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

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

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

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

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

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

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

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

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

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

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

Fiscal Note: Not yet determined

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