The Beau Biden Cancer Moonshot and the NCI Blue Ribbon Panel Recommendations

NAACCR Registry of the Future Presentation

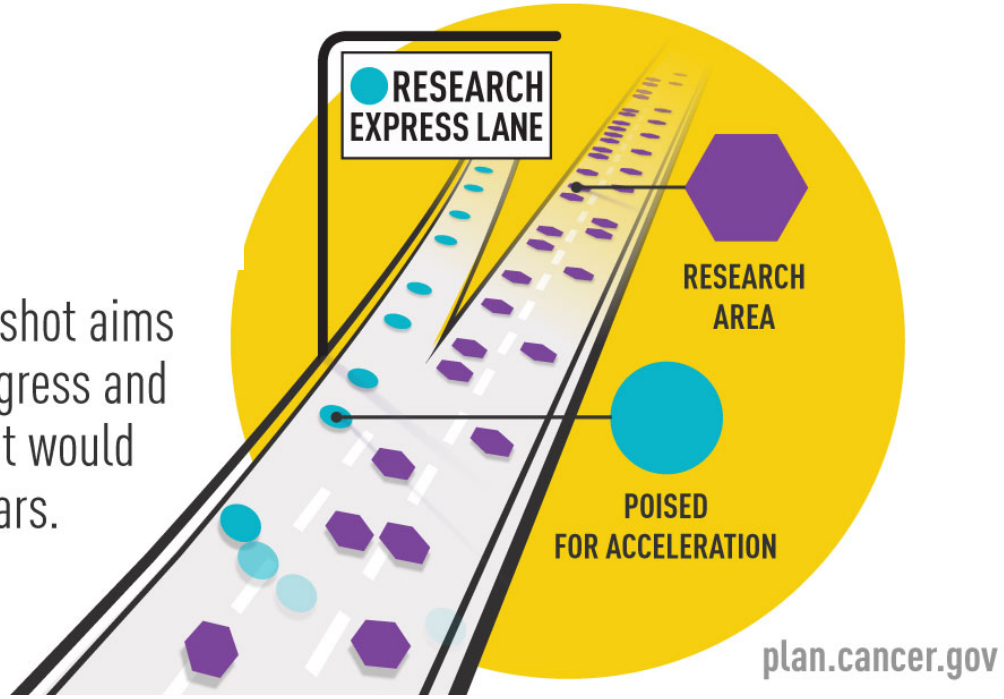
June 19, 2017

NIH NATIONAL CANCER INSTITUTE

The Beau Biden Cancer Moonshot

- Accelerate progress in cancer, including prevention & screening
  - From cutting edge basic research to wider uptake of standard of care
- Encourage greater cooperation and collaboration
  - Within and between academia, government, and private sector
- Enhance data sharing

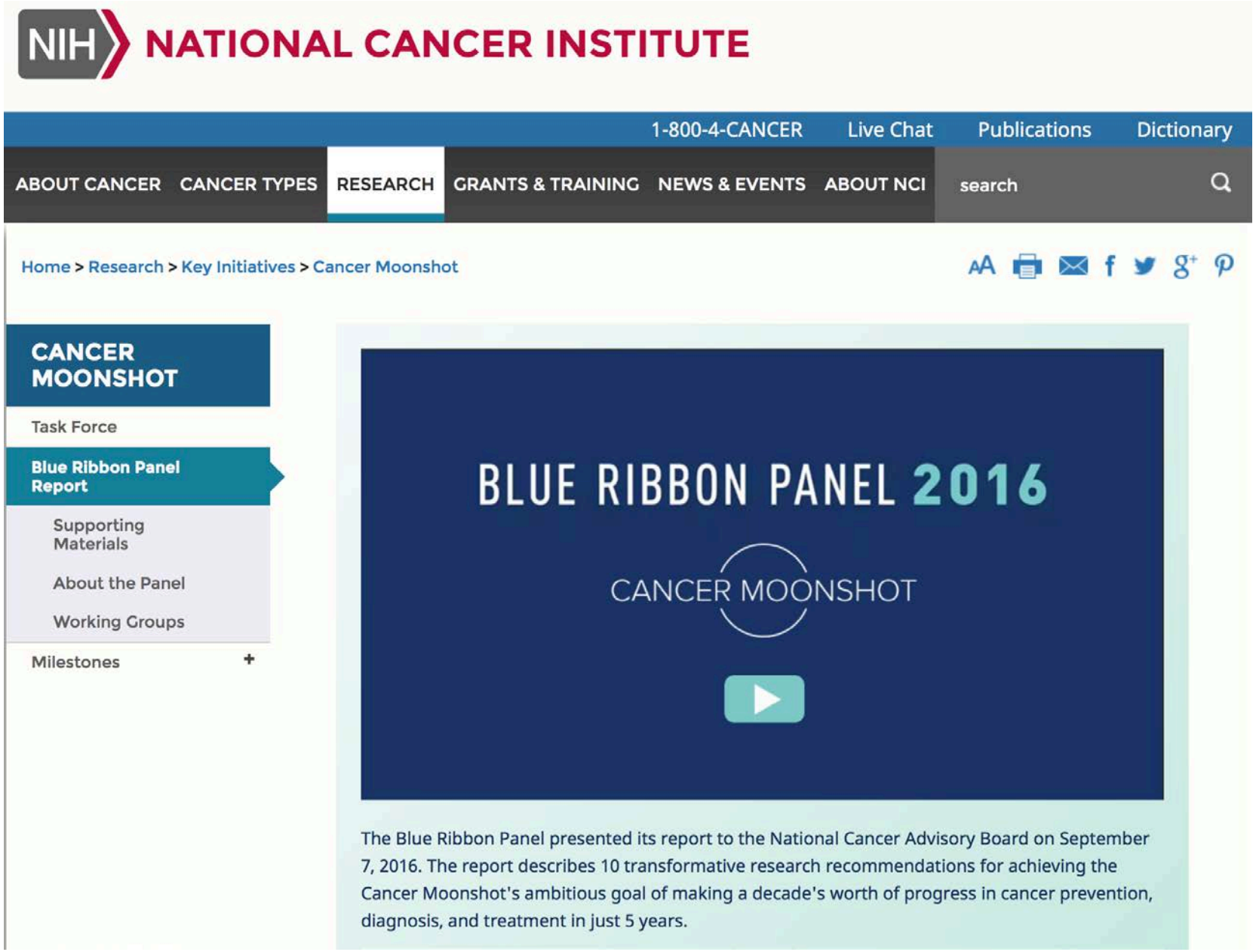
The Cancer Moonshot aims to accelerate progress and do in 5 years what would have taken 10 years.



Blue Ribbon Panel recommendations (Oct); Implementation Working Groups established (Jan)

cancer.gov/brp

- *The 21st Century Cures Act, passed by Congress in December 2016, authorizes $1.8 billion in funding for the Beau Biden Cancer Moonshot℠ over seven years, starting with $300 million for FY 2017.*
- *NCI has established implementation teams to identify how to deploy those funds to accelerate cancer research under 10 topics areas recommended by the Blue Ribbon Panel.*
- *Funding opportunities currently open for applications are posted on Cancer.gov. Researchers with an interest in these areas are encouraged to apply.*



https://cancer.gov/brp

Blue Ribbon Panel Recommendations

- **Network for Direct Patient Engagement**
- Cancer Immunotherapy Translational Science Network
- Therapeutic Target Identification to Overcome Drug Resistance
- **A National Cancer Data Ecosystem for Sharing and Analysis**
- Fusion Oncoproteins in Childhood Cancers
- Symptom Management Research
- Prevention and Early Detection – Implementation of Evidence-based Approaches
- Retrospective Analysis of Biospecimens from Patients Treated with Standard of Care
- Generation of 4D Human Tumor Atlas
- Development of New Enabling Cancer Technologies

Establishing Data Linkages

Cancer Data Ecosystem Implementation Team

Presentation to NAACR Registry of the Future Meeting

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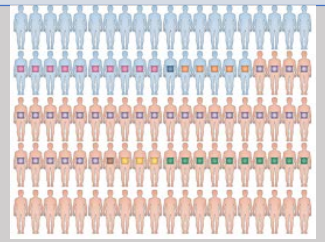
Cancer Research Data Ecosystem – Cancer Moonshot – NCI Blue Ribbon Panel

Discovery	Patient engaged Research	Surveillance Big Data Implementation research
Proteogenomics Imaging data Clinical trials	Clinical Research Observational studies	EHR, Lab Data, Imaging, PROs, Smart Devices, Decision Support
Well characterized research data sets	Cancer cohorts	Patient data
		
Genomic Data Commons Research information donor	Active research participation	**SEER/NPCR** Real World Data to support Learning from every cancer patient

National Cancer Data Ecosystem Recommendation

- Overall goal: Create a data science infrastructure necessary to connect repositories, analytical tools, and knowledge bases.
- Envisioned to consist of multiple components
  - **Fundamental infrastructure** to connect the components and ensure **interoperability**
    - Common APIs
    - Data schemas
    - Common data dictionaries
  - **Components** such as repositories, analytics services, and interactive portals
- The ability to link diverse data types and data sources is fundamental to interoperability of the Cancer Data Ecosystem

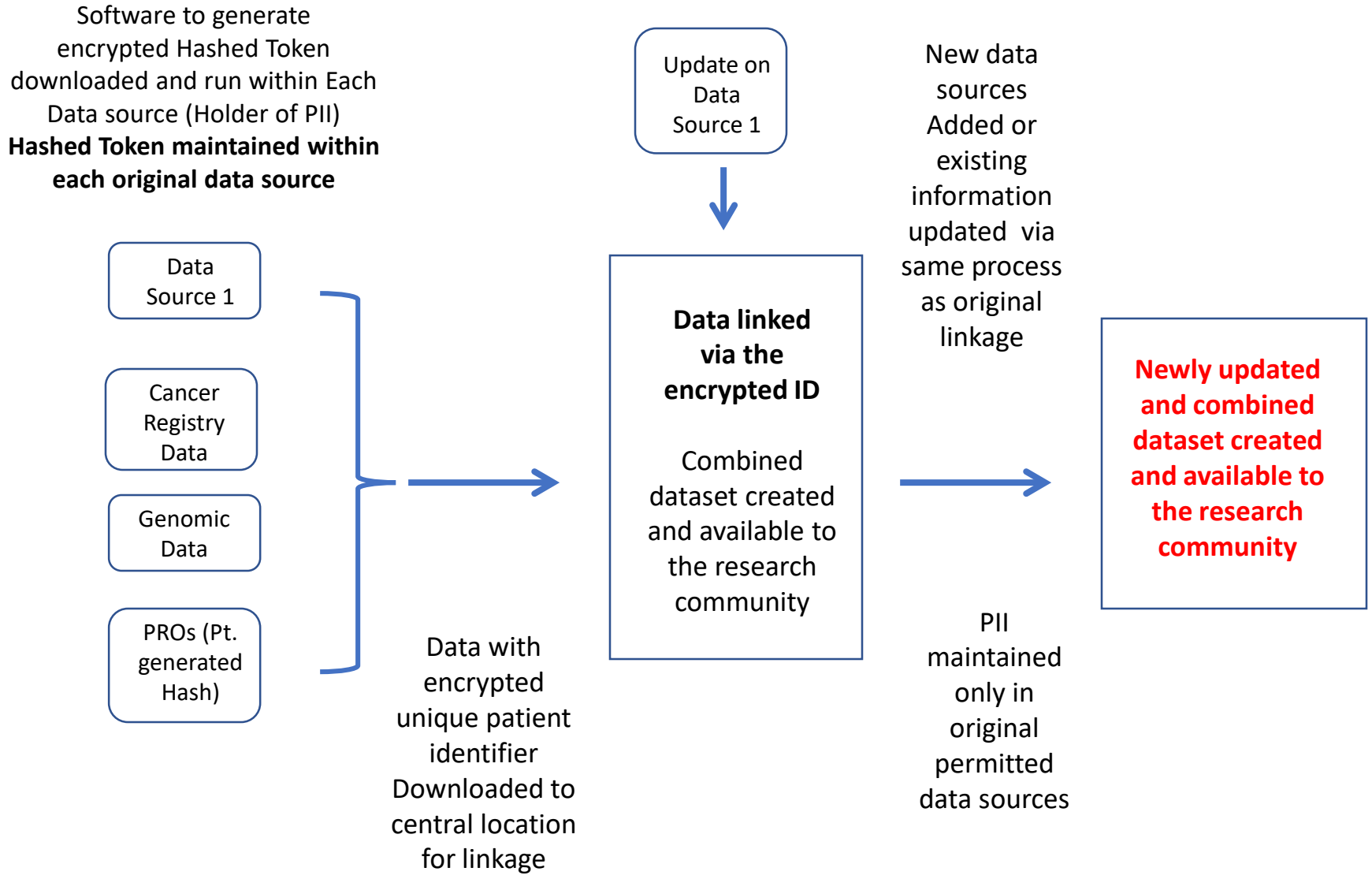
Recommendation 1: Encrypted unique patient identifier

- Pressing need to connect patient-level data across multiple data generators, data sources, data types
- Need to update information over time
- Challenges:
  - Protecting patient confidentiality
  - Consistency of identifying data (PII) available across resources
  - Accuracy of linkage with varying PII
  - Scalability

Proposed solution: Using secure encryption to develop “tokens” to match on PII

- Using a common software application to generate encrypted hashed tokens
  - Tokens represent various combinations of patient identifiers
  - Provide a secure, encrypted format for data linkages
  - Low probability of re-identification
  - Ability to generate the ***same*** hashed encrypted identifier from different data sources when using the same software and set of PII
- Benefits of using hashed/encrypted tokens
  - Allows linkage of diverse data sets WITHOUT release of patient identifying information (PII)
  - PII and crosswalk maintained by the parties (data set owners) who are permitted to have PII to enable subsequent linkages

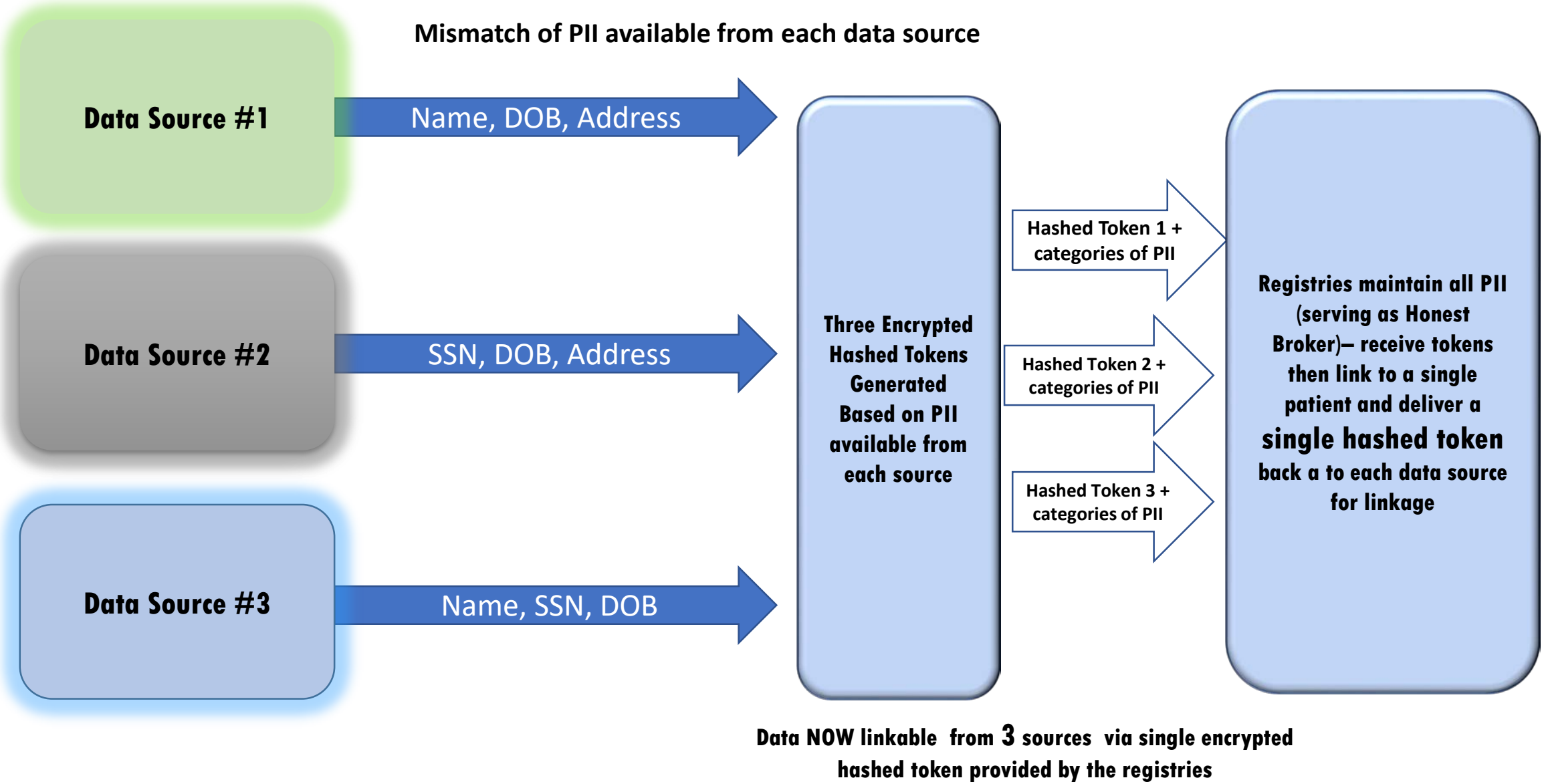
Proposed Process for Encrypted Unique Identifier



Potential Role of Cancer Registries

- Common source of PII
  - Required to maintain PII longitudinally over time (name, address, SSN, DOB, gender) on every cancer patient in the US
  - Could serve as the Honest Broker for permitting linkage of datasets where there is a mismatch of PII in two or more datasets wanting to link
  - As an Honest Broker, serve as an arbitrator of any potential mismatches or perceived inconsistencies.
- Opportunity to:
  - provide cancer registry adjudicated structured clinical information about the cancer and its outcomes
  - highlight the value of cancer surveillance and demonstrate new and enhanced utility of our registries

Encrypted Linkage Process Based on Mismatched PII



Potential benefits to cancer research

- Development of well annotated research data sets
  - Clinical data linked to genomic information
- The ability to routinely update existing data
  - Addition of clinical follow-up information on a TCGA patient to genomic information in GDC
- Patients could generate their own encrypted identifier
  - Enables patients to contribute data in a secure manner
  - Essential component of BRP recommendation for Patient Engagement
- Clinical trial eligibility assessment
  - Identification of patient duplication across multiple platforms and data sources without risking patient confidentiality