

## **PDBP DMR Global Unique Identifier Tool (GUID)**

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How to use the PDBP DMR GUID Tool

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## 1. PDBP DMR GUID Tool

The PDBP DMR is a restricted access portal designed as a tool to support Parkinson's Disease Biomarkers research projects. A PDBP DMR account is required to submit or access Parkinson's Disease Biomarkers-related data. Investigators and data managers at research sites are invited to request an account. To provide maximum protection for the confidentiality of research participants whose data is stored in the PDBP DMR, professional credentials are verified by the PDBP DMR staff during the account request process.

In the PDBP DMR, research data associated with an individual subject are linked by means of a Global Unique Identifier, GUID. The GUID is a subject ID that allows researchers to share data specific to a study participant without exposing personally identifiable information (PII). GUIDs allow investigators to track participants longitudinally, across multiple research sites and across multiple studies. It is important to remember PII is never sent to the PDBP DMR system and that the GUID is a random number not generated from PII.

### There are (5) functions of the GUID Tool:

1. Create GUID
2. Generate Pseudo GUID
3. Convert Pseudo GUID to GUID
4. Create Multiple GUIDs
5. Search if GUID(or Pseudo GUID) exists in PDBP DMR

**NOTE: Participant GUIDs are required to submit data to PDBP DMR.**

## 2. Create GUID

Researchers collect PII from their participants and store that data in a local database that is not made available outside the research institution and is governed by the institution's local rules and regulations. The GUID tool is an application that is downloaded and launched from the PDBP DMR website and run locally on a user's computer. This software performs a one-way encryption, often called a one-way hash, which determines if the research subject hash codes have been seen previously by the PDBP DMR. A one-way hash is a reproducible method of turning some kind of data into a (relatively) small number that may serve as a digital "fingerprint" of the data. The algorithm "chops and mixes" (i.e., substitutes or transposes) the data to create such fingerprints. The hash represents the "fingerprint". However, it cannot be used to recreate the original. In other words, the encrypted hash codes do not have information to recreate the PII, however, the GUID does provide enough information to determine if a research participant already exists in PDBP DMR.

### 1.2. Prerequisites:

- Valid PDBP DMR account with GUID privilege (PDBP DMR Request Additional Account Privileges if needed)

- Java Runtime Environment (JRE) installed on your computer (Version 6 or higher)  
<http://docs.oracle.com/javase/7/docs/webnotes/install/index.html#windows>

### 1.3. Procedure:

- This procedure provides the steps necessary for using the GUID Tool. The entire procedure time varies depending on the number of GUIDs being generated.
1. Point your browser to the PDBP DMR website at <http://pdbp.ninds.nih.gov>.
  2. Log in to PDBP DMR.
  3. There are two ways to find the GUID tool:
    - a) Through Workspace -> GUID Tool  
-OR-
    - b) Through the Contributing Data tab/link -> Global Unique Identifier (GUID Tool) -> GUID Tool
  4. Launch GUID Tool
  5. Read the pop-up window, and click Allow button to launch the GUID tool.
  6. The user may encounter a pop-up window that reads “the application’s digital signature cannot be verified. Do you want to run the application?” If so, click run, then accept the **EULA Agreement**.
  7. Enter in all required fields (1-10) in both columns.

Note:

- a) Do not use abbreviations for city of birth. For example, do not use NYC for New York City or LA for Los Angeles.
  - b) Fields 11 and 12 are optional. However, if you enter in information for #11, you must also fill out #12.
8. Once, all fields are filled out, click the Generate GUID button.
  9. If all fields are successfully entered, a window will pop up entitled “GUID Generation Successful” with New GUID: #####
  10. Click OK
  11. A GUID will appear in the lower left corner dialog box. All other fields will be greyed out at this time.
  12. Copy and paste GUID directly from GUID box or select Copy GUID to Clipboard.

Note: Only one GUID will be stored in the clipboard at a time. The GUID must be pasted somewhere prior to generating the next GUID or else it will be overwritten.

13. Click Clear/New if you have additional conversions otherwise click Exit.

<b>PII FieldName</b>	<b>Abbreviation used in the PDBP DMR GUID WS client</b>	<b>Required minimum for Valid GUID</b>
Complete legal given name of subject at birth	FIRSTNAME	Yes
Complete legal family name/surname of subject at birth	LASTNAME	Yes
Complete additional legal name or names at birth	MIDDLENAME	Yes
Day of month of birth	DOB	Yes
Month of birth	MOB	Yes
Year of Birth	YOB	Yes
City or municipality of birth	COB	Yes
Physical sex of subject at birth [M/F]	SEX	Yes
Country of birth	CNOB	Yes
Indicator if subject has NO Middle Name AT BIRTH	SUBJECTHASMIDDLENAME	Yes
Government Issued / National ID (For the United States, this is the Social Security Number)	GIID	Optional
ISO 3166 STANDARD 2 letter abbreviation of the COUNTRY of origin of THE GIID. See APPENDIX 1 for a Listing of the ISO 3661 Country Abbreviations	GIIDCOUNTRY	Optional

Table 1: GUID PII information

### 3. Generate Pseudo GUID

A Pseudo-GUID is a unique ID that should only be used if a researcher is unable to generate a valid GUID due to insufficient PII for a participant. However, submitting data with psuedo-GUIDs, silos the associated research data from the other data associated with valid GUIDs. Pseudo GUID naming convention is **PD\_INV#... unlike a GUID which is PD#...**

#### 1.4. Prerequisites:

- Valid PDBP DMR account with GUID privilege
- Java Runtime Environment (JRE) installed on your computer (Version 6 or higher)  
<http://docs.oracle.com/javase/7/docs/webnotes/install/index.html#windows>

#### 1.5. Procedure:

This procedure provides the steps necessary for using the GUID Tool. The entire procedure typically takes 1-2 minutes (assuming Prerequisites are already met)

1. Point your browser to the PDBP DMR website at <http://pdbp.ninds.nih.gov>.
  2. Log In to PDBP DMR.
  3. There are two ways to find the GUID tool:
    - a) Through Workspace -> GUID Tool  
-OR-
    - b) Through the Contributing Data tab/link -> Global Unique Identifier (GUID Tool) -> GUID Tool
  4. Launch GUID Tool
  5. Read the pop-up window, and click Accept button to launch the GUID tool.
  6. From the Functions dropdown menu, select Generate Pseudo GUID
  7. A pop up window will alert you prior to using this function, "You are about to generate a unique identifier in the system that is assigned to your account. This Pseudo GUID cannot be generated again. Are you sure you would like to generate a Pseudo GUID?"
  8. Select YES
  9. A Pseudo GUID will be generated and displayed on the screen. Click Copy Pseudo GUID to clipboard.
- Note: Only one GUID will be stored in the clipboard at a time. Must paste GUID somewhere prior to generating the next GUID or else it will be overwritten.
10. Click OK.
  11. Click Clear/New if you have additional conversions otherwise click Exit.

#### **4. Convert Pseudo GUID to GUID**

This functionality allows users to convert Pseudo-GUIDs to Valid GUIDs. Users need to provide the minimum required PII fields and the Pseudo-GUID information.

##### **1.6. Prerequisites:**

- Valid PDBP DMR account with GUID privilege
- Java Runtime Environment (JRE) installed on your computer (Version 6 or higher)  
<http://docs.oracle.com/javase/7/docs/webnotes/install/index.html#windows>
- Information needed to generate a GUID (birth certificates would be helpful, but are not required)
- Pseudo GUID ID numbers

### 1.7. Procedure:

This procedure provides process steps for using the GUID Tool. The entire procedure typically takes 1-2 minutes (assuming Prerequisites are already met)

1. Point your browser to the PDBP DMR website at <http://pdbp.ninds.nih.gov>.
2. Log In to PDBP DMR.
3. There are two ways to find the GUID tool:
  - a) Through Workspace -> GUID Tool
  - OR-
  - b) Through the Contributing Data tab/link -> Global Unique Identifier (GUID Tool) -> GUID Tool
4. Launch GUID Tool
5. From the Functions dropdown menu, select Convert Pseudo GUID to GUID
6. Input Pseudo GUID number into top field for both columns.
7. Enter in all required fields (1-10) in both columns.

Note:

  - a) Do not use abbreviations for city of birth. For example, do not use NYC for New York City or LA for Los Angeles.
  - b) Fields 11 and 12 are optional. However, if you enter in information for #11, you must also fill out #12.
8. Once, all fields are filled out, click the Convert Pseudo button.
9. If successful, a window will pop up entitled "GUID Generation Successful" with New GUID: #####
10. Click OK
11. A GUID will appear in the lower left corner dialog box. All fields will be greyed out at this time.
12. Copy and paste GUID directly from GUID box or select Copy GUID to Clipboard.

Note: Only one GUID will be stored in the clipboard at a time. Must paste GUID somewhere prior to generating the next GUID or else it will be overwritten.

13. Click Clear/New if you have additional conversions otherwise click Exit.

## 5. Create Multiple GUIDs

PDBP DMR accepts an input file in comma separated format (CSV). The first line of the file should contain the PII field names as defined in Table 1. PII Fields. An additional "ID" field is required for the GUID output to map from the original participant to each generated GUID. The content of this field is left to the user's discretion for output mapping, but could be a site's local ID for the participant. If no such ID exists, then a simple ascending integer should be used for

each participant. Below is an excerpt from an example input file format. The complete example file, viewed in MS Excel, is displayed below.

The proper column headers are: id, First\_Name, Middle\_Name, Subject\_Has\_Middle\_Name, Last\_Name, MOB, DOB, YOB, City\_Of\_Birth, Country\_of\_Birth, Sex

The [GUID Batch Template](#) can be downloaded from the PDBP DMR website

### 1.8. Prerequisites:

- Valid PDBP DMR account with GUID privilege
- Java Runtime Environment (JRE) installed on your computer (Version 6 or higher)  
<http://docs.oracle.com/javase/7/docs/webnotes/install/index.html#windows>
- CSV file properly formatted with PII

### 1.9. Procedure:

- This procedure provides process steps for using the GUID Tool. The entire procedure typically takes 1-2 minutes (assuming Prerequisites are already met)
1. Point your browser to the PDBP DMR website at <http://pdbp.ninds.nih.gov>.
  2. Log In to PDBP DMR.
  3. There are two ways to find the GUID tool:
    - a) Through Workspace -> GUID Tool  
-OR-
    - b) Through the Contributing Data tab/link -> Global Unique Identifier (GUID Tool) -> GUID Tool
  4. Launch GUID Tool
  5. Read the popup window, and click Accept button to launch the GUID tool.
  6. From the Functions dropdown menu, select Create Multiple GUIDs
  7. Navigate to location on hard drive where CSV file containing multiple subjects' PII information. Select file.
  8. Once file is selected, Click Generate GUIDs.
  9. If successful, generated GUIDs will appear in the table of the pop up window. Errors will also be shown in the lower half of the pop up window.
  10. Output log files are generated and deposited in the folder where the CSV file for upload is located. The output\_guid\_####.txt log file contains all the generated GUID numbers. The output\_error\_###.txt log file contains all the errors associated with the CSV file used for the Create Multiple GUID submission.
  11. Click Clear/New if you have additional conversions otherwise click Exit.



## 6. Search if GUID (or Pseudo GUID) exists in PDBP DMR

### 1.10. Prerequisites:

- Valid PDBP DMR account with GUID privilege
- Java Runtime Environment (JRE) installed on your computer (Version 6 or higher)  
<http://docs.oracle.com/javase/7/docs/webnotes/install/index.html#windows>
- GUID and Pseudo GUID ID numbers

### 1.11. Procedure:

This procedure provides process steps for using the GUID Tool. The entire procedure typically takes 1-2 minutes (assuming Prerequisites are already met)

1. Point your browser to the PDBP DMR website at <http://pdbp.ninds.nih.gov>.
2. Log In to PDBP DMR.
3. There are two ways to find the GUID tool:
  - a) Through Workspace -> GUID Tool  
-OR-
  - b) Through the Contributing Data tab/link -> Global Unique Identifier (GUID Tool) -> GUID Tool
4. Launch GUID Tool
5. From the Functions dropdown menu, select Search if GUID(or Pseudo GUID) exists in PDBP DMR
6. Enter GUID or Pseudo GUID ID and then click Check GUID.
7. The answer will appear in Result box.
  - a) The GUID already exists within PDBP DMR.
  - b) The GUID does not exist in PDBP DMR.
8. Click Close