

Neurological Global Unique Identifier (NeuroGUID™)

User Manual

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What is NeuroGUID™

The Neurological Global Unique Identifier (NeuroGUID™) is a universal patient identifier that allows researchers in Neurological and other Central Nervous System diseases to share data specific to a study participant without exposing personally identifiable information (PII). It also enables matching participants across studies and research data repositories. In other words, NeuroGUID™:

- Allows aggregation of data from the same patient from multiple studies, regardless of where and when that data was collected
- Prevents a single patient from being created multiple times in the same research database, in case she/he participates in a study at different sites or in multiple studies at the same time
- Enables a researcher to combine patient information with data originating from other sources.

How does it work

A GUID is a string of eleven alpha-numeric characters. The NeuroGUID™ is a GUID in which the first three characters are “NEU” and the other eight are randomly generated by the NeuroGUID™ Tool.

The NeuroGUID™ Tool resides in two places, on a client side and a server side. When a NeuroGUID™ requestor (i.e. patient, researcher) opens the NeuroGUID™ Tool in an internet browser, the Tool accepts patient’s personal information and uses it to create a series of coded strings, called hash strings (“hashes”). These hashes are put into an informational “envelope”, which is encrypted and sent to the NeuroGUID™ server. The NeuroGUID™ server decrypts the “envelope” and checks the received hashes against its database. It is important to remember that the NeuroGUID™ server DOES NOT DECODE the hashes, but rather just checks whether they are already stored in its database. If they do exist, the NeuroGUID™ server will then return the exact same NeuroGUID™ that was created for these hashes before. If no match is found, a new NeuroGUID™ is generated by the NeuroGUID™ server. Such software architecture provides certain advantages:

- No PII ever leaves researcher’s (client) computer
- A NeuroGUID™ does not contain any information that infers the identity of the individual
- When the same PII is used to generate a NeuroGUID™, the same NeuroGUID™ string is returned regardless of who, when, or from where the NeuroGUID™ is requested. This allows researchers to share information from the same individuals across studies, modalities and locations without revealing participants’ identities.

What information is required to create a NeuroGUID™

The following information is required to create a NeuroGUID™:

- Complete legal given first, middle and last names of patient at birth
- Date of birth
- Physical sex of patient at birth

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- Name of city/municipality in which patient was born
- Country of birth

It is recommended that this information is obtained and entered as it appears on the birth certificate. **Using the birth certificate ensures that this information cannot change throughout an individual's lifespan.**

Accessing the NeuroGUID™ Server

Computer requirements:

- An active Internet connection
- An Internet browser with pop-up blockers and JavaScript suppressors disabled

There are two ways to access the NeuroGUID™ server. If you are participating in a NeuroBANK™ study, the NeuroGUID™ tool is integrated and will be available right on your study's *Add Patient* page (also called PharmaPORTAL™). You will not need to log in to NeuroGUID.org website separately. If you do NOT participate in a NeuroBANK™ study, please follow the below steps to access the server:

1. Navigate to <http://www.NeuroGUID.org>
2. Create your account or login with your existing credentials
3. To create a single NeuroGUID™, use the data entry interface of the tool to enter all required PII, and click *Generate GUID* (see instructions below)
4. The software creates one-way hash codes that are sent to NeuroGUID™ server. Based upon these hashes, the server will create a new NeuroGUID™ (if the NeuroGUID™ server's database does not already contain these hashes), or return an existing NeuroGUID™. **No PII ever leaves your computer**
5. To avoid errors and typos, we recommend to Copy (Ctrl-C) NeuroGUID™ and then Paste (Ctrl-V) it into your application/database rather than writing it down by hand.

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How do I Generate a NeuroGUID™ on NeuroBANK

To generate a NeuroGUID™ on NeuroBANK for a patient, complete the following steps:

1. Navigate to NeuroBANK <https://nctu.partners.org/neurobank/>
2. Login to your EDC account
3. Select trial
4. Navigate to the *Data* tab
5. Go to *Manage Patients* page
6. Click on *Add Patient* button
7. *Add / Modify Patient* form will open
8. Click on the Create GUID button

Patients > Manage Patients > Add / Modify Patient

Institution ID: 701

Patient ID: * **Create GUID**

Patient Group: * --- select group ---

Study-specific ID

Date ICF signed (mm/dd/yyyy)

Informed consent form signed or IRB approval obtained to proceed without informed consent *

Patient allows their data to be de-identified and shared *

Cancel Save

9. Fill out all required personally identifiable information (PII) fields. There are 10 required fields which are indicated with an asterisk in the image below

Please, enter information below to generate patient's UNIQUE PATIENT IDENTIFIER (NeuroGUID™)

(*) Indicates required fields	Please enter patient's information	Please confirm (re-enter) information
1. Complete legal given (first) name of patient at birth *	1. <input type="text"/>	<input type="text"/>
2. Does the patient have a middle name? *	2. <input type="radio"/> Yes <input type="radio"/> No	<input type="radio"/> Yes <input type="radio"/> No
3. Complete additional (middle) name or names at birth	3. <input type="text"/>	<input type="text"/>
4. Complete legal family (last) name of patient at birth *	4. <input type="text"/>	<input type="text"/>
5. Day of birth [1-31] *	5. <input type="text"/>	<input type="text"/>
6. Month of birth [1-12] *	6. <input type="text"/>	<input type="text"/>
7. Year of birth [####] *	7. <input type="text"/>	<input type="text"/>
8. Name of city/municipality in which patient was born *	8. <input type="text"/>	<input type="text"/>
9. Country of birth *	9. -- Select --	-- Select --
10. Physical sex of patient at birth *	10. <input type="radio"/> Male <input type="radio"/> Female	<input type="radio"/> Male <input type="radio"/> Female

GENERATE NEUROGUID™ **RESET** **CANCEL**

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10. Enter PII again (double data entry of PII is used to prevent generation of new NeuroGUID™s due to typos)

11. Click **Generate NeuroGUID™**

Please, enter information below to generate patient's UNIQUE PATIENT IDENTIFIER (NeuroGUID™)

(*) Indicates required fields		Please enter patient's information		Please confirm (re-enter) information	
1.	Complete legal given (first) name of patient at birth *	1.	<input type="text" value="Tom"/>	1.	<input type="text" value="Tom"/>
2.	Does the patient have a middle name? *	2.	<input type="radio"/> Yes <input checked="" type="radio"/> No	2.	<input type="radio"/> Yes <input checked="" type="radio"/> No
3.	Complete additional (middle) name or names at birth	3.	<input type="text"/>	3.	<input type="text"/>
4.	Complete legal family (last) name of patient at birth *	4.	<input type="text" value="Brady"/>	4.	<input type="text" value="Brady"/>
5.	Day of birth [1-31] *	5.	<input type="text" value="1"/>	5.	<input type="text" value="1"/>
6.	Month of birth [1-12] *	6.	<input type="text" value="1"/>	6.	<input type="text" value="1"/>
7.	Year of birth [####] *	7.	<input type="text" value="1985"/>	7.	<input type="text" value="1985"/>
8.	Name of city/municipality in which patient was born *	8.	<input type="text" value="Boston"/>	8.	<input type="text" value="Boston"/>
9.	Country of birth *	9.	<input type="text" value="UNITED STATES"/>	9.	<input type="text" value="UNITED STATES"/>
10.	Physical sex of patient at birth *	10.	<input checked="" type="radio"/> Male <input type="radio"/> Female	10.	<input checked="" type="radio"/> Male <input type="radio"/> Female

12. The newly created NeuroGUID™ will appear in the Patient ID field on the Add / Modify Patient form. Note: Users are able to manually add Patient ID (NeuroGUID™ previously generated and existing in NeuroGUID™ server DB) and click save.

Patients > Manage Patients > Add / Modify Patient

Institution ID:

Patient ID: *

Patient Group: *

Study-specific ID

Date ICF signed (mm/dd/yyyy)

Informed consent form signed or IRB approval obtained to proceed without informed consent * ☐

Patient allows their data to be de-identified and shared ☐

13. Complete the rest of the Add / Modify Patient form and click save

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Alternate Way to Generate a NeuroGUID™

To generate a NeuroGUID™ on NeuroGUID.org for a patient, complete the following steps:

1. Navigate to <http://www.NeuroGUID.org>
2. Sign up a new account or Login to your account (if you have a NeuroGUID™.org account)

Forgot password [Sign up a new account](#)

Enter your register e-mail address or username

Password

LOGIN

3. Navigate to *NeuroGUID™* tab
4. Fill out all required personally identifiable information (PII) fields. There are 10 required fields which are indicated with an asterisk in the image below
5. Enter PII again (double data entry of PII is used to prevent generation of new NeuroGUID™s due to typos)
6. Click *Generate NeuroGUID™*
7. The newly created NeuroGUID™ will appear in the GUID field
8. To copy the NeuroGUID™, select it and press Ctrl-C keys. To paste it, use Ctrl-V
9. To create another NeuroGUID™ click *Reset* to clear the fields and enter new information.

Please, enter information below to generate patient's UNIQUE PATIENT IDENTIFIER (NeuroGUID™)

(*) Indicates required fields

1. Complete legal given (first) name of patient at birth *
2. Does the patient have a middle name? *
3. Complete additional (middle) name or names at birth
4. Complete legal family (last) name of patient at birth *
5. Day of birth [1-31] *
6. Month of birth [1-12] *
7. Year of birth [####] *
8. Name of city/municipality in which patient was born *
9. Country of birth *
10. Physical sex of patient at birth *

Please enter patient's information

1. Tom
2. ☐ Yes ☒ No
- 3.
4. Brady
5. 1
6. 1
7. 1985
8. Boston
9. UNITED STATES
10. ☒ Male ☐ Female

Please confirm (re-enter) information

1. Tom
2. ☐ Yes ☒ No
- 3.
4. Brady
5. 1
6. 1
7. 1985
8. Boston
9. UNITED STATES
10. ☒ Male ☐ Female

GENERATE NEUROGUID™

RESET

CANCEL

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NeuroGUID™ Frequently Asked Questions

Question	Answer
What if I only have the middle initial or nickname?	Only full legal names as they appear on the birth certificate should be used. Initials, nicknames, or unknowns/blanks should not be used
What if I don't know the middle name or they left "middle name" blank?	If you know that the participant has no legal middle name on their birth certificate, the tool allows you to specify that the person has no middle name. If you do not have the middle name, or if you do not know whether or not they have one, you cannot create a NeuroGUID™
What should I do with suffixes like Jr., III, etc.?	Suffixes such as these should be omitted from the names when creating a NeuroGUID™
Should I include state/country when entering city/municipality of birth?	No. Only the city/municipality name as it appears on the birth certificate should be entered
What if I wrote NeuroGUID™s down and now I am not sure whether some of the characters are letters or numbers?	While we recommend to copy and paste NeuroGUID™s to avoid any potential typos and confusions, there is a simple rule to remember: letters "I", "O", and "S" could never be found in NeuroGUID™s, so, most likely, you are looking at numbers "1", "0", and "5".