

AMERICAN MEDICAL ASSOCIATION HOUSE OF DELEGATES

Resolution: 021
(A-22)

Introduced by: Mississippi

Subject: National Cancer Research Patient Identifier

Referred to: Reference Committee on Amendments to Constitution and Bylaws

1 Whereas, In the United States, too often critical information needed by medical researchers to
2 improve the safety and effectiveness of medical treatment is distributed in fragments across
3 large databases. To protect patient privacy, these data elements reside in databases stripped of
4 patient identifying information (PII) making it extremely difficult to consistently reassemble the
5 fragments back into a complete picture for research; and
6

7 Whereas, At the time patients present for care, identifying information (e.g. name, date of birth,
8 social security number if available, etc.) could be transformed into a privacy ensuring National
9 Cancer Registry Identifier (NCRI) using novel cryptographic solution (patent pending) that
10 includes a combination of established techniques (hash functions, blinding functions, single use
11 transactional tokens); and
12

13 Whereas, Creating a privacy-ensuring, unique cancer research identifier could travel with the
14 anonymous fragments of medical information currently collected by large databases, and
15 therefore allow the fragments to be reunited into a complete, yet anonymous cancer journey that
16 researchers can study to improve care; and
17

18 Whereas, The proposed initiative would build on existing data-transfer relationships between
19 health care facilities and quality improvement databases. For example, as medical facilities
20 submit information to various databases (e.g. Medicare, National Cancer Database, Society of
21 Thoracic Surgeons Database, etc.) as part of current workflow, the NCRI would remain
22 associated with the transferred medical information (but PII would not leave the health care
23 entity); and
24

25 Whereas, Requests for data could be handled by a separate entity serving as the honest broker
26 that would curate, link, and distribute the data in compliance with state and federal data use
27 agreements; and
28

29 Whereas, Nearly half of the 1.8 million cancer patients diagnosed each year in the U.S. will
30 have their lives shortened by cancer, highlighting the ongoing urgent need for cancer research
31 which is felt by the public, the medical community, and policymakers; and
32

33 Whereas, Prospective clinical trials are considered the gold-standard for cancer research, and
34 advances from trials have transformed cancer care. However, clinical trials typically require
35 more than 5 years and several million dollars to conduct; and
36

37 Whereas, There is simply not enough time or money to test all of the important aspects of
38 cancer care. The NCRI will dramatically increase the speed and power of real-world research;
39 and

1 Whereas, a nonprofit entity could be established to oversee the NCRI process including
2 managing grant funding, subcontracting to private entities to oversee specific functions (e.g. the
3 identifier workflow, and data curation and research distribution), privacy assurance, security,
4 and compliance. The nonprofit entity would engage federal policy makers, cancer organizations,
5 patient advocacy groups and the data science community for support, access and authorization
6 to move forward; therefore be it

7
8 RESOLVED, That in order to increase the power of medical research, our American Medical
9 Association propose a novel approach to linking medical information while still maintaining
10 patient confidentiality through the creation of a National Cancer Research Identifier (NCRI)
11 (Directive to Take Action); and be it further

12
13 RESOLVED, That our AMA encourage the formation of an organization or organizations to
14 oversee the NCRI process, specific functions, and engagement of interested parties to improve
15 care for patients with cancer. (Directive to Take Action)

Fiscal Note: Not yet determined

Received: 05/06/22

