Executive Summary

In January 2021, the Patient ID Now coalition created a work group consisting of member organizations within the coalition representing the breadth of the healthcare sector, including organizations representing patients, physicians, providers, health information professionals, health information technology companies, and public health to create a framework for a national strategy around patient identity. The Patient ID Now coalition offers the following framework to inform the creation of a national strategy to improve patient identity.

Accurate Identification and Match Rates

A national strategy should:

1. Improve matching rates across multiple scenarios to minimize errors, including addressing duplicates, overlays, and overlaps.
2. Provide guidance on the process of matching and identity resolution.
3. Provide guidance, including benchmarks and standards, as to how error rates are calculated across health IT systems and organizations.
4. Identify performance measures, such as minimum acceptable levels of accuracy.
5. Align with guidelines provided by the National Institute of Standards and Technology (NIST).
6. Develop, disseminate, and conduct training on patient identification and matching, and encourage testing, evaluation, and optimization when appropriate.

Privacy

A national strategy should:

1. Leverage public and private sector resources to help address patient privacy issues.
2. Consider ways to advance the ability of patients to invoke more granular consent, while still adhering to the HIPAA minimum necessary requirement as a floor.
3. Allow patient privacy preferences to evolve.
4. Improve the ability of patients to easily understand their privacy options.
5. Support anonymity when appropriate.
6. Not require a federal-level centralized database of Personally Identifiable Information (PII).
7. Be limited to healthcare identification-related purposes.
8. Safeguard patient data, including for public health and research use cases.
9. Support the ability to restore a patient's privacy if a violation has occurred.
10. Safeguard patients' identity when health information is shared amongst providers in line with requirements from current information blocking rules.

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Security

A national strategy should:

1. Support each principle of the CIA triad (confidentiality, integrity, availability) at the highest level possible without sacrificing patient safety.
2. Mitigate fraud by establishing minimum authentication capabilities within every system where a member, patient, employee, or vendor can access patient data.
3. Encourage HIPAA covered entities to thoroughly document where and how electronic protected health information (ePHI) is being used, including by third parties.

Standardization

A national strategy should:

1. Define the minimum standardized data set needed for patient identification and matching.
2. Encourage and facilitate ongoing collaboration with industry-based patient matching efforts, including those led by standards development organizations (SDOs) such as HL7.
3. Encourage a standardized format for addresses, and potentially other data elements, to increase accurate patient matching rates.
4. Be compatible with existing principles and standards.
5. Provide guidance on standardization of data capture and best practices processes post-mergers, during data conversions, and after closure of an institution.

Portability and Interoperability

A national strategy should:

1. Provide maximum achievable accuracy to avoid patient safety issues not only within systems, but across systems.
2. Provide guidance on ensuring semantic integrity for information shared across systems.

Data Quality

A national strategy should:

1. Take a holistic approach and consider underlying and fundamental data integrity and quality processes and practices.
2. Provide the opportunity for patients to self-correct or flag aspects of their record.
3. Be designed to minimize errors and fraud.
4. Provide guidance on the ability to recover quickly and inexpensively from errors.
5. Consider the timeliness of solutions.

Integration with Current Systems

A national strategy should:

1. Be able to integrate with as many current systems as possible, and as simply and inexpensively as possible, throughout the healthcare sphere.
2. Enable each of these integrated systems to achieve improved accuracy and performance.
3. Consider the time and resources needed for healthcare organizations to adopt the national strategy.

Equity and Inclusion

A national strategy should:

1. Be culturally sensitive and respectful and take into consideration the various ways different communities interact with and participate in the healthcare system.
2. Take into account disparate access to technologies and infrastructure in different communities and patient populations.
3. Be simple and easy to understand.
4. Be language independent.
5. Support all potential patients.
6. Support caregivers.
7. Be universally applicable and accessible.

Sustainability and Governance

A national strategy should:

1. Have adequate funding for the creation and implementation of a national approach to address patient identification and matching, and for activities that support improved patient identification, including ongoing data and operability standards-related activities led by ONC.
2. Preclude cost-shifting onto patients.
3. Be designed to serve the US healthcare system for many years.
4. Have governance that is public, transparent, and accountable.

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To read more about the framework, or to learn more about patient identification, visit Patient ID Now.