

# **Subject Management**





# **CHAPTER 6 – SUBJECT MANAGEMENT**

he Subject Management Module enables data to be associated with a research participant without exposing or transferring the research participant's personally identifiable information (PII). This is done by using a GUID (Global Unique Identifier) It is randomly generated, alphanumeric code that is not generated directly from PII. This capability provides two primary benefits. First, it allows data about a research participant to be accumulated across projects over time, regardless of where and when that data were collected. Secondly, it enables a researcher to define a study population while supporting a research hypothesis, even if the data were not collected by the researcher.

This second benefit is further enabled through the use of the Multi-Tenant GUID server (Centralized GUID Solution), which facilitates the sharing of GUIDs across diseases and/or institutes in a secure manner.

The GUID Client software is a JavaScript application that runs directly in your web-browser. The GUID Client is supported on all browsers (Google Chrome, Firefox, Microsoft Edge, and Safari.

# 6.1 Subject Management PROCESS

Researchers collect PII (sometimes referred to as Private Health Information or PHI) from their participants and store that data in a local database that is not made available outside the research institution. Typically, that data is only available to a limited number of individuals. It is the availability of this at the investigator's site that is used to generate GUIDs (Global Unique Identefiers). This is made possible by issuing special software that runs at the research site on an investigator's computer or allowing users to access it through an application. This software performs a one-way encryption, often called a one-way hash, which is sent to the Subject Management Client to determine if the research subject hash codes have been seen by the system before. The encrypted hash codes do not have information to recreate the PII. However, they do have enough information to determine if a research participant and associated GUID already exists in the system.

### **6.2 System Functions**

The following are the service functions that compose the GUID Module:

- Create GUID This function generates a valid GUID, provided the minimum required PII information is available. This module uses a hash function to generate a unique GUID for each participant. (Refer to the valid versus Pseudo-GUID section for more information).
- Convert Pseudo GUID to GUID Allows users to convert Pseudo-GUIDs to valid GUIDs. Users need to provide the minimum required PII fields and the Pseudo-GUIDs.
- Create Multiple GUIDs (With Close Match Checking and Without Close Match Checking) This function generates multiple participant GUIDs from a single call to the server. The batch functionality will process 50 participants at a time with a 5 minute delay between each 50 participants processed. The functionality operates using a .csv file that includes PII information (Refer to Table 1. PII Fields) and creates as an output with the list of GUID(s).

6 - 2 • BRICS USER MANUAL



- Generate Pseudo GUID Generates a Pseudo-GUID with a different format from a valid GUID. A Pseudo-GUID is a unique ID that is not based on PII. PII is not required to obtain a Pseudo-GUID. This function should only be used if a user is unable to get a valid GUID using the Create GUID function due to insufficient PII for a participant. (Refer to the valid GUID versus Pseudo-GUID section for more information on Pseudo-GUIDs.)
- Search if GUID (or Pseudo GUID) exists in the system- Allows users to check if a GUID (or Pseudo GUID) exists in the database. Users must provide a valid GUID or a Pseudo-GUID to use this function. If the submitted GUID exists in the database, the result will state "The GUID already exists". If the GUID does not exist in the database, the result will state "The GUID does not exist."

#### Things to Note:

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#### ICON KEY

🛄 Notes

ImportantInformation

A one-way hash is a reproducible method of turning any 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.

#### **PII FIELDS USED TO GENERATE A GUID** 6.3

The PII fields that are used to generate a GUID are listed below in Table 1. The PII fields are pieces of data that will not change over the lifetime of the participant and are uniquely specific to the participant. Each PII field has an associated probability of a match in the general population. By combining full legal name, date of birth, and municipality of birth, the probability that two individuals share the same information and thus the same hash codes (i.e. a false positive) becomes negligible and is the minimum required information to generate a valid GUID. Additional data that is provided beyond the required minimum further decreases the probability of a false positive.

Additionally, in order to generate a GUID, the following PII is required:

- Complete legal given (first) name of the subject at birth
- If the subject has a middle name
- Complete legal family (last) name of subject at birth
- ✤ Day of birth
- ✤ Month of birth
- ✤ Year of birth
- Name of city/municipality in which subject was born
- Country of birth

### Things to Note:

#### ICON KEY

### D Notes

Important

Information

When inputting participant information, it is recommended that the information is derived from a government issued document/resource, such as a birth certificate or driver's license.



# 6.3.1 PII Fields Table

PII Field name	GUID Client Abbreviations	PII Required for Valid GUID
Complete legal given name of subject at birth	FIRST_NAME	Yes
Indicator if subject has a Middle Name at Birth	SUBJECT_HAS_MIDDLE_NAME	Yes
Complete additional legal name or names at birth	MIDDLE_NAME	No
Complete legal family name/surname of subject at birth	LAST_NAME	Yes
Day of Birth	DOB	Yes
Month of Birth	MOB	Yes
Year of Birth	YOB	Yes
City or Municipality of Birth	CITY_OF_BIRTH	Yes
Country of Birth	COUNTRY_OF_BIRTH	Yes

PII Field name	GUID Client Abbreviations	PII Required for Valid GUID
Government Issued or National ID (For the United States, this is the Social Security Number)	GIID	No
Country Issuing Government- Issued or National ID	GIIDCOUNTRY	No
Organization/Cohort Association	ORGANIZATION_COHORT_ASS OCIATION	No
Physical sex of subject at birth [M/F]	SEX	No

**NOTE:** The "Organization/Cohort Association" field is specific to the Parkinson's Disease Biomarkers Program (PDBP) instance of BRICS. Values for this field will only be available for PBDP.

6 - 5 • BRICS USER MANUAL

# **6.3.2 Special Instructions**

Listed below are some special instructions that must be followed in order to ensure a valid GUID is created:

- 1. The "Last Name" field must contain the family name given at birth, prior to legal name change, or marriage. If there is any doubt as to the original legal name at birth, refer to the information on the birth certificate. Name suffixes such as "Jr.", "Sr.", "III", etc. should be ignored.
- 2. If the participant's "First Name" is a compound name, such as Anne Marie, or Jose- Luis, it may be unclear whether the second part of the compound is a first name or a middle name. In such cases, use the first name as you would report it on other records, such as school transcripts, or credit card billing statements. If in doubt, refer to the birth certificate.
- **3.** If the participant does not have a "Middle Name" (known not to have a middle name at birth), leave this field blank and respond "No" when asked if the individual has a middle name. The GUID Software has a selection to accommodate this possibility. If in doubt, refer to the birth certificate.
- **4.** If the "City or Municipality of Birth" has undergone a name change during a participant's lifetime, use the name of the city at the time of the participant's birth. Examples of this are Peking / Beijing, or Bombay / Mumbai. Again, if there is any doubt, refer to the birth certificate.

It is recommended that the participant's birth certificate and any copies of the participant's birth certificate be returned to the participant and not retained by the site.

# 6.3.3 Valid GUID Versus Pseudo-GUID

A Valid GUID is a GUID that has been successfully issued using PII and is always a random ID. For retrospective data, it is understood that the minimum amount of PII may not be available or sufficient to generate a Valid GUID. For this reason, the tool provides the capability to issue a Pseudo-GUID. A Pseudo- GUID contains no PII and can be generated using the Generate Pseudo GUID function. Like a GUID, a Pseudo-GUID will always be unique. Pseudo-GUIDs are not compared to other participants (including Valid GUIDs). The advantage of using a Pseudo-GUID as an ID within a study is that it can later be updated to get a new Valid GUID while maintaining a mapping in the system for the Pseudo-GUID to the Valid GUID.

A GUID must start with a prefix. The prefix is typically an abbreviation of a disease category. Examples of prefixes are TBI for Traumatic Brain Injury, PD for Parkinson's disease, and GRDR for Global Rare Diseases (Patient) Registry and Data Repository.

An example of a Valid GUID is: TBIAC412JJK

Users participating in the Multi-Tenant GUID server will generate a universal GUID with an NIH prefix consisting of ten (10) alphanumeric characters. An example of a Multi-Tenant GUID is: NIH07HB8I7JK7

6 - 6 • BRICS USER MANUAL



## **6.3.4 GUID Composition**

A GUID must start with a prefix. The prefix is typically an abbreviation of a disease category. Examples of prefixes are TBI for Traumatic Brain Injury, PD for Parkinson's disease, and GRDR for Global Rare Diseases (Patient) Registry and Data Repository. An example of a Valid GUID is: **TBIAC412JJK** 

Users participating in the Multi-Tenant GUID server will generate a universal GUID with an NIH prefix consisting of ten (10) alphanumeric characters. An example of a Multi-Tenant GUID is: NIH07HB8I7JK7

The GUID consists of a prefix, GUID pattern, and check character.

- The prefix is dependent on what BRICS instance you're using.
- The GUID pattern follows the schema: **AANNNAA** Where **A** represents an alphabetic with the exception of the letters: I, O, S (as they are easily confused with certain numbers). **N** represents a number. Both **A** and **N** are generated using a nondeterministic random number generator.
- The check character can be numerical or alphabetic.

Here is a valid GUID sample: TBICJ743PV3

Where,

Prefix:	TBI
Pattern:	CJ743PV
Check:	3

### 6.3.5 Pseudo-GUID Composition

Here is a Pseudo-GUID sample: TBI\_INVZG542YHV

The format of the pseudo-GUID is identical to that of a valid GUID with the exception that the prefix will differ. Here it is **TBI\_INV** instead of **TBI**.



# 6.4 USING THE Subject Management TOOL

The Subject Management client software is a web-based, JavaScript application and is accessible directly through your internet browser.

To access the Subject Management module: Perform the following actions:

**1.** Log in and navigate to the **Workspace screen** where all modules you have access to are displayed.



2. Click the Subject Management module to enter the Subject Management Tool.





**3.** The **Subject Management -** My Subjects page opens where you can view/search your current subjects.

ft Home	Workspace ProFoRM	S Subject Management	Data Dictionary	Data Repository Query	Meta Study Account Manageme	nt Forum	
Menu 😪	🗊 Subject Mana	gement					
Subject Management 🗸	Subject Manag	ement Tool					
My Subjects	Subject Manay	ement 1001					
Create Subject	Add Subject Add Multip	ble Subjects Download				S	earch: 🔻
Manage Multiple Subjects	D	🔷 ТУРЕ	\$ ENTITY	ORGANIZATION     REGISTERED BY	USER REGISTERED BY	DATE REGISTERED	TINKED TO
Narrow your search	TBILK574RNP	GUID	FITBIR	NIH	Sirak, Dagmawi	2023-06-06	
Clear Filters Restore Default	TBIVD698BND	GUID	FITBIR	NIH	Sirak, Dagmawi	2023-04-27	
Ownership     V          ⓐ All Subjects          ᢙ Registered by Me          ⑦ Registered by Others   Type V	Showing 1 to 2 of 2 entrie	s					Frat Previous 1 Next Last

# 6.4.1 Creating GUIDs in the Subject Management TOOL

- 1. Open the Subject Management Module.
- 2. Open the **Create Subject** on the left-side tool bar.

🕇 Home	Workspace ProFoRMS	Subject Management	Data Dictionary	Data Repository Query	Meta Study	Account Management	Forum	
Menu 💝	Subject Manager	nent						
Subject Management 🗸	Subject Manager	nent Tool						
My Subjects Create Subject	Add Subject Add Multiple S	ubjects Download					Sea	ch: •
Manage Multiple Subjects	ID	븆 ТҮРЕ	\$ ENTITY	ORGANIZATION REGISTERED BY		USER REGISTERED BY	DATE REGISTERED	LINKED TO
Narrow your search	TBILK574RNP	GUID	FITBIR	NIH		Sirak, Dagmawi	2023-06-06	
Clear Filters Restore Default	TBIVD698BND Showing 1 to 2 of 2 entries	GUID	FITBIR	NIH		Sirak, Dagmawi	2023-04-27	First Previous 1 Next Last
Ownership All Subjects Registered by Me								
C Registered by Others								



**3.** The Data Privacy user agreement may appear on the page. If it does. Read the agreement and Click **Accept** if you agree. The GUID Client will open and appears directly on the page.

#### Data Privacy

This system is a collaborative environment with privacy rules that pertain to the collection and display of imaging data. Before accessing and using this system, please ensure you familiarize yourself with our privacy rules available through the Data Access Request and supporting documentation.

The collection of this information is authorized under 42 U.S.C. 241, 242, 248, 281(a)(b)(1)(P) and 44 U.S.C. 3101. The primary use of this information is to facilitate medical research. This information may be disclosed to researchers for research purposes, and to system administrators for evaluation and data normalization.

Rules governing the submission of this information are based on the data-sharing rules defined in the Notice of Grant Award (NOGA). If you do not have a grant defining data sharing requirements, data submission is voluntary. Data entered into the system will be used solely for scientific and research purposes and is designed to further the understanding of the disease. Modification of information may be addressed by contacting your system administrator at dcbbrics@nih.gov. The significant system update information may be posted on the site as required

### 4. Click Create a GUID.



I AGREE

I DO NOT AGREE



5. The GUID Client will open directly in the browser on the page. Enter the participant's information (Subject's Personal Identifiable Information (PII)) into the appropriate fields. To ensure the information provided is accurate, the system requires duplicate data entry. Re-enter the Subject's Personal Identifiable Information (PII) to confirm the subject's information.

🕇 Home	Workspace ProFoRMS Subject Management Data Dictionary Data Repository Query Meta Study Account Management Forum
Menu 💝	Subject Management
Subject Management v My Subjects Create Subject	Helpful Documentation  Getting started and need help? Download the GUID User Guide (pdf) Need to generate multiple GUIDs at one time? Download the GUID Batch Template (csv)
Manage Multiple Subjects	RETURN TO GUID OPTIONS
	Required Fields     Please Enter Subject's information (PII)     Please Confirm (Re-Enter) the Subject's information       1. Complete legal given (first) name of the subject at birth     No     No       2. Does the subject have a middle name?     No     No       3. Complete legal family (last) name of subject at birth     Image: Complete legal family (last) name of subject at birth     No       5. Day of birth (1-31)     Image: Complete legal family (last) name of subject at birth     Image: Complete legal family (last) name of subject at birth       6. Month of Birth     Image: Complete legal family (last) name of subject at birth     Image: Complete legal family (last) name of subject at birth       7. Year of Birth [####]     Image: Complete legal family (last) name of subject was born     Image: Complete legal family (last) name of subject was born
	9. Country of Birth Optional Fields 10. Physical sex of subject at birth [M/F] 11. Government Issued or National ID 12. Country Issuing Government-Issued or National ID GUID GUID Generate GUID Copy GUID Copy GUID and PII Clear/New

### The required field names necessary to obtain a valid GUID are listed below:

- Complete legal given (first) name of the subject at birth
- Select YES if the subject DOES HAVE a Middle Name, NO otherwise
- Complete additional (middle) name or names at birth
- Complete legal family (last) name of subject at birth
- Day of birth [1-31]
- Month of birth [January-December]
- Year of birth [####]
- Name of city/municipality in which subject was born
- Country of birth

### The following are additional fields that can be used, but are not required:

- Physical sex of subject at birth [Male/Female]
- Government Issued or National ID number
- Name of the country issuing the Government or National ID
- Organization/Cohort Association



- 6. To register and obtain the GUID, complete the following steps, starting in the left column:
  - a) Enter in the complete legal given (first) name of subject at birth;
  - b) Select Yes or No depending on whether or not the subject has a middle name. If yes, enter information in field 3;
  - c) Complete the required fields 4-9;
  - d) If information is available, complete the optional fields 10-12. Enter the subject's physical sex at birth into #10 field, the government issued or national ID number into #11 field (note that the list box in #12 field becomes available once data is entered into #11);
  - e) Select the country of issued ID from the list provided;
  - f) For PDBP only, select a value in the "Organization/Cohort Association" (field #13) to associate the GUID with a PDBP study, cohort, or other defined study component;
  - g) Enter the same information into the right column of the dialog box
- 7. After inputting the participant's PII into both sets of fields, click the **Generate GUID** button. Note: Spaces, hyphens and apostrophes can be used in the non-numeric GUID fields in the dialog box and are stripped silently by the application.

ff Home	Norkspace ProFoRMS Subject Manage	ment Data Dictionary	Data Repository	Query Meta	a Study Account Ma	anagement	Forum	
Menu 🛛 🗧	Subject Management							
Subject Management My Subjects Create Subject Manage Multiple Subjects	Helpful Documentation Getting started and need help? Download the Need to generate multiple GUIDs at one time? RETURN TO GUID OPTIONS	GUID User Guide (pdf) Download the GUID Batch	Template (csv)					
	Required Fields 1. Complete legal given (first) name of the sub 2. Does the subject have a middle name? 3. Complete additional (middle) name or name 4. Complete legal family (tast) name of subject 5. Day of birth [1-31] 6. Month of Birth 7. Year of Birth [####] 8. Name of Citr/municipality in which subject w 9. Country of Birth Optional Fields 10. Physical sex of subject at birth [M/F] 11. Government issued or National ID 12. Country Issuing Government-Issued or Nat GUID	ect at birth as at birth as birth as born onal ID Generate GUID	Please Enter Subject's In No Do not use abbreviatio	formation (PII) is (e.g. Saint Louis opy GUID and PII	v not St Louis) v Clear/New	Please C No Do not	confirm (Re-Enter) the Subject's Information	



**8.** To copy the new GUID, you must press the "**Copy**" button to copy the GUID to the Clipboard from where you may paste the new GUID. <u>Note</u>: A Clipboard is a location in memory where the system saves information copied.



**9.** A popup window with the GUID information will appear if there was a successful GUID generation. Click the **OK** button to exit the dialog box.

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	<ul> <li>Getting s</li> </ul>	tarted and need h	elp? Download I	GUID	Congration S	uccossful			Ŷ	
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# 6.4.2 Creating Multiple GUIDs Using Batch CSV

The batch capability allows a user to create multiple GUIDs at a time with the option of checking for similar already-entered PII. In order to create multiple GUIDs, you must download and use the GUID batch .csv template.

To Generate GUIDs for multiple Subjects using batch .csv: Perform the following actions:

- 1. Open the Subject Management Module.
- 2. Open the Manage Multiple Subjects on the leftside tool bar.



**3.** Click the **Batch Template (csv)** to download the GUID Batch template to your local machine.





4. The **GUID\_BATCH\_TEMPLATE** download appears on the top right of your browser (i.e Chrome, Firefox, Edge). Click on the download to open the document.



**5.** Upon successful download of the .csv template, Open the template and enter the participant's information into the proper columns. For descriptions of column headers, please refer to Section **6.3.1 PII Fields** above.

4	A	В	C	D	E	F	G	Н		1	J	K	Ĺ	М	N	0
1	REFERENCE_ID	GUID	FIRST_NAME	MIDDLE_NAME	LAST_NAME	SUBJECT_HAS_MIDDLE_NAME	MOB	DOB	Y	OB	CITY_OF_BIRTH	COUNTRY_OF_BIRTH	SEX	GIID	GIIDCountry	
2	1		Joseph		Smith	No	3		4	1989						
3	2		Hannah	Lee	Mulligan	Yes	5		3	2002						
4	3		Allen		Thomas	No	11	. 1	.5	1970						
5	4		Josh	Horatio	Cortez	Yes	2	2	0	1992						
6																

- ✤ Each row contains (1) participant's information
- The REFERENCE\_ID (in cell A2) may be any alphanumeric identifier but must be unique within this batch. This ID will be provided along with the GUID after the batch process completes to ensure the proper GUID is associated with its input PII
- ✤ For MOB, use a numeric value (1-12)
- For COUNTRY\_OF\_BIRTH and GIIDCOUNTRY, please use the country codes listed in Appendix 6-A of the module. For United States, use US.
- ✤ GIID and GIIDCOUNTRY [Optional]
- For GIID, if Country issuing the ID is the United States, please submit data in this format ###-######
- Note: The "Organization/Cohort Association" field is not available for use when generating GUIDs using the batch GUID template. This field is only available when generating a GUID using the GUID client.
- ✤ Save the template in CSV format.



6. Select Choose File and upload the desired .csv file containing the subject(s) information. Then click the Generate button

🕇 Home	Workspace ProFoRMS	Subject Management	Data Dictionary	Data Repository	Query	Meta Study	Account Management	Forum						
Menu 💝	Subject Manager	ment												
Subject Management 🗸	Create Multiple	Subiects												
My Subjects	Lise the below tool to create	or edit multiple Subjects at o	ince. The tool will perform	the correct process	based on you	ir input CSV file								
Create Subject	To begin, download the Batch	se the below tool to create or ealt multiple subjects at once. The tool will perform the correct process based on your input CSV file. to begin, download the <u>Batch Template</u> and fill it in with as much information as you have available.												
Manage Multiple Subjects	You provide a GUID or Ps     You Provide a SeudoGUI     You provide neither a GUI     You provide none of GUID     Upload batch file Choo	succianos. eudoGUID with no PII and a eudoGUID with no PII and a D with PII - The PseudoGUI D or a PseudoGUID with PII o ra PseudoGUID, or PII - an e see File No file chosen	Subject exists for that GI Subject does not exist fo D will be converted to a G - a GUID will be generati rror will be displayed. A S Use close ma	UID - The Subject w r that GUID - A Subj SUID then a Subject ad then a Subject wi ubject requires a GU atch checking?	II be updated ect will be cre will either be II either be edi JID, PseudoG	with any addition ated for that GU ediled or created ited or created d UID, or the abilit	hal fields (an edit operation) ID/PseudoGUID I depending on its existence epending on its existence epending on its existence y to generate one							
	Status: All 🔻 Downloa	d			2			Search:						
	REFERENCE ID	🔺 guid		\$ STATUS		\$	MESSAGE	\$						
				No	data available	e in table								
	Showing 0 to 0 of 0 entries	3						First Previous Next Last						

7. After choosing the desired .csv and clicking generate, the process will begin. You will see the generated GUID's appear in the table and the user can download them.

🕇 Home	Workspace ProFoRMS Su	bject Management Data Di	ctionary Data Repository	Query I	Meta Study	Account Management	Forum								
Menu 💝	Subject Management														
Subject Management 🗸	ubject Management Create Multiple Subjects														
My Subjects Create Subject	Use the below tool to create or edit multiple Subjects at once. The tool will perform the correct process based on your input CSV file. To begin, download the Batch Template and fill if in with as much information as you have available. The tool will consider several scenarios:														
Manage Multiple Subjects	Nanage Multiple Subjects     · You provide a GUID or PseudoGUID with no PII and a Subject exists for that GUID - The Subject will be updated with any additional fields (an edit operation)     · You provide a GUID or PseudoGUID with no PII and a Subject does not exist for that GUID - A Subject will be created for that GUID/PseudoGUID     · You provide a GUID or PseudoGUID with pII - The PseudoGUID will be converted to a GUID then a Subject will either be edited or created depending on its existence     · You provide neither a GUID or a PseudoGUID with PII - a GUID will be generated then a Subject will either be edited or created depending on its existence     · You provide none of GUID, PseudoGUID, or PII - an error will be displayed. A Subject requires a GUID, PseudoGUID, or the ability to generate one														
	Status: All + Download	C CON_DATALCOLON	-				Search: 🗸								
	REFERENCE ID	GUID	🖨 STATUS		÷	MESSAGE	\$								
	ì	TBITP112MTY	success			A Subject has been create	ed with GUID TBITP112MTY								
	2	TBIYV352VVA	success			A Subject has been create	ed with GUID TBIYV352VVA								
	3	TBIZT956LZ2	success			A Subject has been created	ed with GUID TBIZT956LZ2								
	4	TBIFN965BWD	success			A Subject has been create	ed with GUID TBIFN965BWD								
	Showing 1 to 4 of 4 entries						First Previous 1 Next Last								

NOTE: Errors that occurred during processing will appear in the table below

n Home	Workspace ProFoRMS	Subject Management	Data Dictionary	Data Repository	Query	Meta Study	Account Management	Forum						
Menu 🛛 💝	Subject Managem	ent												
Subject Management 🗸 My Subjects Create Subject	Create Multiple Subjects Use the below tool to create or edit multiple Subjects at once. The tool will perform the correct process based on your input CSV file; To begin, download the <u>BatchTemplate</u> and fill it in with as much information as you have available.													
Manage Multiple Subjects	The tool will consider several s • You provide a GUID or Pseu • You provide a GUID or Pseu • You provide a BseudoGUID • You provide a PseudoGUID • You provide none of GUID, f • You provide none of GUID, f • Upload batch file Choos	The tool will consider several scenarios:  You provide a GUID or PseudoGUID with no PII and a Subject exists for that GUID - The Subject will be updated with any additional fields (an edit operation) You provide a GUID or PseudoGUID with no PII and a Subject does not exist for that GUID - A Subject will be created for that GUID/PseudoGUID You provide a PseudoGUID with PII - The PseudoGUID will be converted to a GUID or a PseudoGUID with PII - a GUID will be generated then a Subject will either be edited or created depending on its existence You provide neither a GUID or a PseudoGUID with PII - a GUID will be generated then a Subject will either be edited or created depending on its existence You provide none of GUID, PseudoGUID, or PII - an error will be displayed. A Subject requires a GUID, PseudoGUID, or the ability to generate one Upload batch file Choose File GUID RAT, ATE Vest csy. Use close match checking? I GENERATE												
	Status: All 👻 Download							Search: 🕶						
	REFERENCE ID	A GUID	_	🔷 STATUS		(	MESSAGE	\$						
	2			error			Country of Birth does not	match the required format or values.						
	3			error			Country of Birth does not	match the required format or values.						
	4			error			Country of Birth does not	match the required format or values.						
	Showing 1 to 4 of 4 entries							First Previous 1 Next Last						

6 - 16 • BRICS USER MANUAL

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**NOTE:** If subsequent requests for multiple GUIDs are sent, the required wait time between sending each GUID request containing 50 participants is 30 seconds. Reference the Status field for additional details and confirmation that the .csv file selected uploaded correctly.

**8.** To obtain a full report of errors, potential matches, and/or other information pertaining to the GUID generation process, click the **Download** button.



**9. Save** the .csv report file, which will include the following default filename prefix: "output\_guid." The GUID output file will provide a list of successfully generated GUIDs along with errors and notations:

А	В	С	D
referenceId	guid	serverShortName	notes
1			A close match was found: Month of Birth. Current value: 11
2	TBIHP337FWXVC	FITBIR	
3	TBIHU206FYKXZ	FITBIR	
4	TBINE514UGTLP	FITBIR	

**<u>NOTE</u>**: If you receive a "close match was found" note, but the subject information provided is accurate, retry the upload using the **Create Multiple GUIDs (No Close Match Checking)** option in the Functions menu.



### 6.4.3 Generate a Pseudo GUID

To Generate a Pseudo-GUID: Perform the following actions:

1. Navigate to the Create Subject page (Refer to 6.4.1 steps 1-2).

ff Home 🕚	Workspace ProFoRMS	Subject Management	Data Dictionary	Data Repository Query	Meta Study	Account Management	Forum	
Menu 🛛 🕹	Subject Manager	nent						
Subject Management 🗸 🗸	Out is a Manager	and Table 1						
My Subjects	Subject Manager	nent lool						
Create Subject	Subject Add Multiple S	Subjects Download					Searc	h: 🕶
Manage Multiple Subjects	ID	💠 ТҮРЕ	\$ ENTITY	ORGANIZATION REGISTERED BY		♦ USER REGISTERED BY	DATE REGISTERED 🚽	LINKED TO
Narrow your search	TBIZT040NKJ	GUID	FITBIR	NIH		Sirak, Dagmawi	2023-06-30	
Clear Filters Restore Default	TBITP112MTY	GUID	FITBIR	NIH		Sirak, Dagmawi	2023-06-30	
	TBIYV352VVA	GUID	FITBIR	NIH		Sirak, Dagmawi	2023-06-30	
Ownership 🗸 🗸	TBIZT956LZ2	GUID	FITBIR	NIH		Sirak, Dagmawi	2023-06-30	
All Subjects	TBIFN965BWD	GUID	FITBIR	NIH		Sirak, Dagmawi	2023-06-30	
Registered by Me     Registered by Others	TBILK574RNP	GUID	FITBIR	NIH		Sirak, Dagmawi	2023-06-06	
	TBIVD698BND	GUID	FITBIR	NIH		Sirak, Dagmawi	2023-04-27	
Type 🗸 🗸	Showing 1 to 7 of 7 entries							First Previous 1 Next Last

2. Select Create a Pseudo GUID as shown below.





3. The Generate Pseudo GUID dialog box appears with the following message: "You are about to generate a unique identifier in the system that is assigned to your account. This Pseudo GUID can not be generated again. Are you sure you would like to generate a Pseudo GUID?" Click the Yes button to generate the Pseudo-GUID.



4. The **Get Pseudo GUID** dialog box appears with the Pseudo GUID. Click the **Copy** button to "Copy" the Pseudo GUID to the Clipboard from where you may paste the Pseudo GUID from. **Note:** Only one Pseudo GUID can be saved to the clipboard at a time.

Menu 😸 🗊 Subject Management	
Subject Management  V Helpful Documentation	
My Subjects • Getting started and need help? Download Get Pseudo GUID	
Need to generate multiple GUIDs at one tr     PSEUDO_GUID: TBI_INVJL500LKM	
Manage Multiple Subjects Associate Studies	
Subject Admin >	
	l I

5. Click the **OK** button to exit Get Pseudo GUID dialog box.

-								
Menu	🖸 Sul	bject Manager	nent					
Subject Manage			1					
My Subjects	Getting st		Get Ps	seudo GUID				
Create Subject	• Need to g		GUIDS at one till PSEUD	O_GUID: TBI_INVJL5(	DOLKM			
Manage Multiple	GUID: Associate		TBI_INVJL50			Ok Co	рру	
Subject Admin								

6 - 19 • BRICS USER MANUAL



### 6.4.4 Converting Pseudo GUIDs to valid GUID

To Convert a Pseudo-GUID to valid GUID: Perform the following actions:

1. Navigate to the Create Subject page (Refer to 6.4.1 steps 1-2).

Menu 💝	Subject Mar	nagement					
Subject Management 🗸 🗸	Subject Men	agement Tool					
My Subjects	Subject mana	igement looi					
Create Subject	Subject Add Mu	ultiple Subjects Download				Searc	.h: 🕶
Manage Multiple Subjects	ID	🜲 ТҮРЕ	ENTITY	ORGANIZATION REGISTERED BY	USER REGISTERED BY	DATE REGISTERED 🛛 🔻	LINKED TO
Narrow your search	TBIZT040NKJ	GUID	FITBIR	NIH	Sirak, Dagmawi	2023-06-30	
clear Filters Restore Default	TBITP112MTY	GUID	FITBIR	NIH	Sirak, Dagmawi	2023-06-30	
	TBIYV352VVA	GUID	FITBIR	NIH	Sirak, Dagmawi	2023-06-30	
)wnership 🗸 🗸	TBIZT956LZ2	GUID	FITBIR	NIH	Sirak, Dagmawi	2023-06-30	
All Subjects	TBIEN965BWD	GUID	FITBIR	NIH	Sirak, Dagmawi	2023-06-30	
Registered by Me     Registered by Others	TBILK574RNP	GUID	FITBIR	NIH	Sirak, Dagmawi	2023-06-06	
	TBIVD698BND	GUID	FITBIR	NIH	Sirak, Dagmawi	2023-04-27	
lype 🗸 🗸	Showing 1 to 7 of 7 entr	ries					First Previous 1 Next Last

2. Select the Convert a PseudoGUID option.





**3.** The **Convert Pseudo GUID to GUID** dialog box appears. Fill in the **Input Pseudo GUID ID** field with your pseudo GUID ID then fill out the rest of the required information.

### 4. Click Convert Pseudo GUID button

🕇 Home	Workspace ProFoRMS	Subject Management	Data Dictionary	Data Repository	Query	Meta Study	Account Manage	ement	Forum	
Menu 💝	Subject Manage	ment								
Subject Management My Subjects Create Subject Manage Multiple Subjects	Helpful Documentatio Getting started and need I Need to generate multiple RETURN TO GUID OPTIC	n help? Download the GUID U: GUIDs at one time? Downlo	ser Guide (pdf) ad the GUID Batch Te	emplate (csv)						
Subject Admin >	Required Fields Input Pseudo GUID ID 1. Complete legal given (fi 2. Does the subject have a 3. Complete additional (mi 4. Complete legal family (i 5. Day of birth [1-31] 6. Month of Birth 7. Year of Birth [####] 8. Name of city/municipalil 9. Country of Birth Optional Fields 10. Physical sex of subject 11. Government Issued or 12. Country Issuing Govern GUID	rst) name of the subject at bi a middle name? ddle) name or names at birth ast) name of subject at birth y in which subject was born at birth [M/F] National ID Iment-Issued or National ID	rth Convert Pseudo G	Do not use abbreviation	formation (P	II) Louis not St Loui	s) v Cleat/New	Please C	2onfirm (Re-Enter) the Subject's Information	

5. The **GUID** generation dialog window appears with the newly converted GUID. Click **Copy** to copy the GUID or **OK** to close the dialog box.



6 - 21 • BRICS USER MANUAL



**<u>NOTE</u>:** If you accidentally click **OK** and close the **GUID Generation Successful** dialog box, you can reference and/or copy the generated GUID from the GUID Client. The newly generated GUID will appear in the **GUID** field and can be copied using the **Copy GUID** button.

Menu 💝	Subject Management									
Subject Management 🗸	Helpful Documentation									
My Subjects	Getting started and need help? Download the GUID User Guide (p	Getting started and need help? Download the GUID User Guide (pdf).								
Create Subject	<ul> <li>Need to generate multiple GUIDs at one time? Download the GUID</li> </ul>	Batch Template (csv)								
Manage Multiple Subjects	RETURN TO GUID OPTIONS									
Subject Admin >	Required Fields	Please Enter Subject's Information (PII)		Please Confirm (Re-Enter) the Subject's Information						
	Input Pseudo GUID ID	TBI_INVLN913FA3		TBI_INVLN913FA3						
	1. Complete legal given (first) name of the subject at birth	Luda		Luda						
	<ol><li>Does the subject have a middle name?</li></ol>	No	~	No	~					
	3. Complete additional (middle) name or names at birth									
	4. Complete legal family (last) name of subject at birth	ete legal family (last) name of subject at birth Miano		Miano						
	5. Day of birth [1-31]	3		3						
	6. Month of Birth	June	~	June	~					
	7. Year of Birth [####]	1994		1994						
	8. Name of city/municipality in which subject was born	Boston		Boston						
	9. Country of Birth	UNITED STATES OF AMERICA (THE)	~	UNITED STATES OF AMERICA (THE)	~					
	Optional Fields									
	10. Physical sex of subject at birth [M/F]		~		~					
	11. Government Issued or National ID									
	12. Country Issuing Government-Issued or National ID		$\sim$		~					
	GUID TBIGF592YZW									
	Convert	Pseudo GUID Copy GUID Copy GUID and PII Clea	ar/New							
	GUID: * TBIGF592YZW									
l	TOTOL OVER EN									



# 6.4.5 My Subjects/GUIDs

To View My Subjects/GUIDs: Perform the following actions:

- 1. Open the Subject Management from the workspace and it will load the My Subjects page
- **2.** Here you can use the search box to filter your subjects. Select the fields in which you would like to filter (by default all will be selected) and type your search into the search box. Your results will filter as you type.

🕇 Home	Workspace ProFoRMS	Subject Management	Data Dictionary	Data Repository Query	Meta Study	Account Management	Forum	
Menu 💝	Subject Manage	ement						
Subject Management 🗸 My Subjects Create Subject	Subject Manage	subjects Download					Se	earch: 🗸
Manage Multiple Subjects	ID	🜲 ТҮРЕ	\$ ENTITY	ORGANIZATION REGISTERED BY		USER REGISTERED BY	DATE REGISTERED	
Subject Admin 🔉	TBI_INVJL500LKM	PseudoGUID	FITBIR	NIH		Sirak, Dagmawi	2023-07-07	ORGANIZATION REGISTERED BY USER REGISTERED BY
	TBI_INVLN913FA3	PseudoGUID	FITBIR	NIH		Sirak, Dagmawi	2023-07-07	DATE REGISTERED     LINKED TO
Narrow your search	TBIGF592YZW	GUID	FITBIR	NIH		Sirak, Dagmawi	2023-07-07	TBI_INVLN913FA3
Clear Filters Restore Default	TBIZB915RRK	GUID	FITBIR	NIH		Sirak, Dagmawi	2023-06-15	
Ownership 🗸 🗸	TBIBD063FA1	GUID	FITBIR	NIH		Sirak, Dagmawi	2023-04-27	
All Subjects	TBI_INVGK061ZKU	PseudoGUID	FITBIR	NIH		Sirak, Dagmawi	2023-04-25	
O Registered by Me	TBI_INVDD519LN5	PseudoGUID	FITBIR	NIH		Sirak, Dagmawi	2023-04-25	
Registered by Others	TBIHJ449XDX	GUID	FITBIR	NIH		Sirak, Dagmawi	2023-04-25	
Type 🗸	Showing 1 to 8 of 8 entries							First Previous 1 Next Last



### 6.4.6 Searching if Subject/GUID (or Pseudo GUID) Exists

To Check if a GUID (or Pseudo GUID) already exists: Perform the following actions:

1. Navigate to the Create Subject page (Refer to 6.4.1 steps 1-2). Select Search GUID/ PseudoGUID as shown below.



2. The **Check if GUID Exists on the Server** dialog box appears. Enter the GUID or Pseudo GUID in the GUID/PseudoGUID field, and click the **Check** button. The result appears in the Result field.

Management	
nentation and need help? Download ate multiple GUIDs at one til UID ΟΡΤΙΟΝ S	Check if GUID Exists Please enter the GUID or PseudoCUID you want to chock: GUID/PseudoGUID: TBI_INVDD519LN5 Check Close Close



# 6.5 Accessing the Multi-Tenant GUID Server

Researchers participating in the Multi-Tenant GUID server who want access to another Entity's GUIDs, need to initiate a request through the Entity's Accounts Module. Please contact a member of your designated Operations team for additional details.

# 6.6 APPENDIX 6A – COUNTRY CODES

Country	Country Code
UNITED STATES	US
AFGHANISTAN	AF
ÅLAND ISLANDS	AX
ALBANIA	AL
ALGERIA	DZ
AMERICAN SAMOA	AS
ANDORRA	AD
ANGOLA	AO
ANGUILLA	AI
ANTARCTICA	AQ
ANTIGUA AND BARBUDA	AG
ARGENTINA	AR
ARMENIA	AM
ARUBA	AW
AUSTRALIA	AU
AUSTRIA	AT
AZERBAIJAN	AZ
BAHAMAS	BS
BAHRAIN	ВН
BANGLADESH	BD
BARBADOS	BB
BELARUS	BY
BELGIUM	BE
BELIZE	BZ
BENIN	BJ
BERMUDA	BM
BHUTAN	ВТ
BOLIVIA	BO
BONAIRE, SINT EUSTATIUS, SABA	BQ
BOSNIA AND HERZEGOVINA	ВА
BOTSWANA	BW
BOUVET ISLAND	BV
BRAZIL	BR
BRITISH INDIAN OCEAN TERRITORY	10
BRUNEI DARUSSALAM	BN
BULGARIA	BG



Country	Country Code
BURKINA FASO	BF
BURUNDI	BI
CAMBODIA	КН
CAMEROON	СМ
CANADA	СА
CAPE VERDE	CV
CAYMAN ISLANDS	КҮ
CENTRAL AFRICAN REPUBLIC	CF
CHAD	TD
CHILE	CL
CHINA	CN
CHRISTMAS ISLAND	СХ
COCOS (KEELING) ISLANDS	СС
COLOMBIA	СО
COMOROS	КМ
CONGO	CG
CONGO, THE DEMOCRATIC REPUBLIC OF THE	CD
COOK ISLANDS	СК
COSTA RICA	CR
CÔTE D'IVOIRE	CI
CROATIA	HR
CUBA	CU
CYPRUS	СҮ
CZECH REPUBLIC	CZ
DENMARK	DK
DJIBOUTI	DJ
DOMINICA	DM
DOMINICAN REPUBLIC	DO
ECUADOR	EC
EGYPT	EG
EL SALVADOR	SV
EQUATORIAL GUINEA	GQ
ERITREA	ER
ESTONIA	EE
ETHIOPIA	ET
FALKLAND ISLANDS (MALVINAS)	FK
FAROE ISLANDS	FO
FIJI	FJ



Country	Country Code
FINLAND	FI
FRANCE	FR
FRENCH GUIANA	GF
FRENCH POLYNESIA	PF
FRENCH SOUTHERN TERRITORIES	TF
GABON	GA
GAMBIA	GM
GEORGIA	GE
GERMANY	DE
GHANA	GH
GIBRALTAR	GI
GREECE	GR
GREENLAND	GL
GRENADA	GD
GUADELOUPE	GP
GUAM	GU
GUATEMALA	GT
GUERNSEY	GG
GUINEA	GN
GUINEA-BISSAU	GW
GUYANA	GY
HAITI	НТ
HEARD ISLAND AND MCDONALD ISLANDS	НМ
HOLY SEE (VATICAN CITY STATE)	VA
HONDURAS	HN
HONG KONG	нк
HUNGARY	HU
ICELAND	IS
INDIA	IN
INDONESIA	ID
IRAN, ISLAMIC REPUBLIC OF	IR
IRAQ	IQ
IRELAND	IE
ISLE OF MAN	IM
ISRAEL	IL
ITALY	ІТ
JAMAICA	ML



Country	Country Code
JAPAN	JP
JERSEY	JE
JORDAN	JO
KAZAKHSTAN	KZ
KENYA	KE
KIRIBATI	KI
KOREA, DEMOCRATIC PEOPLE'S REPUBLIC OF	КР
KOREA, REPUBLIC OF	KR
KOSOVO	ХК
KUWAIT	KW
KYRGYZSTAN	KG
LAO PEOPLE'S DEMOCRATIC REPUBLIC	LA
LATVIA	LV
LEBANON	LB
LESOTHO	LS
LIBERIA	LR
LIBYAN ARAB JAMAHIRIYA	LY
LIECHTENSTEIN	LI
LITHUANIA	LT
LUXEMBOURG	LU
MACAO	МО
MACEDONIA, THE FORMER YUGOSLAV REPUBLIC OF	МК
MADAGASCAR	MG
MALAWI	MW
MALAYSIA	MY
MALDIVES	MV
MALI	ML
MALTA	MT
MARSHALL ISLANDS	МН
MARTINIQUE	MQ
MAURITANIA	MR
MAURITIUS	MU
MAYOTTE	YT
MEXICO	MX
MICRONESIA, FEDERATED STATES OF	FM
MOLDOVA, REPUBLIC OF	MD
MONACO	MC
MONGOLIA	MN



Country	Country Code
MONTENEGRO	ME
MONTSERRAT	MS
MOROCCO	MA
MOZAMBIQUE	MZ
MYANMAR	MM
NAMIBIA	NA
NAURU	NR
NEPAL	NP
NETHERLANDS	NL
NETHERLANDS ANTILLES	AN
NEW CALEDONIA	NC
NEW ZEALAND	NZ
NICARAGUA	NI
NIGER	NE
NIGERIA	NG
NIUE	NU
NORFOLK ISLAND	NF
NORTHERN MARIANA ISLANDS	MP
NORWAY	NO
OMAN	ОМ
PAKISTAN	РК
PALAU	PW
PALESTINIAN TERRITORY, OCCUPIED	PS
PANAMA	РА
PAPUA NEW GUINEA	PG
PARAGUAY	РҮ
PERU	PE
PHILIPPINES	РН
PITCAIRN	PN
POLAND	PL
PORTUGAL	РТ
PUERTO RICO	PR
RÉUNION	RE
ROMANIA	RO
RUSSIAN FEDERATION	RU
RWANDA	RW
SAINT BARTHÉLEMY	BL



Country	Country Code
SAINT HELENA	SH
SAINT KITTS AND NEVIS	KN
SAINT LUCIA	LC
SAINT MARTIN	MF
SAINT PIERRE AND MIQUELON	PM
SAINT VINCENT AND THE GRENADINES	VC
SAMOA	WS
SAN MARINO	SM
SAO TOME AND PRINCIPE	ST
SAUDI ARABIA	SA
SENEGAL	SN
SERBIA	RS
SEYCHELLES	SC
SIERRA LEONE	SL
SINGAPORE	SG
SLOVAKIA	SK
SLOVENIA	SI
SOLOMON ISLANDS	SB
SOMALIA	SO
SOUTH AFRICA	ZA
SOUTH GEORGIA AND THE SOUTH SANDWICH ISLANDS	GS
SPAIN	ES
SRI LANKA	LK
SUDAN	SD
SURINAME	SR
SVALBARD AND JAN MAYEN	SJ
SWAZILAND	SZ
SWEDEN	SE
SWITZERLAND	СН
SYRIAN ARAB REPUBLIC	SY
TAIWAN	TW
TAJIKISTAN	TJ
TANZANIA, UNITED REPUBLIC OF	TZ
THAILAND	ТН
TIMOR-LESTE	TL
TOGO	TG
TOKELAU	ТК



Country	Country Code
TONGA	ТО
TRINIDAD AND TOBAGO	TT
TUNISIA	TN
TURKEY	TR
TURKMENISTAN	ТМ
TURKS AND CAICOS ISLANDS	ТС
TUVALU	TV
UGANDA	UG
UKRAINE	UA
UNITED ARAB EMIRATES	AE
UNITED KINGDOM	GB
UNITED STATES MINOR OUTLYING ISLANDS	UM
URUGUAY	UY
UZBEKISTAN	UZ
VANUATU	VU
VATICAN CITY STATE	VA
VENEZUELA	VE
VIET NAM	VN
VIRGIN ISLANDS, BRITISH	VG
VIRGIN ISLANDS, U.S.	VI
WALLIS AND FUTUNA	WF
WESTERN SAHARA	EH
YEMEN	YE
ZAIRE	CD
ZAMBIA	ZM
ZIMBABWE	ZW
VANUATU	VU
VATICAN CITY STATE	VA
VENEZUELA	VE
VIET NAM	VN
VIRGIN ISLANDS, BRITISH	VG
VIRGIN ISLANDS, U.S.	VI
WALLIS AND FUTUNA	WF
WESTERN SAHARA	EH
YEMEN	YE
ZAIRE	CD
ZAMBIA	ZM
ZIMBABWE	ZW

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