

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 194A IS CREATED TO  
4       READ AS FOLLOWS:

5       (1) The Kentucky statewide health data utility is established in Sections 1 to 10 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 10 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 194A IS CREATED TO  
2 READ AS FOLLOWS:

3 *As used in Sections 1 to 10 of this Act:*

4 *(1) "Authorized recipient" means any of the following:*

5           *(a) The General Assembly, the Legislative Research Commission, or a*  
6           *committee, task force, or other body established by the General Assembly or*  
7           *Legislative Research Commission;*

8           *(b) Health care professionals;*

9           *(c) Health facilities;*

10           *(d) Health care payers;*

11           *(e) Health care purchasers;*

12           *(f) Patients;*

13           *(g) The executive director; and*

14           *(h) Members of academia engaged in health-related research;*

15           *(2) "Board" means the Kentucky Health Information Technology Board established*  
16           *in Section 7 of this Act;*

17           *(3) "Consortium of public health colleges" or "consortium" means the consortium*  
18           *created in Section 6 of this Act to operate and govern the Kentucky statewide*  
19           *health data utility;*

20           *(4) "Electronic longitudinal health record" means an electronic collection of health*  
21           *information about the health status of an individual that:*

22           *(a) Is compiled over time;*

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

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

25            *1. Clinical data;*

26            *2. Health care claims data;*

27            *3. Social referrals; and*

1           4. Designated public health data, including but not limited to  
2           immunizations and laboratory data;

3       (5) "Executive director" means the executive director of the Office of Data Analytics  
4           created in Section 12 of this Act;

5       (6) "Federally-qualified health center" has the same meaning as in 42 U.S.C. sec.  
6           1396d, as amended;

7       (7) "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, rehabilitative, and  
11           laboratory;

12           (b) Dental;

13           (c) Pharmacy; and

14           (d) Any other health care services designated by the executive director by  
15           administrative regulation promulgated in accordance with KRS Chapter  
16           13A;

17       (8) "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

any plan offered to the Public Employee Health Insurance Program for public employees under KRS 18A.225 or 18A.2254;

(e) Any federal health plan or program that provides coverage in Kentucky for health care services;

(f) Any insurers or administrators offering or administering a plan or program identified in paragraph (d) or (e) of this subsection;

(g) Any federal, state, or local government cabinet, agency, department, entity, or official that provides, or contracts with a third-party administrator to administer, a plan or program identified in paragraph (d) or (e) of this subsection:

(h) Workers' compensation insurers, including governmental and nongovernmental workers' compensation self-insurers and self-insured groups;

*(i) Insurers, self-insurers, and self-insured groups, including governmental and nongovernmental self-insured employers, self-insured health plans, and self-insured employer-organized associations, that provide:*

#### 1. Coverage for health care services:

## 2. *Health care benefits: or*

**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 (g) *Pharmacy benefit managers:*

(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                   (9) "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                   (10) "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                   (11) "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 rehabilitative 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                   (12) "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           (13) "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, monitor, and manage health care delivery within a care delivery organization;
- 2        b. The legal record of a patient's encounter with the care delivery organization; and
- 3        c. Owned by the care delivery organization;
- 4        4. Diagnostic and treatment services records, including records of the prescribing and dispensing of medication;
- 5        5. Decision support functions to assist health care professionals in making clinical decisions by providing electronic alerts and reminders to:
  - 6        a. Improve compliance with best practices;
  - 7        b. Promote regular screenings; or
  - 8        c. Promote other preventive practices to facilitate diagnosis and treatments; and
- 9        6. Tools to allow for the collection, analysis, and reporting of information or data on:
  - 10        a. Adverse health events;
  - 11        b. The quality and efficiency of health care;
  - 12        c. Patient satisfaction; and
  - 13        d. Other performance measures related to health care;

14        (14) "HIPAA" means the federal Health Insurance Portability and Accountability Act of 1996, Pub. L. No. 104-191, as amended, and any related federal regulations, as amended;

15        (15) "Interoperability":

16        (a) Means the ability of two (2) or more persons, systems, or components to 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                   (16) "Kentucky statewide health data utility" or "statewide health data utility" means  
11                   the statewide health data utility established in Sections 1 to 10 of this Act;

12                   (17) "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                   (18) "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                   (19) "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 194A 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 executive director, who may use or  
16        direct 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 194A IS CREATED TO  
19        READ AS FOLLOWS:

20        (1) The executive director shall be responsible for the development, implementation,  
21        operation, and maintenance of the Kentucky statewide health data utility in  
22        accordance with Sections 1 to 10 of this Act.

23        (2) In carrying out the duties in subsection (1) of this section, the executive director:

24        (a) Shall make good-faith efforts to:

25        1. Seek and accept grants or gifts, or raise funds, from any available  
26        source, public or private, to support the development, implementation,  
27        operation, and maintenance of the statewide health data utility; and

1           2. Establish agreements:

2           a. For voluntary reporting of health information from participants  
3                   that are not subject to the mandatory reporting requirements  
4                   under Section 8 of this Act; and  
5           b. With the federal Centers for Medicare and Medicaid Services to  
6                   obtain Medicare health care claims data and other health  
7                   information;

8           (b) 1. Subject to subparagraph 2. of this paragraph, may establish the  
9                   following:

10           a. Agreements with health data utilities in other states, including  
11                   all-payer claims databases, to establish a single application for  
12                   access to data by authorized recipients across multiple states;  
13                   and  
14           b. Agreements with state and federal agencies and other health  
15                   data utilities and health databases to share and receive health  
16                   information or other data, including confidential and proprietary  
17                   information or data, if:  
18                   i. The recipient agrees in a written or electronic record to  
19                           maintain any confidential or proprietary status afforded to  
20                           the information or data; and  
21                   ii. The information or data is shared or received in a manner  
22                           that does not violate any applicable laws.

23           2. Prior to establishing an agreement authorized under subparagraph 1.

24                   of this paragraph, the executive director shall:

25           a. Submit a draft of the proposed agreement to the board;  
26           b. Provide the board not less than thirty (30) days to review, and  
27                   advise the executive director on, the proposed agreement

submitted under subdivision a. of this subparagraph; and

*c. Determine, after review and comment from the board, that the agreement:*

i. Is consistent with the policies and procedures adopted by the board under subsection (1)(a) of Section 7 of this Act; and

**ii. Supports the purposes set forth in Section 1 of this Act;**

**(c) Shall:**

1. Within one hundred eighty (180) days after the effective date of the consortium's organizing documents, contract with the consortium of public health colleges to operate and govern the statewide health data utility in accordance with Sections 1 to 10 of this Act;

2. Submit the contract entered into with the consortium under subparagraph 1. of this paragraph to the Government Contract Review Committee for review pursuant to KRS 45A.705; and

**3. Enforce and ensure compliance with the contract entered into with the consortium under this paragraph;**

*(d) Shall monitor, and provide input and oversight to the consortium in, the operation and governance of the statewide health data utility;*

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

### 1. *HIPAA; and*

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

(f) Subject to subsection (3) of this section, shall promulgate administrative regulations in accordance with KRS Chapter 13A to establish policies and procedures necessary for the administration, operation, and oversight of the

1                   statewide health data utility, which shall include:

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

3              i. Health information sharing and submission requirements

4                   for participants; and

5              ii. The reporting format, and frequency of submissions, for

6                   health information submitted by participants to the

7                   consortium of public health colleges.

8            b. The requirements established under this subparagraph shall

9                   comply with:

10            i. Interoperability guidance published by the federal Centers

11                   for Medicare and Medicaid Services;

12            ii. Policies and procedures adopted by the board under

13                   subsection (1)(a) of Section 7 of this Act; and

14            iii. 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. Subject to subdivisions b. and c. of this subparagraph, the data

20                   elements that will be available to authorized recipients and the

21                   public.

22            b. Data shall not be made available to an authorized recipient or

23                   the public 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

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

c. The Legislative Research Commission shall, for the purpose of collecting and analyzing data to inform public policy as to health care access, utilization, cost, safety, and quality in Kentucky, be provided direct, read-only access to data contained in the statewide health data utility that:

- i. Complies with all applicable federal and state data privacy and security laws, including without limitation HIPAA; and*
- ii. Cannot be used to identify an individual; and*

4. Any fees that may be charged to authorized recipients for access to data in the statewide health data utility, except that a fee or cost of any kind shall not be charged to or required of the General Assembly, the Legislative Research Commission, or a committee, task force, or other body established by the General Assembly or Legislative Research Commission for those entities to access, receive, or use data contained in the statewide health data utility; and

(g) May contract with one (1) or more vendors or contractors for any expertise, service, or function that is necessary to assist the executive director in carrying out the executive director's duties under Sections 1 to 10 of this Act.

1. Submit drafts of any new, amended, or repealer emergency or ordinary administrative regulation along with any forms required

1                   under KRS 13A.230, required or authorized under Sections 1 to 10 of  
2                   this Act or otherwise related to the statewide health data utility, to the  
3                   board; and

4                   2. Provide the board not less than thirty (30) days to review, and advise  
5                   the executive director on, the drafts submitted under subparagraph 1.  
6                   of this paragraph.

7                   (b) In addition to the requirements of paragraph (a) of this subsection, the  
8                   executive director and the consortium of public health colleges shall keep  
9                   the board informed about, and consult with the board regarding, the  
10                   development, implementation, operation, and maintenance of the statewide  
11                   health data utility.

12                  ➔ SECTION 5. A NEW SECTION OF KRS CHAPTER 194A IS CREATED TO  
13                  READ AS FOLLOWS:

14                  (1) As used in this section:

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

17                  (b) "Community information exchange":

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

21                  a. Enhanced community care planning; and

22                  b. Tools to enable partners to integrate data from multiple sources  
23                  and make bi-directional referrals to create shared longitudinal  
24                  records; and

25                  2. Includes any system that:

26                  a. Stores an individual's personal identifiable information in a  
27                  database that is shared by a network of one (1) or more health

1                   facilities, health care professionals, health care payers, public  
2                   agencies, or community-based organizations for referral  
3                   purposes; and

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

9                   (c) "Health care information exchange" means the movement and exchange  
10                   among and between health facilities and health care professionals of health  
11                   information electronically across organizations within a state, region,  
12                   community, or hospital system; and

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

18                   (2) The Kentucky statewide health data utility shall:

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

21                   (b) Utilize health information technology to:

22                   1. Aggregate health information received from participants;  
23                   2. Provide access, in a form and manner that ensures the privacy and  
24                   security of personal health information as required under federal and  
25                   state law, including without limitation HIPAA, to health information  
26                   in the statewide health data utility to authorized recipients for the  
27                   purposes of:

1           a. Collecting and analyzing data to inform the authorized recipients  
2           as to health care access, utilization, cost, safety, and quality in  
3           Kentucky;  
4           b. Enabling any health care professional or health facility to  
5           evaluate and monitor care and treatment of patients; and  
6           c. Enabling any patient to access, through a technology enabled  
7           interface, the patient's electronic longitudinal health record; and  
8           3. Make information about health care services available to the public in  
9           a manner that allows consumers to draw meaningful comparisons  
10           between health facilities, health care payers, and other health care  
11           professionals as relevant data is available; and

12           (c) Contain the following:

13           1. A health care information exchange;  
14           2. A pharmacy information exchange;  
15           3. An all-payer claims database;  
16           4. A community information exchange; and  
17           5. Other referential sources, including without limitation public health  
18           data and self-generated data.

19           (3) (a) The information and data acquired by or contained in the statewide health  
20           data utility shall not be subject to disclosure under KRS 61.870 to 61.884.

21           (b) This subsection shall not be construed to limit or prohibit the public release  
22           of aggregated, deidentified information, reports, analyses, or dashboards by  
23           the statewide health data utility in accordance with Sections 1 to 10 of this  
24           Act.

25           ➔ SECTION 6. A NEW SECTION OF KRS CHAPTER 194A IS CREATED TO  
26           READ AS FOLLOWS:

27           (1) (a) There is hereby established a consortium between the:

- 1      1. University of Kentucky College of Public Health;
- 2      2. University of Louisville School of Public Health and Information
- 3      Services;
- 4      3. Eastern Kentucky University College of Health Sciences; and
- 5      4. Western Kentucky University Department of Public Health.

6      (b) Within sixty (60) days after the effective date of this Act, the consortium  
7      shall adopt organizing documents that provide for:

- 8      1. A governing board to govern the consortium, consisting of  
9      representatives from each member of the consortium in equal  
10     proportion;
- 11     2. The appointment of a director by the governing board to manage the  
12     consortium's daily operations; and
- 13     3. The delegation of such powers and responsibilities to the director as  
14     may be necessary for the consortium's efficient operation.

15    (2) (a) Within one hundred eighty (180) days after the effective date of the  
16    consortium's organizing documents, the consortium shall enter into a  
17    contract with the executive director to operate and govern the Kentucky  
18    statewide health data utility in accordance with Sections 1 to 10 of this Act.

19    (b) The consortium shall:

- 20    1. Not release, publish, or otherwise use any health information, records,  
21    or data to which the consortium, or any vendor or contractor of the  
22    consortium, has access to under Sections 1 to 10 of this Act without  
23    express authorization in a written or electronic record from the  
24    executive director; and
- 25    2. Monitor and supervise any vendor or contractor of the consortium to  
26    ensure that the vendor or contractor complies with Sections 1 to 10 of  
27    this Act.

1        (3) In operating and governing the statewide health data utility, the consortium  
2        shall:

3        (a) Ensure that the statewide health data utility:

4        1. Is value-driven and responsive to the needs of health care, public  
5        health, and community stakeholders;

6        2. Provides a variety of services from which to choose to best fit the needs  
7        of authorized recipients;

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

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

13        ii. The accuracy, completeness, and timeliness of the  
14        information.

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

19        4. Protects the:

20        a. Privacy of patients; and

21        b. Security and confidentiality of health information;

22        5. Facilitates and supports the secure, electronic exchange of health  
23        information;

24        6. Promotes interoperability;

25        7. Provides a mechanism for participants without electronic health  
26        information to provide health information to the statewide health data  
27        utility;

- 1       8. Has a disaster recovery mechanism that allows access to health
- 2       information in the event of a disaster, a use of ransomware, a
- 3       cyberattack, or another emergency scenario;
- 4       9. Increases the accuracy, completeness, and uniformity of health
- 5       information;
- 6       10. Allows a patient to opt out from including the patient's electronic
- 7       longitudinal health record in the statewide health data utility, except
- 8       an opt-out under this subparagraph shall not prevent the statewide
- 9       health data utility from including the patient's deidentified or
- 10       aggregated health care claims data or encounter data for the purpose
- 11       of population health monitoring, public health reporting, academic
- 12       research, or policy analysis, if the data cannot reasonably be used to
- 13       reidentify the patient; and
- 14       11. Provides education to the general public and the health care sector
- 15       about the value and benefits of a statewide health data utility;

16       (b) Operate the statewide health data utility:

- 17       1. Efficiently and effectively, using sound business and data governance
- 18       practices consistent with the goals of:
  - 19       a. Public accountability;
  - 20       b. Transparency; and
  - 21       c. Improving health outcomes; and
- 22       2. Independently in its technical and analytic functions;

23       (c) Report to the executive director and secretary any finding made, or

24       information received, by the consortium that:

- 25       1. Relates to a person who is required to comply with Section 8 of this
- 26       Act; and
- 27       2. Indicates that the person referenced in subparagraph 1. of this

1                   paragraph has, or may have, materially failed or willfully refused to  
2                   comply with Section 8 of this Act;

3                   (d) Ensure that health information is accessible to authorized recipients and  
4                   the public in a manner that:

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

7                   a. Geographic, demographic, and economic factors; and  
8                   b. Institutional size; and

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

11                   (e) For data that is made available to authorized recipients and the public,  
12                   establish a process for requesting and accessing the data that:

13                   1. Complies with subsection (2)(f)3. and 4. of Section 4 of this Act; and  
14                   2. May include requiring authorized recipients to enter into additional  
15                   data service agreements or memoranda of understanding prior to  
16                   accessing or using health information in the statewide health data  
17                   utility;

18                   (f) Prohibit any person, including an authorized recipient, from accessing or  
19                   using health information in the statewide health data utility for any of the  
20                   following purposes:

21                   1. To obtain or disclose trade secrets;

22                   2. To reidentify or attempt to reidentify an individual's data or  
23                   information;

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

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

27                   5. For any purpose not identified in subsection (2)(b)2. or 3. of Section 5

**of this Act;**

(g) Require all authorized recipients and the public to agree in a written or electronic record to comply with paragraph (f) of this subsection prior to accessing or using health information in the statewide health data utility;

(h) 1. Conduct a risk assessment and prepare a mitigation remediation plan in the form of a privacy impact assessment, which shall be submitted to and approved by the board.

**2. The assessment and plan shall:**

*a. Assess risks to an individual's right to privacy within the statewide health data utility where the individual does not possess immediate control over the individual's information;*

**b. Recommend alternatives to both mitigate the risks and achieve the stated objectives of the statewide health data utility; and**

*c. Identify those individuals within the consortium who shall be directly accountable for:*

*i. The assessment and plan;*

*ii. The statewide health data utility at the time the assessment and plan are conducted and prepared; and*

*iii. The implementation of any approved alternatives and mitigations as a result of the assessment and plan; and*

(i) Administer data governance and HIPAA training to all members of the board within sixty (60) days of each member's appointment.

23 ➔SECTION 7. A NEW SECTION OF KRS CHAPTER 194A IS CREATED TO  
24 READ AS FOLLOWS:

25 (1) There is hereby established the Kentucky Health Information Technology Board,  
26           *whose duties shall be to:*

27 (a) Establish policies and procedures for the sharing of health information by

1                   participants under Sections 1 to 10 of this Act, including the submission of  
2                   health information by participants to the consortium of public health  
3                   colleges;

4                   (b) Actively promote improved health data utility governance practices across  
5                   the state;

6                   (c) Identify and approve pivotal health data utility governance roles and  
7                   responsibilities between government agencies and the private sector, as  
8                   permitted by applicable federal and state law;

9                   (d) Advise on, review, and approve the consortium's data control, governance,  
10                   and privacy practices in compliance with federal and state information  
11                   privacy and security policies and laws;

12                   (e) Drive strategic and timely implementation of the consortium's privacy  
13                   policies, related procedures, and processes to operationalize policy-driven  
14                   controls and effective risk management methodologies, using industry  
15                   standards;

16                   (f) Review and approve the risk assessment and mitigation remediation plan  
17                   conducted and prepared by the consortium under Section 6 of this Act; and

18                   (g) Advise on, review, and make recommendations for:

19                   1. The data elements that will be available to authorized recipients and  
20                   the public, including specific strategies for ensuring the accessibility  
21                   of data related to health care access, utilization, cost, safety, and  
22                   quality;

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

24                   3. Any other matters submitted to the board relating to the development,  
25                   implementation, operation, and maintenance of the statewide health  
26                   data utility.

27                   (2) (a) The board shall consist of the following members:

- 1      1. One (1) individual who has experience in pharmacy informatics;
- 2      2. One (1) member of academia with experience in health care data
- 3      research;
- 4      3. One (1) hospital administrator who is appointed from a list of at least
- 5      three (3) candidates submitted by the Kentucky Hospital Association;
- 6      4. One (1) representative from the Kentucky Hospital Association;
- 7      5. One (1) representative from the Kentucky Medical Association;
- 8      6. One (1) representative from the Kentucky Pharmacists Association;
- 9      7. One (1) representative from the Kentucky Dental Association;
- 10     8. One (1) representative from the Kentucky Primary Care Association;
- 11     9. One (1) representative of a Medicaid managed care organization or an
- 12     organization that represents Medicaid managed care organizations;
- 13     10. One (1) representative of a commercial health care payer or an
- 14     organization that represents health insurers;
- 15     11. One (1) representative of a health care purchaser or an organization
- 16     that represents health care purchasers;
- 17     12. One (1) representative of:
  - 18     a. A property and casualty insurer;
  - 19     b. A workers' compensation insurer; or
  - 20     c. An organization that represents property and casualty or
  - 21     workers' compensation insurers;
- 22     13. One (1) individual representing health care consumers; and
- 23     14. One (1) privacy officer of a health care payer, health care purchaser,
- 24     or health facility;

25     **(b) In addition to the members listed in paragraph (a) of this subsection:**

26     1. The following persons, or their designees, shall serve as voting ex

27     officio members of the board:

- 1        a. The commissioner of the Department of Insurance;
- 2        b. The executive director of the Commonwealth Office of
- 3        Technology;
- 4        c. The commissioner of the Department of Employee Insurance;
- 5        and
- 6        d. The Attorney General;
- 7        2. The following persons, or their designees, shall serve as nonvoting ex
- 8        officio members:
- 9        a. A member of the House of Representatives, who shall be
- 10        appointed by the Speaker of the House of Representatives;
- 11        b. A member of the Senate, who shall be appointed by the President
- 12        of the Senate;
- 13        c. The commissioner of the Department for Medicaid Services;
- 14        d. The commissioner of the Department for Public Health;
- 15        e. The commissioner of the Department for Behavioral Health,
- 16        Developmental and Intellectual Disabilities; and
- 17        f. The director of the consortium of public health colleges; and
- 18        3. The executive director shall serve as chair of the board, but shall not
- 19        have a vote unless there is a tie, in which case the executive director
- 20        may cast the deciding vote.
- 21        (c) The members listed in paragraph (a) of this subsection:
- 22        1. Shall be appointed by the secretary;
- 23        2. Shall serve a term of four (4) years; and
- 24        3. May be reappointed.
- 25        (d) 1. The secretary shall fill all vacancies under paragraph (a) of this
- 26        subsection within sixty (60) days of the vacancy.
- 27        2. In the event a representative or person listed in paragraph (a) of this

1                   subsection is not available or willing to serve, the secretary shall  
2                   appoint a person with expertise or experience in the applicable  
3                   referenced industry or subject matter.

4                   (e) Within sixty (60) days of appointment, each board member shall complete  
5                   the data governance and HIPAA training administered by the consortium.

6                   (3) The policies and procedures adopted by the board for the sharing and submission  
7                   of health information by participants under Sections 1 to 10 of this Act shall:

8                   (a) Set forth:

9                   1. The data elements to be shared and submitted by participants to the  
10                   consortium, which shall include without limitation the information  
11                   that shall be included in the clinical data captured by participants in  
12                   their existing electronic health records;

13                   2. The reporting format for the sharing and submission of health  
14                   information, which:

15                   a. May vary based on the type of data reported; and  
16                   b. If feasible, shall adopt the reporting format for self-insured  
17                   group health plans described in 29 U.S.C. sec. 1191d, as  
18                   amended, for the reporting of health care claims data; and

19                   3. The frequency of submissions; and

20                   (b) Comply with:

21                   1. Interoperability guidance published by the federal Centers for  
22                   Medicare and Medicaid Services; and

23                   2. All applicable federal and state data privacy and security laws,  
24                   including without limitation HIPAA.

25                   (4) The board may seek information from any person if the board deems that the  
26                   information is relevant to better inform the board of its duties.

27                   (5) The first meeting of the board shall be held within thirty (30) days after

1        appointment of all of the members.

2        (6) (a) The board shall meet upon the call of the chair, but not less than quarterly  
3                    for the first two (2) years after the date of the first board meeting.

4                    Thereafter, the board shall meet not less than semiannually.

5        (b) A majority of the voting members, which includes the chair, shall constitute  
6                    a quorum to do business.

7        (c) Actions of the board shall require a:

8                    1. Quorum; and

9                    2. Majority of the voting members present.

10        (d) A member shall be permitted to participate and vote in board business  
11                    through distance communication technology.

12        (7) The board shall be a budget unit of the cabinet, which shall:

13        (a) Pay the board's necessary operating expenses; and

14        (b) Furnish all office space, personnel, equipment, supplies, and technical or  
15                    administrative services required by the board in the performance of the  
16                    functions established in this section.

17        (8) Members of the board, other than cabinet employees, shall not receive  
18                    compensation from the cabinet for the member's service on the board, but shall  
19                    receive actual and necessary travel expenses associated with attending meetings  
20                    in accordance with state administrative regulations relating to travel  
21                    reimbursement.

22        ➔SECTION 8. A NEW SECTION OF KRS CHAPTER 194A IS CREATED TO  
23        READ AS FOLLOWS:

24        (1) To the extent permitted under federal law:

25        (a) A participant shall comply with all health information sharing and  
26                    submission requirements established for the participant by the executive  
27                    director in administrative regulations promulgated in accordance with

1                   *Section 4 of this Act; and*

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

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

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

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

12                   ➔ SECTION 9. A NEW SECTION OF KRS CHAPTER 194A IS CREATED TO  
13                   READ AS FOLLOWS:

14                   *(1) (a) The secretary shall enforce the mandatory reporting requirements in*  
15                   *Section 8 of this Act.*

16                   *(b) In carrying out the duties under paragraph (a) of this subsection, the*  
17                   *secretary:*

18                   *1. Has the authority to receive complaints and conduct investigations,*  
19                   *which includes:*

20                   *a. Receiving sworn statements; and*

21                   *b. Issuing subpoenas to compel the:*

22                   *i. Attendance and testimony of witnesses; and*

23                   *ii. Production of records and other documents;*

24                   *2. May enter an order assessing a civil penalty in accordance with this*  
25                   *section;*

26                   *3. Has the power to invoke the aid of the courts through injunction or*  
27                   *other proper process to:*

1                   a. Enjoin any existing or threatened violation of Section 8 of this  
2                   Act; or  
3                   b. Enforce any proper order entered under this section; and  
4                   4. Shall provide a right to an administrative hearing in accordance with  
5                   KRS Chapter 13B prior to the entry of a final order assessing a civil  
6                   penalty under this section, except that if a person fails to request an  
7                   administrative hearing within twenty (20) days of the date of service of  
8                   any notice of intent to assess a civil penalty under this section, the  
9                   secretary may enter a final order assessing the civil penalty without  
10                   conducting a hearing.

11                   (2) (a) Subject to paragraphs (b), (c), (d), and (e) of this subsection, the executive  
12                   director shall promulgate an administrative regulation designating a  
13                   schedule of penalties, not to exceed one thousand dollars (\$1,000) per day,  
14                   for any participant that fails to comply with a mandatory reporting  
15                   requirement for that person under Section 8 of this Act.

16                   (b) Local government, state, and federal agencies or entities shall not be subject  
17                   to or assessed a civil penalty under this section.

18                   (c) The executive director may, by administrative regulation, adjust the  
19                   maximum penalty established under paragraph (a) of this subsection every  
20                   two (2) years based on the percent change in the nonseasonally adjusted  
21                   annual average Consumer Price Index for All Urban Consumers (CPI-U),  
22                   U.S. City Average, Medical Care, between the two (2) most recent calendar  
23                   years available, as published by the United States Bureau of Labor  
24                   Statistics.

25                   (d) The secretary shall promulgate an administrative regulation designating the  
26                   process for notice, hearing, and collection of any penalty assessed under  
27                   section.

1                   (e) *The secretary may, upon terms and conditions that are determined by the*  
2                   *secretary to be in the public interest, remit or mitigate any penalty assessed*  
3                   *under section.*

4                   (3) *Any penalties collected by the secretary under this section shall be deposited into*  
5                   *the Kentucky statewide health data utility fund established in Section 3 of this*  
6                   *Act.*

7                   → SECTION 10. A NEW SECTION OF KRS CHAPTER 194A IS CREATED  
8 TO READ AS FOLLOWS:

9                   (1) *No later than June 1 of each year, the consortium shall submit a written report to*  
10                   *the executive director, and the Legislative Research Commission for referral to*  
11                   *the appropriate interim joint committees or other appropriate committees, that*  
12                   *sets forth the following relating to the statewide health data utility:*

13                   (a) *The status of any development and implementation efforts;*

14                   (b) *A detailed summary of the utility's operations for the previous year;*

15                   (c) *The financial stability of the utility;*

16                   (d) *An assessment of:*

17                   1. *The cost, performance, and effectiveness of the utility;*

18                   2. *The performance of any vendors or contractors that the consortium*  
19                   *has retained; and*

20                   3. *Whether the utility has advanced the purposes set forth in Sections 1*  
21                   *to 10 of this Act; and*

22                   (e) *Any recommendations for changes or improvements to the utility.*

23                   (2) *No later than September 1 of each year, the executive director shall submit a*  
24                   *written report to the Legislative Research Commission for referral to the*  
25                   *appropriate interim joint committees or other appropriate committees that sets*  
26                   *forth the following relating to the statewide health data utility:*

27                   (a) *A summary of the executive director's oversight and enforcement activities;*

- 1        **(b) Whether the consortium is in compliance with the contract to operate and**
- 2        **govern the utility;**
- 3        **(c) If the consortium is not in compliance with the contract to operate and**
- 4        **govern the utility, a detailed listing and summary of the compliance issues;**
- 5        **(d) An assessment of:**
  - 6        **1. The financial stability of the utility;**
  - 7        **2. The cost, performance, and effectiveness of the utility;**
  - 8        **3. The performance of any vendors or contractors that the consortium of**
  - 9        **public health colleges or executive director has retained; and**
  - 10       **4. Whether the utility has advanced the purposes set forth in Sections 1**
  - 11       **to 10 of this Act; and**
- 12       **(e) Any recommendations for changes or improvements to the utility.**

13       ➔Section 11. KRS 194A.030 is amended to read as follows:

14       The cabinet consists of the following major organizational units, which are hereby  
15       created:

16       (1) Office of the Secretary. Within the Office of the Secretary, there shall be an Office  
17       of Legal Services, an Office of Inspector General, an Office of Public Affairs, an  
18       Office of Human Resource Management, an Office of Finance and Budget, an  
19       Office of Legislative and Regulatory Affairs, an Office of Administrative Services,  
20       an Office of Application Technology Services, an Office of Data Analytics, and an  
21       Office of Medical Cannabis as follows:

22       (a) The Office of Legal Services shall provide legal advice and assistance to all  
23       units of the cabinet in any legal action in which it may be involved. The  
24       Office of Legal Services shall employ all attorneys of the cabinet who serve  
25       the cabinet in the capacity of attorney, giving legal advice and opinions  
26       concerning the operation of all programs in the cabinet. The Office of Legal  
27       Services shall be headed by a general counsel who shall be appointed by the

6 (b) The Office of Inspector General shall be headed by an inspector general who  
7 shall be appointed by the secretary with the approval of the Governor. The  
8 inspector general shall be directly responsible to the secretary. The Office of  
9 Inspector General shall be responsible for:

1. The conduct of audits and investigations for detecting the perpetration of fraud or abuse of any program by any client, or by any vendor of services with whom the cabinet has contracted; and the conduct of special investigations requested by the secretary, commissioners, or office heads of the cabinet into matters related to the cabinet or its programs;
2. Licensing and regulatory functions as the secretary may delegate;
3. Review of health facilities participating in transplant programs, as determined by the secretary, for the purpose of determining any violations of KRS 311.1911 to 311.1959, 311.1961, and 311.1963;
4. The duties, responsibilities, and authority pertaining to the certificate of need functions and the licensure appeals functions, pursuant to KRS Chapter 216B;
5. The notification and forwarding of any information relevant to possible criminal violations to the appropriate prosecuting authority;
6. The oversight of the operations of the Kentucky Health Information Exchange **in accordance with Section 13 of this Act**; and
7. The support and guidance to health care providers related to telehealth

1 services, including the development of policy, standards, resources, and  
2 education to expand telehealth services across the Commonwealth;

3 (c) The Office of Public Affairs shall be headed by an executive director  
4 appointed by the secretary with the approval of the Governor in accordance  
5 with KRS 12.050. The office shall provide information to the public and news  
6 media about the programs, services, and initiatives of the cabinet;

7 (d) The Office of Human Resource Management shall be headed by an executive  
8 director appointed by the secretary with the approval of the Governor in  
9 accordance with KRS 12.050. The office shall coordinate, oversee, and  
10 execute all personnel, training, and management functions of the cabinet. The  
11 office shall focus on the oversight, development, and implementation of  
12 quality improvement services; curriculum development and delivery of  
13 instruction to staff; the administration, management, and oversight of training  
14 operations; health, safety, and compliance training; and equal employment  
15 opportunity compliance functions;

16 (e) The Office of Finance and Budget shall be headed by an executive director  
17 appointed by the secretary with the approval of the Governor in accordance  
18 with KRS 12.050. The office shall provide central review and oversight of  
19 budget, contract, and cabinet finances. The office shall provide coordination,  
20 assistance, and support to program departments and independent review and  
21 analysis on behalf of the secretary;

22 (f) The Office of Legislative and Regulatory Affairs shall be headed by an  
23 executive director appointed by the secretary with the approval of the  
24 Governor in accordance with KRS 12.050. The office shall provide central  
25 review and oversight of legislation, policy, and administrative regulations.  
26 The office shall provide coordination, assistance, and support to program  
27 departments and independent review and analysis on behalf of the secretary;

1 (g) The Office of Administrative Services shall be headed by an executive  
2 director appointed by the secretary with the approval of the Governor in  
3 accordance with KRS 12.050. The office shall provide central review and  
4 oversight of procurement, general accounting including grant monitoring, and  
5 facility management. The office shall provide coordination, assistance, and  
6 support to program departments and independent review and analysis on  
7 behalf of the secretary;

8 (h) The Office of Application Technology Services shall be headed by an  
9 executive director appointed by the secretary with the approval of the  
10 Governor in accordance with KRS 12.050. The office shall provide  
11 application technology services including central review and oversight. The  
12 office shall provide coordination, assistance, and support to program  
13 departments and independent review and analysis on behalf of the secretary;

14 (i) The Office of Data Analytics shall be headed by an executive director who  
15 shall be appointed by the secretary with the approval of the Governor under  
16 KRS 12.050, and shall:

17 1. Identify and innovate strategic initiatives to inform public policy  
18 initiatives and provide opportunities for improved health outcomes for  
19 all Kentuckians through data analytics;~~1. The office shall~~

20 2. Provide leadership in the redesign of the health care delivery system  
21 using electronic information technology to improve patient care and  
22 reduce medical errors and duplicative services; and

23 3. Comply with Sections 1 to 10 of this Act;

24 (j) The Office of Medical Cannabis shall be headed by an executive director  
25 appointed by the Governor in accordance with KRS 12.040 and shall  
26 implement, operate, oversee, and regulate the medicinal cannabis program.  
27 The office shall be composed of the Division of Enforcement and Compliance

1 and the Division of Licensure and Access. Each division in the office shall be  
2 headed by a director appointed by the secretary with the approval of the  
3 Governor in accordance with KRS 12.050.

4 (2) Department for Medicaid Services. The Department for Medicaid Services shall  
5 serve as the single state agency in the Commonwealth to administer Title XIX of  
6 the Federal Social Security Act. The Department for Medicaid Services shall be  
7 headed by a commissioner for Medicaid services, who shall be appointed by the  
8 secretary with the approval of the Governor under KRS 12.050. The commissioner  
9 for Medicaid services shall be a person who by experience and training in  
10 administration and management is qualified to perform the duties of this office. The  
11 commissioner for Medicaid services shall exercise authority over the Department  
12 for Medicaid Services under the direction of the secretary and shall only fulfill  
13 those responsibilities as delegated by the secretary;

14 (3) Department for Public Health. The Department for Public Health shall develop and  
15 operate all programs of the cabinet that provide health services and all programs for  
16 assessing the health status of the population for the promotion of health and the  
17 prevention of disease, injury, disability, and premature death. This shall include but  
18 not be limited to oversight of the Division of Women's Health and the Office for  
19 Children with Special Health Care Needs. The duties, responsibilities, and authority  
20 set out in KRS 200.460 to 200.490 shall be performed by the Department for Public  
21 Health. The Department for Public Health shall advocate for the rights of children  
22 with disabilities and, to the extent that funds are available, shall ensure the  
23 administration of services for children with disabilities as are deemed appropriate  
24 by this office pursuant to Title V of the Social Security Act. The Department for  
25 Public Health may promulgate administrative regulations under KRS Chapter 13A  
26 as may be necessary to implement and administer its responsibilities. The Office for  
27 Children with Special Health Care Needs may be headed by an executive director

1 appointed by the secretary with the approval of the Governor in accordance with  
2 KRS 12.050. The Department for Public Health shall be headed by a commissioner  
3 for public health who shall be appointed by the secretary with the approval of the  
4 Governor under KRS 12.050. The commissioner for public health shall be a duly  
5 licensed physician who by experience and training in administration and  
6 management is qualified to perform the duties of this office. The commissioner  
7 shall advise the head of each major organizational unit enumerated in this section  
8 on policies, plans, and programs relating to all matters of public health, including  
9 any actions necessary to safeguard the health of the citizens of the Commonwealth.  
10 The commissioner shall serve as chief medical officer of the Commonwealth. The  
11 commissioner for public health shall exercise authority over the Department for  
12 Public Health under the direction of the secretary and shall only fulfill those  
13 responsibilities as delegated by the secretary;

14 (4) Department for Behavioral Health, Developmental and Intellectual Disabilities. The  
15 Department for Behavioral Health, Developmental and Intellectual Disabilities shall  
16 develop and administer programs for the prevention of mental illness, intellectual  
17 disabilities, brain injury, developmental disabilities, and substance use disorders  
18 and shall develop and administer an array of services and support for the treatment,  
19 habilitation, and rehabilitation of persons who have a mental illness or emotional  
20 disability, or who have an intellectual disability, brain injury, developmental  
21 disability, or a substance use disorder. The Department for Behavioral Health,  
22 Developmental and Intellectual Disabilities shall be headed by a commissioner for  
23 behavioral health, developmental and intellectual disabilities who shall be  
24 appointed by the secretary with the approval of the Governor under KRS 12.050.  
25 The commissioner for behavioral health, developmental and intellectual disabilities  
26 shall be by training and experience in administration and management qualified to  
27 perform the duties of the office. The commissioner for behavioral health,

1       developmental and intellectual disabilities shall exercise authority over the  
2       department under the direction of the secretary, and shall only fulfill those  
3       responsibilities as delegated by the secretary;

4       (5) Department for Family Resource Centers and Volunteer Services. The Department  
5       for Family Resource Centers and Volunteer Services shall streamline the various  
6       responsibilities associated with the human services programs for which the cabinet  
7       is responsible. This shall include, but not be limited to, oversight of the Division of  
8       Family Resource and Youth Services Centers and Serve Kentucky. The Department  
9       for Family Resource Centers and Volunteer Services shall be headed by a  
10       commissioner who shall be appointed by the secretary with the approval of the  
11       Governor under KRS 12.050. The commissioner for family resource centers and  
12       volunteer services shall be by training and experience in administration and  
13       management qualified to perform the duties of the office, shall exercise authority  
14       over the department under the direction of the secretary, and shall only fulfill those  
15       responsibilities as delegated by the secretary;

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

23       (7) Department for Aging and Independent Living. The Department for Aging and  
24       Independent Living shall serve as the state unit as designated by the Administration  
25       on Aging Services under the Older Americans Act and shall have responsibility for  
26       administration of the federal community support services, in-home services, meals,  
27       family and caregiver support services, elder rights and legal assistance, senior

1       community services employment program, the state health insurance assistance  
2       program, state home and community based services including home care,  
3       Alzheimer's respite services and the personal care attendant program, certifications  
4       of assisted living facilities, and the state Council on Alzheimer's Disease and other  
5       related disorders. The department shall also administer the Long-Term Care  
6       Ombudsman Program and the Medicaid Home and Community Based Waivers  
7       Participant Directed Services Option (PDS) Program. The department shall serve as  
8       the information and assistance center for aging and disability services and  
9       administer multiple federal grants and other state initiatives. The department shall  
10      be headed by a commissioner appointed by the secretary with the approval of the  
11      Governor in accordance with KRS 12.050.

12      ➔Section 12. KRS 194A.101 is amended to read as follows:

13      (1) The Office of Data Analytics is hereby created in the Office of the Secretary. The  
14      office shall:

15      (a) Provide oversight and strategic direction for, and be responsible for the  
16      coordinating of, the data analysis initiatives ~~offor~~ the various departments  
17      that regulate health care and social services to ensure that policy is consistent  
18      with the long-term goals across the Commonwealth; and

19      (b) Comply with Sections 1 to 10 of this Act.

20      (2) The office shall have the authority to review all data requests received by the  
21      cabinet from the public, review the requests for content to determine the cabinet's  
22      response, and approve the release of the requested information. The office shall  
23      review data analyses conducted by the departments within the cabinet to ensure the  
24      consistency, quality, and validity of the analysis prior to its use in operational and  
25      policy decisions. The office shall facilitate the process of data integration by  
26      initiating and maintaining data-sharing agreements in order to improve inter-agency  
27      and cross-cabinet collaboration.

1 (3) The Office of Data Analytics shall promulgate administrative regulations in  
2 accordance with KRS Chapter 13A to implement this section.

3 ➔Section 13. KRS 194A.103 is amended to read as follows:

4 (1) **(a)** The Division of Kentucky Health Information Exchange is hereby created in  
5 the Office of Inspector General.

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

7 **1. Continue to operate and support the Kentucky Health Information**  
8 **Exchange until the Kentucky statewide health data utility established**  
9 **in Sections 1 to 10 of this Act becomes operational; and**

10 **2. Cooperate with, support, and provide assistance to the executive**  
11 **director of the Office of Data Analytics and the consortium of public**  
12 **health colleges created in Section 6 of this Act in the implementation**  
13 **of the health care information exchange and the prescription**  
14 **information exchange within the Kentucky statewide health data**  
15 **utility established in Sections 1 to 10 of this Act**~~[provide leadership in~~  
16 ~~the redesign of the health care delivery system using electronic~~  
17 ~~information technology as a means to improve patient care and reduce~~  
18 ~~medical errors and duplicative services].~~

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

21 ➔Section 14. KRS 194A.095 is amended to read as follows:

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

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

26 (b) Analyzing and communicating trends in women's health issues and mental  
27 health;



1 State Treasury and all provider tax revenues collected pursuant to KRS 142.301 to  
2 142.363 shall be deposited in the State Treasury and transferred on a quarterly basis  
3 to the Department for Medicaid Services for use as specified in this section. All  
4 investment earnings of the fund shall be credited to the fund. Provider tax revenues  
5 collected in accordance with KRS 142.301 to 142.363 may be used to fund the  
6 provisions of Sections 1 to 10 of this Act~~[KRS 216.2920 to 216.2929]~~ and to  
7 supplement the medical assistance-related general fund appropriations for fiscal  
8 year 1994 and subsequent fiscal years. Notwithstanding the provisions of KRS  
9 48.500 and 48.600, the MART fund shall be exempt from any state budget  
10 reduction acts.

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

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

22 a. The allocation required in subparagraph 2. of this paragraph for  
23 the psychiatric pool; and  
24 b. The initial or final, as applicable, DSH payments to be made to  
25 hospitals in the university pool in subparagraph 3. of this  
26 paragraph;

27 2. A psychiatric pool, composed of private psychiatric hospitals and state

1 mental hospitals, shall receive the percentage allowable by federal law  
2 pursuant to 42 U.S.C. sec. 1396r-4(h), up to nineteen and eight-  
3 hundredths percent (19.08%) of the total disproportionate share funds,  
4 with the allocation between each respective group of hospitals  
5 established by the biennial budget; except, however, that the allocation  
6 to state mental hospitals shall not exceed ninety-two and three-tenths  
7 percent (92.3%) of the total allotment to the psychiatric pool. If there are  
8 remaining funds within the psychiatric pool after all private psychiatric  
9 hospitals reach their hospital-specific DSH limit, state mental hospitals  
10 may exceed the ninety-two and three-tenths percent (92.3%) limit but  
11 may not exceed their hospital-specific DSH limit;

3. A university hospital pool, composed of university hospitals, shall  
4. receive thirty-seven percent (37%) of the state's DSH allotment; except,  
5. however, that initial and final DSH payments to university hospitals  
6. shall be determined according to paragraph (e) of this subsection and not  
7. exceed the pool's overall allotment;
8. 4. If there are any remaining disproportionate share funds from the  
9. psychiatric pool, fifty-four percent (54%) of those funds shall be  
10. distributed to the acute care pool and forty-six percent (46%) shall be  
11. distributed to the university pool. If the university hospitals are unable to  
12. absorb additional DSH payment dollars, remaining funds shall be  
13. distributed to the acute care pool; and
14. 5. If, in any year, university hospitals fail to provide state matching funds  
15. necessary to secure federal financial participation for the funds allocated  
16. to university hospitals under this subsection, the portion of the funding  
17. allocation that is not matched by university hospitals shall be made  
18. available to the acute care pool.

1 (b) The MART fund shall be used to compensate acute care hospitals, private  
2 psychiatric hospitals, state mental hospitals, critical access hospitals,  
3 comprehensive physical rehabilitation hospitals, long-term acute care  
4 hospitals, and university hospitals participating in the disproportionate share  
5 program for uncompensated care costs.

6 (c) An individual hospital shall receive distributions if the hospital meets the  
7 requirements of the disproportionate share program pursuant to 42 U.S.C. sec.  
8 1396r-4.

9 (d) 1. An individual hospital shall not receive an initial DSH payment unless  
10 the hospital submits a Medicaid DSH survey by the deadline established  
11 by subsection (8)(a) of this section, unless the deadline has been  
12 extended by the commissioner of the department. Extension requests  
13 shall be received at least ten (10) days prior to the deadline. Extensions  
14 shall be limited to rare circumstances which prevent the hospital from  
15 meeting the deadline despite due diligence. Extensions shall be granted  
16 for no more than thirty (30) calendar days from the original due date for  
17 the Medicaid DSH survey. Failure to submit a DSH survey in a timely  
18 manner or other required information for receipt of an initial DSH  
19 payment shall result in an individual hospital's final DSH payment being  
20 reduced by twenty percent (20%).  
21 2. A hospital newly enrolled in the Medicaid program, which does not  
22 have at least six (6) months of cost report information necessary to  
23 calculate an initial DSH payment, may submit a limited DSH survey for  
24 the purpose of determining if the hospital is eligible to receive an initial  
25 DSH payment.

26 (e) Distributions shall be made as follows:  
27 1. For state fiscal year 2018-2019, the department shall use the examined

1 state fiscal year 2014-2015 DSH survey to calculate an initial DSH  
2 payment. Providers who did not receive a DSH payment for state fiscal  
3 year 2014-2015 shall be eligible to submit data for the purpose of the  
4 2019 payment, subject to limited review. For state fiscal year 2019-  
5 2020, and each year thereafter, the department shall use the Medicaid  
6 DSH survey covering the hospital's fiscal year ending in the calendar  
7 year preceding July 1 of the applicable state fiscal year to calculate an  
8 initial DSH payment. Using the surveys submitted in accordance with  
9 this subsection, payments shall be made as follows:

- 10 a. Each university hospital in the university pool shall receive an  
11 initial DSH payment equal to one hundred percent (100%) of the  
12 hospital's total uncompensated care costs if the total initial DSH  
13 payments to all hospitals in the university pool do not exceed the  
14 maximum allotment to the university pool as set forth in  
15 subsection (3)(a) of this section. If the total uncompensated care  
16 costs for the pool exceed the pool's maximum allotment, the initial  
17 uncompensated care factor for university hospitals shall be  
18 determined by calculating the percentage of each hospital's total  
19 uncompensated care costs toward the sum of the total  
20 uncompensated care costs of all hospitals in the university pool,  
21 and each hospital's initial DSH payment shall be calculated by  
22 multiplying the hospital's initial uncompensated care factor by the  
23 total funds allocated to the university hospital pool;
- 24 b. For each private psychiatric and state mental hospital in the  
25 psychiatric pool, the department shall calculate an initial  
26 uncompensated care factor. The initial uncompensated care factor  
27 for a private psychiatric or state mental hospital shall be

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

26 d. For any hospital that is newly enrolled in the Medicaid program  
27 and lacks at least six (6) months of cost report information, the



- ii. Total uncompensated care costs;
- iii. The status of the MIUR and LIUR calculations;
- iv. The uncompensated care factor; and
- v. The estimated initial annual payment amount;

h. Hospitals shall notify the department by October 31 of any adjustments in the department's initial calculations;

i. The department shall make any necessary adjustments and shall issue an initial DSH payment to each hospital in one (1) lump-sum payment on or before November 30, for the disproportionate share funds available during the corresponding federal fiscal year. If the federal disproportionate share allotment for the Commonwealth has not been published through the Federal Register by November 15, the department may pay a portion but no less than ninety percent (90%) of the expected annual payment prior to the publication of the annual federal allotment. If a partial initial payment is made, the remaining amount shall be paid within sixty (60) days after the date upon which notice of the Commonwealth's federal allotment is published through the Federal Register; and

j. An initial DSH payment shall not be subject to appeal;

2. a. Each hospital's total initial DSH payment shall be reconciled to a final DSH payment using the examined Medicaid DSH surveys and shall correspond to the applicable state fiscal year DSH payment year.

b. Using the surveys submitted in accordance with subsection (8)(a) of this section, the department shall make a final determination of whether an acute care hospital qualifies as a MIUR or as a LIUR hospital. Any qualifying hospital will be deemed an essential

hospital. Critical access hospital status will also be confirmed to make a final determination of essential hospital status.

- c. The department shall calculate a final DSH payment as follows:
  - i. Each university hospital shall receive a final DSH payment equal to one hundred percent (100%) of the hospital's total uncompensated costs so long as the total final DSH payments to all university hospitals do not exceed the maximum allotment to the university pool as set forth in subsection (3)(a) of this section. If total uncompensated care cost for the pool exceeds the pool's maximum allotment, the final uncompensated care factor for university hospitals shall be determined by calculating the percentage of each hospital's total uncompensated care costs toward the sum of the total uncompensated care costs for all hospitals within the university pool. In this event, each hospital's final DSH payment shall be calculated by multiplying the hospital's uncompensated care factor by the total fund allocated to the hospitals within the respective pool under subsection (3)(a) of this section;
  - ii. For hospitals in the acute care pool and the psychiatric pool, the department shall recalculate each hospital's uncompensated care factor using examined data. The final uncompensated care factor for each hospital that qualifies as an essential hospital shall be computed using two hundred percent (200%) of the hospital's total uncompensated care costs using examined data;
  - iii. If a hospital has a negative uncompensated care cost, their

uncompensated care cost will be excluded in the calculation of uncompensated care factors; and

iv. The department shall compare each hospital's initial DSH payment with the hospital's final DSH payment and with the hospital's hospital-specific DSH limit to determine if any underpayment or an overpayment exists.

- i. A hospital's final MIUR and LIUR status;
- ii. Final uncompensated care factor and underlying data;
- iii. Final DSH payment; and
- iv. If applicable, the amount of any overpayment to be paid to the department and the due date for repayment.

19 f. Hospitals shall notify the department by October 31 of any  
20 corrections to the department's calculations.

21 g. If a hospital's initial DSH payment was less than the hospital's  
22 final DSH payment, the department shall pay the hospital the  
23 amount of the difference. Final DSH payments shall be issued by  
24 the department within sixty (60) days of the due date for the  
25 repayment of funds from hospitals with a DSH overpayment. If all  
26 repayments have not yet been received by the due date, the  
27 department shall distribute the funds collected as of the due date,

1 and shall issue additional payments on a timely basis upon  
2 collection of all remaining outstanding overpayments.

3 h. Any funds remaining after the reconciliation process shall be  
4 redistributed pursuant to subparagraph 3. of this paragraph; and

5 3. Disproportionate share payments remaining after reconciling each  
6 hospital's initial DSH payment with the hospital's final DSH payment  
7 shall be distributed to other hospitals in the acute care pool, university  
8 pool, or to private psychiatric hospitals in the psychiatric pool as  
9 follows:

10 a. Funds shall first be distributed to all hospitals in the same pool as  
11 the hospitals from which the overpayments were recovered, and  
12 the funds shall be distributed in a proportional manner in relation  
13 to each hospital's remaining total uncompensated care costs in  
14 accordance with the hospital's examined DSH survey for the  
15 applicable DSH year;

16 b. In the proportional distribution, the distribution factor for each  
17 hospital that qualifies as an essential hospital shall be computed  
18 using two hundred percent (200%) of the hospital's total remaining  
19 uncompensated care costs; and

20 c. If DSH funds remain after making this distribution to other  
21 hospitals in the same pool, funds shall be distributed  
22 proportionally to hospitals in the acute care pool, university pool,  
23 and private psychiatric hospitals in the psychiatric pool in relation  
24 to each hospital's remaining total uncompensated care costs in  
25 accordance with the hospital's examined Medicaid DSH survey for  
26 the applicable DSH year.

27 (4) Notwithstanding any other provision to the contrary, total annual disproportionate

1 share payments made to state mental hospitals, university hospitals, acute care  
2 hospitals, critical access hospitals, comprehensive physical rehabilitation hospitals,  
3 long-term acute care hospitals, and private psychiatric hospitals in each state fiscal  
4 year shall be equal to the maximum amount of disproportionate share payments  
5 established under the Federal Balanced Budget Act of 1997 and any amendments  
6 thereto. Disproportionate share payments made to a hospital shall not exceed the  
7 hospital's total uncompensated costs or the hospital's hospital-specific DSH limit.

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

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

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

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

immediately prior to the department's initial DSH payment calculation. A hospital may submit corrections to an applicable Medicaid DSH survey prior to the scheduled start date of the department's desk review.

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

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

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

20 → Section 16. KRS 205.6489 is amended to read as follows:

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

24 (2) The program shall include a system of outreach and referral for children who may  
25 be eligible for the Kentucky Children's Health Insurance Program. The program  
26 shall work with the Department for Medicaid Services, the Department for  
27 Community Based Services, schools, pediatricians, public health departments, and

1       other entities interested in the health of children in developing the system of  
2       outreach and referral.

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

6       (4) The Kentucky Children's Health Insurance Program shall collect, analyze, and  
7       publicly disseminate comprehensive data on the number of children enrolled in the  
8       program, services received through the program, and the effect on health outcomes  
9       of children served by the program including the special health needs of minority  
10      children. The information collected by the program shall be subject to the Kentucky  
11      statewide health data utility established in Sections 1 to 10 of this Act or, to the  
12      extent the statewide health data utility is not operational, to any other operational  
13      health data reporting law of this state~~[KRS 216.2927(1)]~~. The program shall ~~have~~  
14      ~~access to all data collected by the cabinet under KRS 216.2920 to 216.2929 and~~  
15      ~~shall~~] coordinate program data collection efforts with the data collection efforts of  
16      the Kentucky statewide health data utility~~[the cabinet under KRS 216.2920 to~~  
17      ~~216.2929]~~.

18      ➔ Section 17. KRS 211.474 is amended to read as follows:

19      The board shall:

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

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

24       (a) The trust fund shall serve as a funding source of last resort for residents of the  
25       Commonwealth of Kentucky. To be eligible for assistance from the trust fund,  
26       an individual must have exhausted all other funding sources that cover the  
27       type of services sought through the trust fund. Individuals who have

1 continuing health insurance benefits, including Medicaid, may access the trust  
2 fund for services that are needed but not covered by insurance or any other  
3 funding source. Individuals who qualify for institutional care through  
4 Medicaid shall not qualify for services through the trust fund;

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

7 (c) Expenditures on behalf of any one (1) brain-injured individual may not  
8 exceed fifteen thousand dollars (\$15,000) for any twelve (12) month period,  
9 and may not exceed a lifetime maximum of sixty thousand dollars (\$60,000).  
10 At its discretion and subject to fund availability, the board may waive the  
11 expenditure or time limitations or both in special circumstances;

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

13 1. Case management;

14 2. Community residential services;

15 3. Structured day program services;

16 4. Psychological and mental health services;

17 5. Prevocational services;

18 6. Supported employment;

19 7. Companion services;

20 8. Respite care;

21 9. Occupational therapy; and

22 10. Speech and language therapy;

23 (e) Covered services shall not include institutionalization, hospitalization, or  
24 medications;

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



6 ➔Section 18. KRS 214.375 is amended to read as follows:

7 (1) As used in this section:

8 (a) "Advisory committee" means the Kentucky Parkinson's Disease Research  
9 Registry Advisory Committee established under subsection (3) of this section;

10 (b) "Cabinet" means the Cabinet for Health and Family Services;

11 (c) "Movement disorder center" means a health facility licensed under KRS  
12 Chapter 216B that operates outpatient clinics or ambulatory care facilities that  
13 employ movement disorder health care providers;

14 (d) "Movement disorder health care provider" means a licensed physician or  
15 osteopath licensed under KRS Chapter 311 that is fellowship trained in  
16 movement disorders as specified by either the American Academy of  
17 Neurology's Movement Disorders Section or the Movement Disorder  
18 Society's Pan American Section;

19 (e) "Parkinson's disease" means a chronic and progressive neurologic disorder  
20 resulting from a deficiency of the neurotransmitter dopamine as a  
21 consequence of specific degenerative changes in the area of the brain called  
22 the basal ganglia characterized by tremor at rest, slow movements, muscle  
23 rigidity, stooped posture, and unsteady or shuffling gait;

24 (f) "Parkinsonisms":

25 1. Means Parkinson's disease-related conditions that cause a combination  
26 of movement abnormalities such as tremor at rest, slow movement,  
27 muscle rigidity, impaired speech, and muscle stiffness, which often

overlap with and can evolve from what appears to be Parkinson's disease; and

3                   2. Includes multiple system atrophy, dementia with Lewy bodies,  
4                   corticobasal degeneration, and progressive supranuclear palsy;

5 (g) "Registry" means the Kentucky Parkinson's Disease Research Registry  
6 established in subsection (2) of this section; and

7 (h) "Secretary" means the secretary of the cabinet.

8 (2) The Kentucky Parkinson's Disease Research Registry is hereby established within  
9 the cabinet under the direction of the secretary, who may enter into contracts,  
10 grants, or other agreements as necessary to administer the registry in accordance  
11 with this section.

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

16 (b) The advisory committee shall be appointed by the secretary and include at  
17 least one (1);

## 18 1. Neurologist;

## 19 2. Movement disorder specialist;

### 20 3. Primary care provider;

#### 21 4. Physician informaticist;

## 22 5. Patient living with Parkinson's disease;

23 6. Public health professional;

24           7. Population health researcher familiar with health data registries;

25 8. Parkinson's disease researcher;





1 movement disorder health care provider shall notify the cabinet and the  
2 cabinet shall remove the patient from the registry.

3 (c) To ensure compliance with the reporting and notification requirements of this  
4 subsection, the secretary or his or her agent may, upon reasonable notice,  
5 inspect a representative sample of the medical records of patients admitted,  
6 diagnosed, or treated for Parkinson's disease or Parkinsonisms at a movement  
7 disorder center.

8 (d) A movement disorder center or movement disorder health care provider who  
9 in good faith submits a report in accordance with paragraph (a) of this  
10 subsection is not liable in any cause of action arising from the submission of  
11 the report.

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

16 (6) The cabinet shall make data from the registry, with or without identifiers, available  
17 to researchers that have the approval of an institutional review board in accordance  
18 with requirements of the Federal Policy for the Protection of Human Subjects, 45  
19 C.F.R. pt. 46, and, as applicable, 21 C.F.R. pt. 56, 45 C.F.R. pt. 164, ~~{ KRS~~  
20 ~~216.2920 to 216.2929, 900 KAR 7:030 and 7:040,}~~ and any other relevant federal  
21 or state requirements.

22 (7) (a) The cabinet may enter into agreements to furnish data collected in the registry  
23 to other states' Parkinson's disease registries, federal Parkinson's disease  
24 control agencies, local health officers, or health researchers not described in  
25 subsection (6) of this section for the study of Parkinson's disease.  
26 (b) Before confidential information is disclosed pursuant to paragraph (a) of this  
27 subsection, the out-of-state registry, agency, officer, or researcher shall agree

1                   in writing to maintain the confidentiality of the information. A researcher  
2                   shall also:

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

5                   2. Provide documentation to the cabinet that demonstrates to the cabinet's  
6                   satisfaction that the researcher has established the procedures and ability  
7                   to maintain the confidentiality of the information.

8 (8) (a) Except as specifically provided in this section, all information collected  
9                   pursuant to this section shall be confidential.

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

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

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

22                   1. The name of the person authorizing access;  
23                   2. Name, title, address, and organizational affiliation of persons given  
24                   access;  
25                   3. Dates of access; and  
26                   4. The specific purpose for which accessed information is to be used.

27                   The record of access shall be open to public inspection during normal

1 operating hours of the cabinet.

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

6           2. Deemed admissible as evidence in any civil, criminal, administrative, or  
7           other proceeding for any reason.

8 (9) This section does not:

9 (a) Prohibit the publication by the cabinet of reports and statistical compilations  
10 that do not in any way identify individual patients, cases, or sources of  
11 information:

12 (b) Restrict in any way a patient's access to his or her own information; or

13 (c) Prohibit movement disorder center or movement disorder health care  
14 providers from maintaining their own facility-based Parkinson's disease  
15 registries.

16 (10) (a) Nothing in this section shall be deemed to compel any individual to submit to  
17 any medical examination or supervision by the cabinet, any of its authorized  
18 representatives, or an approved researcher.

19 (b) A person who seeks information or obtains registry data pursuant to this  
20 section shall not contact a patient on the registry or the patient's family unless  
21 the cabinet has first obtained permission for the contact from the patient or the  
22 patient's family.

23 (11) The cabinet shall provide notice of the mandatory reporting of Parkinson's disease  
24 and Parkinsonisms required under this section on its website and to professional  
25 associations representing movement disorder center and movement disorder health  
26 care providers.

27 (12) (a) By October 1, 2027, and October 1 of each year thereafter, the cabinet shall

1 submit to the Legislative Research Commission for referral to the Interim  
2 Joint Committee on Health Services a yearly program summary update that  
3 includes:

4 1. The incidence and prevalence of Parkinson's disease and Parkinsonisms  
5 in the state by county;

6 2. The number of records that have been reported to the cabinet and  
7 included in the registry; and

8 3. Demographic information, including but not limited to patients' age,  
9 gender, and race.

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

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

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

21 ➔Section 19. KRS 311A.190 is amended to read as follows:

22 (1) Each licensed ambulance provider, mobile integrated healthcare program, and  
23 medical first response provider as defined in this chapter shall collect and provide  
24 to the board patient care record data and information required by the board by this  
25 chapter and administrative regulation.

26 (2) The board shall develop a patient care record form for the use of each class of  
27 ambulance provider, mobile integrated healthcare program, and medical first

1 response provider containing the data required in subsection (1) of this section. An  
2 ambulance provider, mobile integrated healthcare program, or medical first  
3 response provider may utilize any patient care record form it chooses in lieu of or in  
4 addition to the board developed patient care record form. However, the data  
5 captured on the patient care record form utilized by the ambulance service, mobile  
6 integrated healthcare program, or medical first response provider shall include at  
7 least the data that is required by the administrative regulations promulgated  
8 pursuant to subsection (1) of this section.

9 (3) An ambulance provider, mobile integrated healthcare program, or medical first  
10 response provider shall report the required patient care record data as prescribed  
11 through administrative regulations promulgated by the board by transmitting the  
12 required data and information to the board in an electronic format. If the board  
13 requires the use of a specific electronic format, it shall provide a copy of the file  
14 layout requirements, in either written or electronic format, to the licensed  
15 ambulance provider or medical first response provider at no charge.

16 (4) The board shall publish a comprehensive annual report reflecting the data collected,  
17 injury and illness data, treatment utilized, and other information deemed important  
18 by the board. The annual report shall not include patient identifying information or  
19 any other information identifying a natural person. A copy of the comprehensive  
20 annual report, if issued, shall be forwarded to the Governor and the General  
21 Assembly.

22 (5) Ambulance provider, mobile integrated healthcare program and medical first  
23 response provider patient care records and the information transmitted  
24 electronically to the board shall be confidential and in compliance with HIPAA  
25 privacy rules referenced in 45 C.F.R. pt. 164. No person shall make an unauthorized  
26 release of information on an ambulance provider, mobile integrated healthcare  
27 program, or medical first response provider patient care record. Only the patient or

1       the patient's parent or legal guardian if the patient is a minor, or the patient's legal  
2       guardian or person with proper power of attorney if the patient is under legal  
3       disability as being incompetent or mentally ill, or a court of competent jurisdiction  
4       may authorize the release of information on a patient's care record or the inspection  
5       or copying of the patient care record. Any authorization for the release of  
6       information or for inspection or copying of a patient care record shall be in writing.

7       (6) An ambulance provider or medical first response provider that collects patient data  
8       through electronic means shall have the means of providing a patient care record or  
9       summary report that includes all required data elements to the medical care facility.  
10       A copy of the medical first response patient care record or summary report of the  
11       patient care record and patient information shall be made available to the  
12       ambulance service that transports the patient. A copy of the ambulance  
13       transportation and medical report forms shall be made available to any medical care  
14       facility to which a patient is transported and shall be included in the patient's  
15       medical record by that facility. If a patient is not transported to a medical facility,  
16       the copy of the patient care record that is to be given to the transporting ambulance  
17       provider or medical care facility shall be given to the patient or to the patient's  
18       parent or legal guardian upon request. If the ambulance provider, medical facility,  
19       patient, or patient's legal guardian refuses delivery of their patient care record or is  
20       unavailable to receive the form, that copy of the patient care record shall be  
21       returned to the medical first response provider or ambulance provider and  
22       destroyed.

23       (7) All ambulance services and mobile integrated healthcare programs shall be required  
24       to keep adequate reports and records to be maintained at the ambulance base  
25       headquarters and to be available for periodic review as deemed necessary by the  
26       board. Required records and reports are as follows:

27       (a) Employee records, including a resume of each employee's training and

experience and evidence of current certification or licensure; and

(b) Health records of all personnel including records of all illnesses or accidents occurring while on duty.

(8) Data and records generated and kept by the board or its contractors regarding the evaluation of emergency medical care, mobile integrated healthcare programs, and trauma care in the Commonwealth, including the identities of patients, emergency medical services personnel, ambulance providers, medical first-response providers, and emergency medical facilities, shall be confidential, shall not be subject to disclosure under KRS 61.805 to 61.850 or KRS 61.870 to 61.884, shall not be admissible in court for any purpose, and shall not be subject to discovery. However, nothing in this section shall limit the discoverability or admissibility of patient medical records regularly and ordinarily kept in the course of a patient's treatment that otherwise would be admissible or discoverable.

(9) The Cabinet for Health and Family Services shall have complete and immediate access to all data and records maintained by the board or its contractors and may use information contained in the data and records to fulfill its responsibilities and requirements for health facilities and services, including but not limited to those duties assigned to the cabinet by KRS 194A.101[~~, 216.2920 to 216.2929,~~] and 216B.042.

➔Section 20. The following KRS sections are repealed:

216.2920 Definitions for KRS 216.2920 to 216.2929.

216.2921 Duties of cabinet -- Chief administrative officer -- Secretary or employee not subject to personal liability.

216.2923 Health data collection powers and duties -- Analysis of health-care and insurance experience -- Administrative regulations.

216.2925 Administrative regulations -- Reports, lists, forms, and formats required.

216.2927 To be deleted

1       use data agreements and privacy rules -- Confidentiality of raw data -- Penalty for  
2       violation.

3   216.2929 Data on health-care services charges and quality and outcome measures to be  
4       publicly available on cabinet's website -- Reports required.

5       ➔Section 21. Section 20 of this Act takes effect July 1, 2028.

6       ➔Section 22. (1) The secretary of the Cabinet for Health and Family Services  
7       shall make all initial appointments under subsection (2)(a) of Section 7 of this Act within  
8       90 days after the effective date of that section.

9       (2) Notwithstanding subsection (2)(c)2. of Section 7 of this Act, initial  
10      appointments under subsection (2)(a) of Section 7 of this Act shall be staggered so that,  
11      of the initial 14 appointments:

- 12       (a) Five of the appointments expire four years after the initial appointment;
- 13       (b) Five of the appointments expire three years after the initial appointment; and
- 14       (c) Four of the appointments expire two years after the initial appointment.

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

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

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

25       ➔Section 24. Sections 8 and 23 of this Act constitute the specific authorization  
26      required under KRS 205.5372(1).