INPDR NP Global Unique Identifier (GUID) Standard

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Background

Multiple disparate data repositories exist to capture the natural history, genetics and outcomes of Niemann-Pick disease (NPD) patients. Whilst generally straight forward to establish, standalone repositories can quickly become data silos, severely limiting their potential value.

Given that NPDs are categorised as rare diseases with quality data scarce, the ability to connect data from multiple sources can facilitate research. By implementing a standard NPD community wide identifier, NPD data sets can be linked, merged and aggregated by approved researchers.

In addition to providing researchers with a wider data pool, the use of a standard identifier can improve data quality by removing duplicates and enabling accurate matching. Finally, the use of a standard identifier enables multiple facets of data to be taken into consideration when designing and performing studies (e.g. linking trial data with natural history data).

The use of a Global Unique Identifier (GUID) facilitates the linking of Niemann-Pick patient data across data repositories. Whilst the concept of a GUID is not new, its application in medical research requires stringent compliance with global data protection, legislation and ethical obligations.

Method

In consultation with researchers and IT specialists, INPDR have developed a method to ensure the generation of a unique and irreversible Niemann-Pick disease Global Unique Identifier (NP GUID).

A Technical Standard was published to define the input of Personal Identifiable (PII) data, the processing and encryption of the PII and the format of the resultant pseudonymised NP GUID. In addition, the Standard provides guidelines for the use and deployment of NP GUID creation tools to ensure compliance with privacy legislation and ethical considerations. Finally, an online NP GUID Creation Tool based on the Standard is hosted on the INPDR website for use by research partners.

The NP GUID Standard and Creation Tool are intended for use by organisations who wish to code the identity of registry, study or trial participants with a unique, pseudonymised standard identifier.

The adoption of privacy preserving techniques enables a consistent GUID to be generated per patient based on the input of a standard set of personal data. The resulting GUID's are unique to the patient but importantly, cannot be reverse engineered to reveal their true identity.

NPD GUID Example: Charlie Brown

Family Name	Given Name	Sex	Date of Birth
Brown	Charlie	M	19501030

Input Standard:
np-brown-charlie-m-19501030

Encryption:
(Salt + SHA256 +CRC32 Hash)

NP GUID:
ac5517a3

Conclusion

The use of the NP GUID facilitates the linking of Niemann-Pick patient data across disparate data repositories. The NP GUID enables researchers to aggregate and share data from multiple sources to develop new treatments whilst reducing timescales.

Whilst the project focused on the Niemann-Pick community, the applied methods are suitable for all rare disease cohorts. To access the NP GUID please scan the QR code on the right.

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