospitals in the same pool as
6 the hospitals from which the overpayments were recovered, and
7 the funds shall be distributed in a proportional manner in relation
8 to each hospital's remaining total uncompensated care costs in
9 accordance with the hospital's examined DSH survey for the
10 applicable DSH year;
- 11 b. In the proportional distribution, the distribution factor for each
12 hospital that qualifies as an essential hospital shall be computed
13 using two hundred percent (200%) of the hospital's total remaining
14 uncompensated care costs; and
- 15 c. If DSH funds remain after making this distribution to other
16 hospitals in the same pool, funds shall be distributed
17 proportionally to hospitals in the acute care pool, university pool,
18 and private psychiatric hospitals in the psychiatric pool in relation
19 to each hospital's remaining total uncompensated care costs in
20 accordance with the hospital's examined Medicaid DSH survey for
21 the applicable DSH year.

22 (4) Notwithstanding any other provision to the contrary, total annual disproportionate
23 share payments made to state mental hospitals, university hospitals, acute care
24 hospitals, critical access hospitals, comprehensive physical rehabilitation hospitals,
25 long-term acute care hospitals, and private psychiatric hospitals in each state fiscal
26 year shall be equal to the maximum amount of disproportionate share payments
27 established under the Federal Balanced Budget Act of 1997 and any amendments

1 thereto. Disproportionate share payments made to a hospital shall not exceed the
2 hospital's total uncompensated costs or the hospital's hospital-specific DSH limit.

3 (5) The secretary of the Cabinet for Health and Family Services shall promulgate
4 administrative regulations, pursuant to KRS Chapter 13A, for the administration
5 and implementation of this section.

6 (6) All hospitals receiving reimbursement under this section shall display prominently a
7 sign which reads as follows: "This hospital will accept patients regardless of race,
8 creed, ethnic background, or ability to pay."

9 (7) The hospital shall, upon request by the Cabinet for Health and Family Services,
10 submit any supporting documentation to substantiate compliance with the audit
11 requirements established by 42 C.F.R. sec. 455.

12 (8) (a) An in-state hospital participating in the Medicaid Program shall submit a
13 Medicaid DSH survey corresponding to the hospital's cost reporting period to
14 the department no later than sixty (60) days following the hospital's
15 submission of their annual cost report, unless an extension has been granted
16 by the commissioner. Extension requests shall be received ten (10) days prior
17 to the deadline. Extensions shall be limited to rare circumstances which
18 prevent the hospital from meeting the deadline despite its due diligence.
19 Extensions shall be granted for no more than thirty (30) calendar days from
20 the original due date. A new in-state hospital lacking six (6) months of cost
21 report information necessary to calculate an initial DSH payment shall submit
22 a limited DSH survey to determine eligibility no later than the September 1
23 immediately prior to the department's initial DSH payment calculation. A
24 hospital may submit corrections to an applicable Medicaid DSH survey prior
25 to the scheduled start date of the department's desk review.

26 (b) The department shall notify each hospital in advance of the desk review of the
27 opportunity to submit corrections to the Medicaid DSH survey.

1 (c) The department and each Medicaid managed care organization shall supply a
2 paid claims listing (PCL) to each hospital within ninety (90) days of the last
3 day of the hospital's fiscal year end date and a second set of data twelve (12)
4 months after the hospital's fiscal year end date. The PCL shall include all
5 claims with discharge dates or service dates, as applicable, within the
6 hospital's fiscal year that are paid from the first day of the hospital's fiscal
7 year to ninety (90) days or twelve (12) months, respectively, after the end of
8 the hospital's fiscal year. For all hospitals, the department and each Medicaid
9 managed care organization shall provide separate reports for adjudicated
10 claims associated with both inpatient services and outpatient services
11 provided to eligible members. If the PCL data is inaccurate or unavailable,
12 providers shall complete the DSH survey using internal data.

13 (d) The department shall specify a timetable for hospitals to update DSH audit
14 survey data.

15 ➔Section 14. KRS 205.6489 is amended to read as follows:

16 (1) The Kentucky Children's Health Insurance Program shall be administered by the
17 Cabinet for Health and Family Services in terms of conducting eligibility
18 determination and providing oversight over enrollment and claims payment.

19 (2) The program shall include a system of outreach and referral for children who may
20 be eligible for the Kentucky Children's Health Insurance Program. The program
21 shall work with the Department for Medicaid Services, the Department for
22 Community Based Services, schools, pediatricians, public health departments, and
23 other entities interested in the health of children in developing the system of
24 outreach and referral.

25 (3) The cabinet shall promulgate administrative regulations in accordance with KRS
26 Chapter 13A to establish a structure for quality assurance and utilization review
27 under KRS 205.6481 to 205.6495 and KRS 304.17A-340.

1 (4) The Kentucky Children's Health Insurance Program shall collect, analyze, and
2 publicly disseminate comprehensive data on the number of children enrolled in the
3 program, services received through the program, and the effect on health outcomes
4 of children served by the program including the special health needs of minority
5 children. The information collected by the program shall be subject to KRS
6 216.2927(1). The program shall have access to all data collected by the cabinet
7 under KRS 216.2920 to 216.2929 and shall coordinate program data collection
8 efforts with the data collection efforts of the Kentucky statewide health data utility
9 or the cabinet under KRS 216.2920 to 216.2929, as applicable.

10 ➔Section 15. KRS 211.474 is amended to read as follows:

11 The board shall:

12 (1) Promulgate administrative regulations in accordance with KRS Chapter 13A as
13 necessary to carry out the provisions of KRS 211.470 to 211.478;

14 (2) Formulate policies and procedures for determining individual eligibility for
15 assistance from the trust fund in accordance with the following guidelines:

16 (a) The trust fund shall serve as a funding source of last resort for residents of the
17 Commonwealth of Kentucky. To be eligible for assistance from the trust fund,
18 an individual must have exhausted all other funding sources that cover the
19 type of services sought through the trust fund. Individuals who have
20 continuing health insurance benefits, including Medicaid, may access the trust
21 fund for services that are needed but not covered by insurance or any other
22 funding source. Individuals who qualify for institutional care through
23 Medicaid shall not qualify for services through the trust fund;

24 (b) All individuals receiving assistance from the fund shall receive case
25 management services;

26 (c) Expenditures on behalf of any one (1) brain-injured individual may not
27 exceed fifteen thousand dollars (\$15,000) for any twelve (12) month period,

1 and may not exceed a lifetime maximum of sixty thousand dollars (\$60,000).
2 At its discretion and subject to fund availability, the board may waive the
3 expenditure or time limitations or both in special circumstances;

4 (d) Services covered by the trust fund shall include:

- 5 1. Case management;
- 6 2. Community residential services;
- 7 3. Structured day program services;
- 8 4. Psychological and mental health services;
- 9 5. Prevocational services;
- 10 6. Supported employment;
- 11 7. Companion services;
- 12 8. Respite care;
- 13 9. Occupational therapy; and
- 14 10. Speech and language therapy;

15 (e) Covered services shall not include institutionalization, hospitalization, or
16 medications;

17 (3) Establish a confidential medical registry for traumatic brain and spinal cord injuries
18 occurring in the Commonwealth of Kentucky, or to residents of the Commonwealth
19 of Kentucky.

20 (a) 1. The board may promulgate administrative regulations requiring licensed
21 or certified professionals or health services providers to report the
22 occurrence of brain and spinal cord injuries, relevant medical and
23 epidemiological information about the injuries, and other information
24 describing the circumstances of the injury to the board or its designated
25 agent.

26 2. The reporting of data by licensed hospitals under this section shall be
27 limited to that which is reported to:

1 a. The Kentucky statewide health data utility established in
 2 Sections 1 to 9 of this Act; or

3 b. To the extent the statewide health data utility is not yet
 4 operational or accessible, the cabinet pursuant to KRS 216.2920
 5 to 216.2929;

6 and the board shall obtain this data from the cabinet.

7 **3.** Each licensed hospital shall grant the board, upon presentation of proper
 8 identification, access to the medical records of patients with reportable
 9 brain and spinal cord injuries for the sole purpose of collecting
 10 additional information that is not available in the data obtained from the
 11 cabinet. All costs associated with copying medical records shall be
 12 borne by the board. No liability of any kind shall arise or be enforced
 13 against any licensed hospital or hospital employee for providing the
 14 board access to a patient's medical record.

15 (b) The board and its designated agent, if one is appointed, shall observe the same
 16 confidentiality requirements established for the Kentucky birth surveillance
 17 registry in KRS 211.670;

18 (4) Investigate the needs of brain-injured individuals and identify gaps in current
 19 services;

20 (5) Assist the cabinet in developing programs for brain-injured individuals;

21 (6) Monitor and evaluate services provided by the trust fund; and

22 (7) Provide the Governor~~[, the General Assembly,]~~ and the Legislative Research
 23 Commission an annual report by January 1 of each year summarizing the activities
 24 of the board and the trust fund.

25 ➔Section 16. KRS 214.375 is amended to read as follows:

26 (1) As used in this section:

27 (a) "Advisory committee" means the Kentucky Parkinson's Disease Research

- 1 Registry Advisory Committee established under subsection (3) of this section;
- 2 (b) "Cabinet" means the Cabinet for Health and Family Services;
- 3 (c) "Movement disorder center" means a health facility licensed under KRS
4 Chapter 216B that operates outpatient clinics or ambulatory care facilities that
5 employ movement disorder health care providers;
- 6 (d) "Movement disorder health care provider" means a licensed physician or
7 osteopath licensed under KRS Chapter 311 that is fellowship trained in
8 movement disorders as specified by either the American Academy of
9 Neurology's Movement Disorders Section or the Movement Disorder
10 Society's Pan American Section;
- 11 (e) "Parkinson's disease" means a chronic and progressive neurologic disorder
12 resulting from a deficiency of the neurotransmitter dopamine as a
13 consequence of specific degenerative changes in the area of the brain called
14 the basal ganglia characterized by tremor at rest, slow movements, muscle
15 rigidity, stooped posture, and unsteady or shuffling gait;
- 16 (f) "Parkinsonisms":
- 17 1. Means Parkinson's disease-related conditions that cause a combination
18 of movement abnormalities such as tremor at rest, slow movement,
19 muscle rigidity, impaired speech, and muscle stiffness, which often
20 overlap with and can evolve from what appears to be Parkinson's
21 disease; and
- 22 2. Includes multiple system atrophy, dementia with Lewy bodies,
23 corticobasal degeneration, and progressive supranuclear palsy;
- 24 (g) "Registry" means the Kentucky Parkinson's Disease Research Registry
25 established in subsection (2) of this section; and
- 26 (h) "Secretary" means the secretary of the cabinet.
- 27 (2) The Kentucky Parkinson's Disease Research Registry is hereby established within

1 the cabinet under the direction of the secretary, who may enter into contracts,
2 grants, or other agreements as necessary to administer the registry in accordance
3 with this section.

4 (3) (a) The secretary shall establish the Kentucky Parkinson's Disease Research
5 Registry Advisory Committee to assist in the development and
6 implementation of the registry, determine what data will be collected, and
7 advise the cabinet.

8 (b) The advisory committee shall be appointed by the secretary and include at
9 least one (1):

- 10 1. Neurologist;
- 11 2. Movement disorder specialist;
- 12 3. Primary care provider;
- 13 4. Physician informaticist;
- 14 5. Patient living with Parkinson's disease;
- 15 6. Public health professional;
- 16 7. Population health researcher familiar with health data registries;
- 17 8. Parkinson's disease researcher;
- 18 9. Representative from the University of Kentucky College of Medicine
19 with specific expertise in Parkinson's disease; and
- 20 10. Representative from the University of Louisville School of Medicine
21 with specific expertise in Parkinson's disease.

22 The secretary may appoint additional members to the advisory committee as
23 he or she deems necessary.

24 (4) The cabinet shall:

25 (a) Promulgate administrative regulations in consultation with the advisory
26 committee and in accordance with KRS Chapter 13A to:

- 27 1. Designate Parkinson's disease and identified Parkinsonisms as diseases

- 1 that are required to be reported to the cabinet;
- 2 2. Establish a system of collection and dissemination of information on the
- 3 incidence and prevalence of Parkinson's disease and Parkinsonisms in
- 4 Kentucky and related epidemiological data;
- 5 3. Identify specific data points to be collected based on the following four
- 6 (4) core categories of data:
- 7 a. Patient demographics;
- 8 b. Geography;
- 9 c. Diagnosis; and
- 10 d. Sufficient information to allow for deduplication of patient records
- 11 in the registry;
- 12 4. Periodically review and revise data points to be collected to ensure data
- 13 and data collection procedures adapt to new knowledge and technology;
- 14 5. Establish a coding system that removes a patient's name, address, Social
- 15 Security number, fingerprints, photograph, and any other information by
- 16 which the identity of a patient can be determined with reasonable
- 17 accuracy; and
- 18 6. Develop guidelines and procedures for reviewing and approving
- 19 requests to use registry data for valid scientific research;
- 20 (b) Receive and collect data for the registry on the incidence and prevalence of
- 21 Parkinson's disease and Parkinsonisms in Kentucky and related
- 22 epidemiological data, and may enter into data-sharing contracts with data-
- 23 reporting entities and their associated medical record system vendors to
- 24 securely and confidentially receive information related to Parkinson's disease
- 25 testing, diagnosis, and treatment; and
- 26 (c) Be responsible for any costs incurred in administering the registry and
- 27 implementing this section.

- 1 (5) (a) Beginning January 1, 2026, each movement disorder center that treats a
2 patient with Parkinson's disease and each movement disorder health care
3 provider who treats or diagnoses Parkinson's disease or Parkinsonisms for a
4 patient not otherwise reported shall submit a Parkinson's disease report to the
5 cabinet in a format required or approved by the cabinet.
- 6 (b) 1. Movement disorder centers and movement disorder health care
7 providers shall provide each patient diagnosed with Parkinson's disease
8 or Parkinsonisms with a notice regarding the reporting and collection of
9 information and patient data on Parkinson's disease.
- 10 2. A patient who does not wish to participate in the collection of data for
11 the purposes of research in the registry may affirmatively opt out in
12 writing after an opportunity to review the documents and ask questions.
- 13 3. If a patient has chosen not to participate and has opted out under
14 subparagraph 2. of this paragraph, the movement disorder center and the
15 movement disorder health care provider shall only report that a
16 Parkinson's disease case exists and no further data shall be reported to
17 the cabinet for the purposes of the registry.
- 18 4. If a patient has been diagnosed with Parkinson's disease or
19 Parkinsonisms in error, the movement disorder center and the
20 movement disorder health care provider shall notify the cabinet and the
21 cabinet shall remove the patient from the registry.
- 22 (c) To ensure compliance with the reporting and notification requirements of this
23 subsection, the secretary or his or her agent may, upon reasonable notice,
24 inspect a representative sample of the medical records of patients admitted,
25 diagnosed, or treated for Parkinson's disease or Parkinsonisms at a movement
26 disorder center.
- 27 (d) A movement disorder center or movement disorder health care provider who

1 in good faith submits a report in accordance with paragraph (a) of this
2 subsection is not liable in any cause of action arising from the submission of
3 the report.

4 (e) A movement disorder center or movement disorder health care provider may
5 use automated reporting methods supplied by the cabinet or ~~a~~[the Kentucky]
6 health information exchange established under KRS Chapter 7 or 194A to
7 meet the requirements of this subsection.

8 (6) The cabinet shall make data from the registry, with or without identifiers, available
9 to researchers that have the approval of an institutional review board in accordance
10 with requirements of the Federal Policy for the Protection of Human Subjects, 45
11 C.F.R. pt. 46, and, as applicable, 21 C.F.R. pt. 56, 45 C.F.R. pt. 164, KRS 216.2920
12 to 216.2929, 900 KAR 7:030 and 7:040, and any other relevant federal or state
13 requirements.

14 (7) (a) The cabinet may enter into agreements to furnish data collected in the registry
15 to other states' Parkinson's disease registries, federal Parkinson's disease
16 control agencies, local health officers, or health researchers not described in
17 subsection (6) of this section for the study of Parkinson's disease.

18 (b) Before confidential information is disclosed pursuant to paragraph (a) of this
19 subsection, the out-of-state registry, agency, officer, or researcher shall agree
20 in writing to maintain the confidentiality of the information. A researcher
21 shall also:

22 1. Obtain approval of the researcher's respective committee for the
23 protection of human subjects under 45 C.F.R. pt. 46; and

24 2. Provide documentation to the cabinet that demonstrates to the cabinet's
25 satisfaction that the researcher has established the procedures and ability
26 to maintain the confidentiality of the information.

27 (8) (a) Except as specifically provided in this section, all information collected

1 pursuant to this section shall be confidential.

2 (b) Notwithstanding any other provision of law, a disclosure authorized by this
3 section shall include only the information necessary for the stated purpose of
4 the requested disclosure, used for the approved purpose, and not be further
5 disclosed.

6 (c) Provided the security of confidentiality has been documented, the furnishing
7 of confidential information to the cabinet or its authorized representative in
8 accordance with this section shall not expose any person, agency, or entity
9 furnishing information to liability, and shall not be considered a waiver of any
10 privilege or a violation of a confidential relationship.

11 (d) The cabinet shall maintain an accurate record of all persons who are given
12 access to information collected by the cabinet pursuant to this section, which
13 shall include:

- 14 1. The name of the person authorizing access;
- 15 2. Name, title, address, and organizational affiliation of persons given
16 access;
- 17 3. Dates of access; and
- 18 4. The specific purpose for which accessed information is to be used.

19 The record of access shall be open to public inspection during normal
20 operating hours of the cabinet.

21 (e) Notwithstanding any other provision of law, information collected by the
22 cabinet pursuant to this section shall not be:

- 23 1. Available for subpoena or disclosed, discoverable, or compelled to be
24 produced in any civil, criminal, administrative, or other proceeding; or
- 25 2. Deemed admissible as evidence in any civil, criminal, administrative, or
26 other proceeding for any reason.

27 (9) This section does not:

- 1 (a) Prohibit the publication by the cabinet of reports and statistical compilations
2 that do not in any way identify individual patients, cases, or sources of
3 information;
- 4 (b) Restrict in any way a patient's access to his or her own information; or
- 5 (c) Prohibit movement disorder center or movement disorder health care
6 providers from maintaining their own facility-based Parkinson's disease
7 registries.
- 8 (10) (a) Nothing in this section shall be deemed to compel any individual to submit to
9 any medical examination or supervision by the cabinet, any of its authorized
10 representatives, or an approved researcher.
- 11 (b) A person who seeks information or obtains registry data pursuant to this
12 section shall not contact a patient on the registry or the patient's family unless
13 the cabinet has first obtained permission for the contact from the patient or the
14 patient's family.
- 15 (11) The cabinet shall provide notice of the mandatory reporting of Parkinson's disease
16 and Parkinsonisms required under this section on its website and to professional
17 associations representing movement disorder center and movement disorder health
18 care providers.
- 19 (12) (a) By October 1, 2027, and October 1 of each year thereafter, the cabinet shall
20 submit to the Legislative Research Commission for referral to the Interim
21 Joint Committee on Health Services a yearly program summary update that
22 includes:
- 23 1. The incidence and prevalence of Parkinson's disease and Parkinsonisms
24 in the state by county;
- 25 2. The number of records that have been reported to the cabinet and
26 included in the registry; and
- 27 3. Demographic information, including but not limited to patients' age,

1 gender, and race.

2 (b) In consultation with the advisory committee, the cabinet may include
3 recommendations on necessary changes to the registry in the yearly program
4 summary update.

5 (c) The cabinet shall publish the yearly program summary update in a
6 downloadable format on the website created under subsection (13) of this
7 section.

8 (13) By October 1, 2027, the cabinet shall create, and update annually thereafter, the
9 Kentucky Parkinson's Disease Research Registry website where the public can find
10 information related to the Parkinson's disease and the registry, the yearly program
11 summary update, and any other information deemed relevant by the advisory
12 committee.

13 ➔SECTION 17. A NEW SECTION OF KRS 216.2920 TO 216.2929 IS
14 CREATED TO READ AS FOLLOWS:

15 **(1) Notwithstanding any other law to the contrary, the cabinet shall cease performing**
16 **any one (1) or more of the health data collection functions of KRS 216.2920 to**
17 **216.2929 if the Kentucky statewide health data utility established in Sections 1 to**
18 **9 of this Act becomes operational or accessible to perform the function or**
19 **functions.**

20 **(2) A person that reports data in accordance with an administrative regulation**
21 **promulgated by the Legislative Research Commission under Section 4 of this Act**
22 **shall not be required to make any report under KRS 216.2920 to 216.2929.**

23 ➔Section 18. If the Cabinet for Health and Family Services or the Department for
24 Medicaid Services determines that a state plan amendment, waiver, or any other form of
25 authorization or approval from any federal agency to implement Section 8 of this Act is
26 necessary to prevent the loss of federal funds or to comply with federal law, the cabinet
27 or department:

1 (1) Shall, within 90 days after the effective date of this section, request the
2 necessary federal authorization or approval to implement Section 8 of this Act; and

3 (2) May only delay implementation of the provisions of Section 8 of this Act for
4 which federal authorization or approval was deemed necessary until the federal
5 authorization or approval is granted.

6 ➔Section 19. Sections 8 and 18 of this Act constitute the specific authorization
7 required under KRS 205.5372(1).