

GUID Global Unique Identifier





CHAPTER 6 – GLOBAL UNIQUE IDENTIFIER

he **Global Unique Identifier, GUID,** enables data to be associated with a research participant without exposing or transferring the research participant's personally identifiable information (PII). 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, Safari, and Internet Explorer v10 and higher).

6.1 GUID 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. 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 GUID 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).

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- 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:

ICON KEY

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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.

6.3 PII FIELDS USED TO GENERATE A GUID

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

ICON KEY

Things to Note:

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.

Notes

✤ Important

Information



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	Yes
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
Physical sex of subject at birth [M/F]	SEX	No

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

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.



6.3.2 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 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.

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**



6.3.5 Pseudo-GUID Composition

The format of the Pseudo-GUID is identical to that of a Valid GUID with the exception that after the prefix, _INV is added.

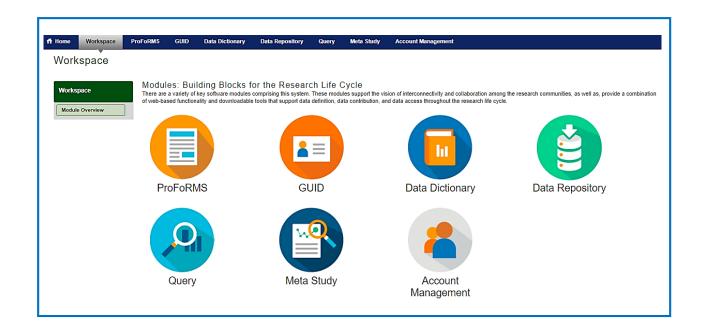
An example of a Pseudo-GUID is: **TBI_INVZG542YHV**An example of a Pseudo-GUID generated in the Multi-Tenant GUID server is: **NIH_INV78H8G0TJ8N**

6.4 USING THE GUID TOOL

The GUID Client software is a web-based, JavaScript application and is accessible directly through your internet browser.

To access the GUID module: Perform the following actions:

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





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2. Click the **GUID** module to enter the GUID Tool.

ff Home Workspace	ProFoRMS G	UID Data Dictionary	Data Repository	Query	Meta Study	Account Management	
Workspace							
Workspace Module Overview	There are a var		comprising this system.	These module	s support the vis	ion of interconnectivity and collaboration amon d data access throughout the research life cyc	ng the research communities, as well as, provide a combination le.
	ProF		GL			Data Dictionary	Data Repository
						8	
	Qu	uery	Meta	Study		Account Management	

3. The **GUID** Overview page opens where you can learn more about the fields required to create a GUID, create GUIDs, View your GUIDs etc.

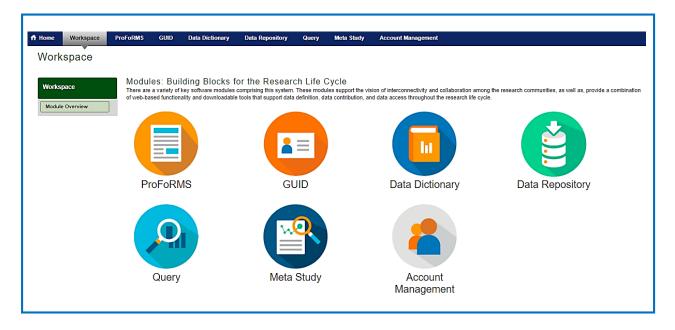
ft Home Workspace P	ProFoRMS GUID Data Dictionary Data Repository Query Meta Study Account Management
GUID (Global Ur	nique Identifier)
GUID Tool	GUID Overview The GUID Tool is a customized software application that generates a Global Unique Identifier for each study participant. A GUID is a subject ID that allows researchers to share data specific to a study participant without exposing personally identifiable information (FIII). A GUID is made up of random alpha-numeric characters and is NOT generated from PII/PHI. By using GUIDs in your research data, the system can associate a single research participant's genetic, imaging, clinical assessment data even if the data was collected at different locations or through different studies.
Create GUIDs My GUIDs	In order to submit data to the system, the system expects all prospective studies to include a GUID in the data submission. For retrospective studies, the team understands that the participant data needed to generate a GUID may not be available. To account for this, the capability to generate pseudo-GUIDs is provided. However submitting data with pseudo-GUIDs, slios the associated research data from the other data associated with valid GUIDs.
	Fields required to generate a GUID In order to generate a GUID, the following PII is required:
	Complete legal given (first]name of 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



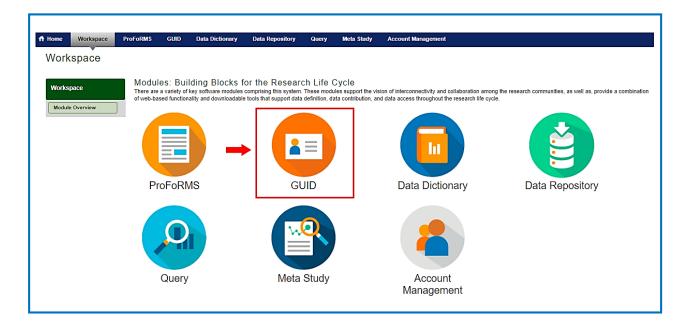
6.4.1 Creating a GUID

To Create a GUID: 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 **GUID** module to enter the GUID Tool.





3. The **GUID Overview** page opens where you can learn more about the fields required to generate a GUID, access the GUID creation tool, view your GUIDs, reference the GUID module user guide, etc.

nt Home	Workspace	ProFoRMS	GUID	Data Dictionary	Data Repository	Query	Meta Study	Account Management
GUID	D (Global Tool ^{Overview}	GUID The GUID participan system ca	Overvi Tool is a cu t without exp n associate	eW ustomized software app posing personally identi e a single research parti	fiable information (PII). cipant's genetic, imagin	A GUID is m g, clinical ass	ade up of random a essment data ever	ch study participant. A GUID is a subject ID that allows researchers to share data specific to a study alpha-numeric characters and is NOT generated from PII/PHI. By using GUIDs in your research data, the if the data was collected at different locations or through different studies.
Creat My G	e GUIDs JIDs	generate a data asso Fields r	a GUID may ciated with v equired t		count for this, the capa			n the data submission. For retrospective studies, the team understands that the participant data needed to is provided. However submitting data with pseudo-GUIDs, silos the associated research data from the other
		● liftt ● Coi ● Da; ● Mo ● Yez ● Na:	ne subject h mplete legal y of birth nth of birth ar of birth	nunicipality in which sub	ubject at birth			

4. Click the **Create GUIDs** on the left-side tool bar. The Create GUIDs page opens.



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

ff Home	Workspace	ProFoRMS	GUID	Data Dictionary	Data Repository	Query	Meta Study	Account Management
GUID	(Global I	Jnique l	dentifi	er)				
GUID Too GUID Ove Create GU My GUIDs	rview JIDs	tool requires Helpful Do Gettin Need	otect the pri a version of DCUMENT g started an to generate	Java to be installed or ation d need help? Downloa multiple GUIDs at one	i your computer. d the GUID User Guide	e (pdf)	-	elow, the GUID tool will be downloaded and executed automatically from your computer. The GUID
		with our pri Collection may be dis Rules gove submission	ncy m is a collab ivacy rules a of this inform closed to re eming subm n is voluntar	orative environment wi wailable through the D nation is authorized un searchers for research ission of this informatio , Data entered into the	ata Access Request ar der 42 U.S.C. 241, 242 purposes, and to syste n are based on the dat system will be used s	d supporting , 248, 281(a) em administra a sharing ruk plely for scier	documentation. (b)(1)(P) and 44 U ators for evaluation as defined in the N atific and research	sy of imaging data. Before accessing and using this system, please ensure you familiarize yourself S.C. 3101. The primary use of this information is to facilitate medical research. This information and data normalization. olice of Grant Award (NOGA). If you do not have a grant defining data sharing requirements, data purposes and is designed to further the understanding of the disease. Modification of information update information may be posted on the site as required.
	-	Accept	Declin	e				

6. 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.

lome	Workspace	ProFoRMS	GUID	Data Dictionary	Data Repository	Query	Meta Study	Account Management		
guid) (Global			er)						
GUID T			otect the pri	vacy of study particip Java to be installed o		n locally. By s	electing the link be	elow, the GUID tool will be do	wnload	led and executed automatically from your computer. The GUII
GUID O Create My GUI			started an	d need help? Downlo	ad the GUID User Guid e time? Download the G		mplate (csv)			
		Functions	Ab	out						
		2. Does th 3. Comple 4. Comple 5. Day of t 6. Month of 7. Year of 8. Name of 9. Country Optional Fi 10. Physic: 11. Govern	te legal give e subject ha te additiona te legal fam birth [1-31] f Birth Birth [####] f city/munici of Birth elds al sex of sub ment Issued	n (first) name of the s we a middle name? I (middle) name or na Iy (last) name of subj pality in which subjec ject at birth [M/F] I or National ID werment-Issued or N	mes at birth ect at birth t was born	Please Enter	Subject's Informa		× × ×	Please Confirm (Re-Enter) the Subject's Information
		GUID	ig ot	100000						
					Generate GU	Сору	GUID Copy	GUID and PII Clear/Ne	w	



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
- 7. 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



8. 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.

	orkspace Global I	ProForms Jnique la	^{GUID} dentifi	Data Dictionary	Data Repository	Query	Meta Study	Account Manager	N/IIC		
GUID Tool GUID Overvi Create GUID	ew	Create (In order to pri tool requires Helpful Do Getting	GUIDS otect the pri a version of ocumenta g started an	vacy of study participa Java to be installed o	n your computer. Id the GUID User Gui	de (pdf)	-	slow, the GUID tool will	be downloa	ded and executed automatically from your computer.	The GUI
My GUIDs		Functions	-	-	time? Download the	GOID Balon le	inplate (csv)				
		2. Does th 3. Complet 4. Complet 5. Day of th 6. Month of 7. Year of 1 8. Name of 9. Country Optional Fi 10. Physica 11. Govern	te legal give e subject ha te additiona te legal fam irth [1-31] f Birth Birth [####] f city/munici of Birth elds I sex of sub ment Issued	in (first) name of the s ive a middle name? I (middle) name or nar ily (last) name of subje pality in which subject pality in which subject of a thirth [M/F] J or National ID wernment-Issued or N	nes at birth cct at birth was born	Paul No Smith 1 January 1957 Rockville UNITED ST Male			T T T T	Please Confirm (Re-Enter) the Subject's Informatio Paul No Smith 1 January 1957 Rockville UNITED STATES Male	on

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.

GUID Tool GUID Overview	Create GUIDs In order to protect the privacy of study particip tool requires a version of Java to be installed Helpful Documentation Copy Copy Copy Copy Copy Copy Copy Copy	
Create GUIDs My GUIDs	Getting started and need help? Downlo Need to generate multiple GUIDs at one time? Download the GUID Batch Template (csv) Functions About	

10. 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.



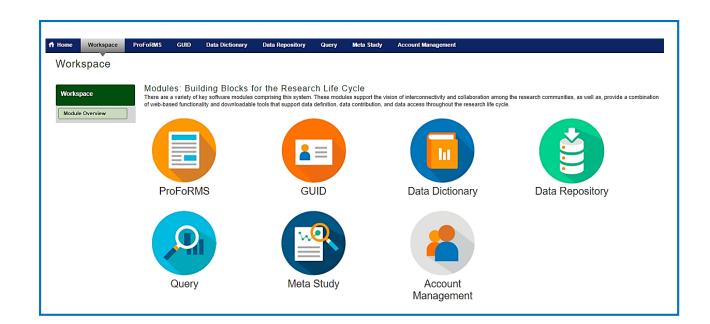
GUID Tool	Create GUIDs In order to protect the privacy of study particip tool requires a version of Java to be installed New GUID: TBIXY080ATARJ	and e
GUID Overview Create GUIDs	Helpful Documentation	
My GUID₅	Need to generate multiple GUIDs at one time? Download the GUID Batch Template (csv) Functions About	

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.

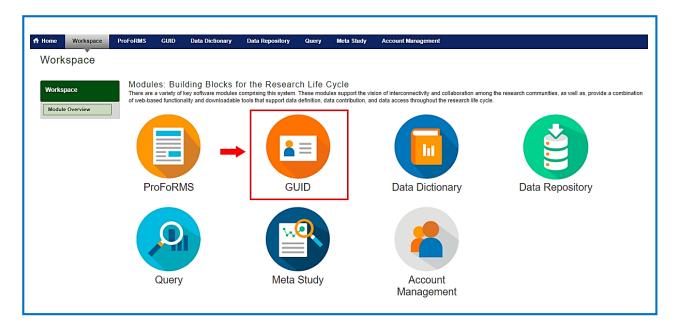
To Generate GUIDs for multiple Subjects using batch .csv: Perform the following actions:

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





2. Click the **GUID** module to enter the GUID Tool.



3. The **GUID Overview** page opens where you can learn more about the fields required to create a GUID, create GUIDs, and View your GUIDs etc.

ft Home Workspace P	roFoRMS GUID Data Dictionary Data Repository Query Meta Study Account Management
GUID (Global Ur	ique Identifier)
GUID Tool	GUID Overview The GUID Tool is a customized software application that generates a Global Unique Identifier for each study participant. A GUID is a subject ID that allows researchers to share data specific to a study participant without exposing genorality identifiable information (PII). A GUID is made up of random alpha-numeric characters and is NOT generated from PII/PHI. By using GUIDs in your research data, the system can associate a single research participant's genetic, imaging, clinical assessment data even if the data was collected at different locations or through different studies.
Create GUIDs My GUIDs	In order to submit data to the system, the system expects all prospective studies to include a GUID in the data submission. For retrospective studies, the team understands that the participant data needed to generate a GUID may not be available. To account for this, the capability to generate pseudo-GUIDs is provided. However submitting data with pseudo-GUIDs, silos the associated research data from the other data associated with valid GUID.
	Fields required to generate a GUID In order to generate a GUID, the following PII is required:
	Complete legal given (firstjname of 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



4. Click the **"Create GUIDs"** on the left-side GUID Tool navigation. The **"Create GUIDs**" page appears with links to some helpful documentation.

ft Home Wo	space	ProFoRMS	GUID	Data Dictionary	Data Repository	Query	Meta Study	Account Management
GUID (G GUID Tool GUID Overview Create GUIDs My GUIDs	obal U	GUID The GUID participant system ca. In order to generate a data assoc Fields rd In order to Cor • Cor • Cor • Day • Mor • Vea • Nar	dentifi Overvin Tool is a cu without exp n associate submit dat. GUID may clated with v equired t generate a mplete legal of birth nth of birth of birth	er) ew stomized software app sosing personally ident a to the system, the sy: not be available. To are aid CUIDs. o generate a GUI GUID, the following PI given (fristhame of st as a middle name family (last) name of st unicipality in which sut	lication that generates : ifable information (PII), cipant's genetic, imagin tem expects all prospe coount for this, the capa D I is required: biject at birth ubject at birth	a Global Uniq A GUID is m g, clinical ass ctive studies	ue Identifier for ea ade up of random : essment data even to include a GUID i	ch study participant. A GUID is a subject ID that allows researchers to share data specific to a study alpha-numeric characters and is NOT generated from PII/PHI. By using GUIDs in your research data, the nif the data was collected at different locations or through different studies. In the data submission. For refrospective studies, the team understands that the participant data needed to s is provided. However submitting data with pseudo-GUIDs, silos the associated research data from the other

5. Click the <u>GUID Batch Template (csv)</u> to download the GUID Batch template to your local machine.

ff Home	Workspace	ProFoRMS	GUID	Data Dictionary	Data Repository	Query	Meta Study	Account Management	
GUID	GUID (Global Unique Identifier)								
GUID T	ool		otect the pri	vacy of study participa Java to be installed or		l locally. By se	electing the link be	slow, the GUID tool will be downloaded and executed automatically from your computer. The GUID	
GUID O	verview	Helpful Documentation							
Create My GUI					d the GUID User Guide time? Download the GU		mplate (csv)	←	

6. The **GUID_BATCH_TEMPLATE** launcher opens. Select the Open with or Save File option to download the template.

-	ing GUID_BATCH u have chosen to	-
Ę	GUID_BATCH	I_TEMPLATE.csv
	which is: Micr from: https://	osoft Excel Comma Separated Values File (136 bytes) fitbir.nih.gov
W	/hat should Firefo	x do with this file?
	Open with	Microsoft Excel (default)
	Save File	
	Do this <u>a</u> uto	omatically for files like this from now on.
		OK Cancel



7. 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 <u>6.3.1 PII Fields</u> above.

	А	В	С	D	E	F	G	Н		J	Κ	L	М
1	REFERENCE_ID	FIRST_NAME	MIDDLE_NAME	LAST_NAME	SUBJECT_HAS_MIDDLE_NAME	MOB	DOB	YOB	CITY_OF_	COUNTRY	SEX	GIID	GIIDCountry
2	1	Thomas	Jacob	Lee	Yes	9	13	1988	dc	US	М	123-24-2455	US
3	2	Gerald	Dean	White	Yes	10	14	1989	dc	US		134-15-2114	US
4	3	Joe		Schmoe	No	11	12	1976	Bethesda	US			
5	4	Linda		Johnson	No	8	1	1980	Wheaton	US	F		
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.



8. Click on the Create GUIDs option in the left-hand GUID Tool navigation.

ff Home	Workspace	ProFoRMS	GUID	Data Dictionary	Data Repository	Query	Meta Study	Account Management
GUIE) (Global	Unique I	dentifi	er)				
GUID GUID Create	Overview GUIDs	The GUIL participar system ci In order t generate data asso Fields	nt without exp an associate o submit dat a GUID may ociated with y required t	stomized software app posing personally ident a single research part a to the system, the sy not be available. To a valid GUIDs. o generate a GU	ifiable information (PII). icipant's genetic, imagin stem expects all prospe ccount for this, the capa	A GUID is ma g, clinical ass ctive studies f	ade up of random sessment data eve to include a GUID	ach study participant. A GUID is a subject ID that allows researchers to share data specific to a study alpha-numeric characters and is NOT generated from PI/PHI. By using GUIDs in your research data, the an if the data was collected at different locations or through different studies. in the data submission. For retrospective studies, the team understands that the participant data needed t is is provided. However submitting data with pseudo-GUIDs, silos the associated research data from the of
		 Co If t Co Da Mo Ye Na 	emplete legal he subject h emplete legal by of birth onth of birth ar of birth	GUID, the following P given (first)name of si as a middle name family (last) name of s unicipality in which sul	ubject at birth			

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

fHome Wo	orkspace Pro	oFoRMS GUID	Data Dictionary	Data Repository	Query	Meta Study	Account Management
		ique Identif	ier)				
GUID Tool GUID Overvie Create GUIDs My GUIDs	ew H	ool requires a version o lelpful Document Getting started a	rivacy of study participa of Java to be installed or ation nd need help? Downloa		(pdf)	-	low, the GUID tool will be downloaded and executed automatically from your computer. The GUID
		Data Privacy	oout	ith privacy rules that per	tain to the coll	lection and displa	v of imaging data. Before accessing and using this system, please ensure you familiarize yourself
		with our privacy rules Collection of this infor	available through the D mation is authorized un	ata Access Request and der 42 U.S.C. 241, 242,	d supporting d 248, 281(a)(b	ocumentation. (1)(P) and 44 U.	S.C. 3101. The primary use of this information is to facilitate medical research. This information and data normalization.
		submission is volunta	ry. Data entered into the	e system will be used so	lely for scienti	fic and research p	ptice of Grant Award (NOGA). If you do not have a grant defining data sharing requirements, data purposes and is designed to further the understanding of the disease. Modification of information
		may be addressed by	contacting your system	administrator at dobbrid	is@nin.gov. 5	ignificant system	update information may be posted on the site as required.

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10. Select Functions in the GUID Client menu to open the drop-down menu.

<i>*</i>			0.000	B (B (f)		ē					
ff Home	Workspace	ProFoRMS	GUID	Data Dictionary	Data Repository	Query	Meta Study	Account Managem	nent		
GUID	(Global	Unique lo	dentifi	ier)							
	`			,							
GUID T	ool		otect the pr	ivacy of study participa f Java to be installed o		in locally. By s	electing the link b	elow, the GUID tool will I	be download	ded and executed automatically from your computer. The C	JUID
GUID O	verview	Helpful Do	ocument	ation							
Create	GUIDs	Gettin	started ar	nd need help? Downloa							
My GUI	Ds	 Need to the second s 	-	multiple GUIDs at one	time? Download the 0	OID Batch Te	mplate (csv)				
	-	Functions	Ab	out							
			e legal give	en (first) name of the si ave a middle name?	ubject at birth	Please Enter	Subject's Informa	tion (PII)	•	Please Confirm (Re-Enter) the Subject's Information	
				al (middle) name or nar							
		 Complete Day of b 	-	nily (last) name of subje	ect at birth						
		6. Month o							•		•
		7. Year of 8. Name of		 ipality in which subject	was born						
		9. Country							•		•
		Optional Fi 10. Physica		bject at birth [M/F]					-		
				d or National ID					· ·		-
			Issuing G	overnment-Issued or N	ational ID				Ŧ		Ŧ
		GUID			Generate GU	D Conv	GUID Copy	GUID and PII Cle	ear/New		
					Generale GO	Сору	Copy		- California - Cal		

11. Select Create multiple GUIDs (With Close Match Checking) as shown below:

<u>Note</u>: It is advised to always use this function first. Only use **Functions** > **Create multiple GUIDs (No Close Match Checking)** in the case when you are certain that the PII that has been entered is indeed correct (review all warnings line by line first). If this option is selected, the information entered will not be checked against pre-existing GUIDs.

Contact a member of your designated Operations team if needed before using this functionality.

Home Workspace	ProFoRMS GUID Data Dictionary Data Repos	itory Query	Meta Study	Account Management	
GUID (Global	Unique Identifier)				
COID (CIODA	i oliquo luolitilioi)				
_					
GUID Tool	Create GUIDs		and a strength of the barts to		
	In order to protect the privacy of study participants, the GUID to tool requires a version of Java to be installed on your computer		selecting the link b	elow, the GUID tool will be downl	oaded and executed automatically from your computer. The Gu
GUID Overview					
Create GUIDs	Helpful Documentation	Oulds (add)			
	 Getting started and need help? Download the GUID Use Need to generate multiple GUIDs at one time? Downloa 		emplate (csv)		
My GUIDs					
	Functions About				
	Create GUID	Please Ente	r Subject's Informa	tion (PII)	Please Confirm (Re-Enter) the Subject's Information
	Convert PseudoGuid to GUID	Thouse Ente			rease committee citely the cabject's momental
	Create Multiple GUIDs (With Close Match Checking)	No		•	No
	Create Multiple GUIDs (No Close Match Checking)				
	Generate Pseudo GUID				
				٣	
	Search if GUID (or PseudoGUID) exists in the system				
	Name of city/municipality in which subject was born	-			
	9. Country of Birth Optional Fields			۲	
	10. Physical sex of subject at birth [M/F]			•	
	11. Government Issued or National ID				
	12. Country Issuing Government-Issued or National ID			Ŧ	
	GUID				



12. Select **Choose File** and upload the desired .csv file containing the subject(s) information to upload.

		Create GUIDs
	GUID Tool	to order to protect the privacy of study participants, the GUID tool is run locally. By selecting the link below, the GUID tool will be downloaded and executed automatically from your computer. The GUID tool requires a version of Java to be installed on your computer.
	GUID Overview	Helpful Documentation
	Create GUIDs	Getting started and need help? Download the GUID User Guide (pdf)
L	My GUIDs	Need to generate multiple GUIDs at one time? Download the GUID Batch Template (csv)
L		Functions About
		Select a file in the file input below to begin batch processing Source File: Choose File No file chosen Status: Waiting on Input Number of subjects successfully processed: 0 Reference ID GUID
l		Number of subjects processed with errors: 0 Reference ID Error(s)

13. When you upload the desired .csv, the GUID generation process will initiate automatically. The generated GUIDs will appear in the **Number of subjects successfully processed** table along with a quantity of successfully generated GUIDs.

GUID Tool	Create GUIDs In order to protect the privacy of study participants, the GUID tool is run locally. By selecting the link below, the GUID tool will be downloaded and executed automatically from your computer. The GUID tool requires a version of Java to be installed on your computer.
GUID Overview Create GUIDs My GUIDs	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)
	Functions About Select a file in the file input below to begin batch processing Source File: Choose File: No file chosen Number of subjects successfully processed: 3 Reference ID GUID 2 TBIH/2307FVXVC 3 TBIH/200FVKXZ 4 TBIH/250FVKXZ 4 TBIH/250FVKXZ 1 A close match was found. Month of Birth. Current value: 11 If this PII is correct, you can submit it using the menu option "Create Multiple GUIDs (No Close Match Checking)" Download Results Status

Errors that occurred during processing will appear in the **Number of subjects processed** with errors table along with a quantity of unsuccessfully generated GUIDs.

GUID Tool GUID Overview Create GUIDs My GUIDs	Create GUIDs In order to protect the privacy of study participants, the GUID tool is run locally. By selecting the link below, the GUID tool will be downloaded and executed automatically from your computer. The GUID tool requires a version of Java to be installed on your computer. 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)	
-	Functions About Select a file in the file input below to begin batch processing Source File: Choose File No file chosen Status: Finished GUID batch request for C:tfakepath/GUID_BATCH_TEMPLATE_im.csv Number of subjects successfully processed: 3 Reference ID GUID 2 TBIHP037FVXCZ Edited Structure 3 TBIHP026FYKXZ Edited Structure 4 TBIHP0514UGTLP Edited Structure Number of subjects processed with errors: 1 Reference Fror(s) Edited Structure 1 A close match was found: Month of Birth. Current value: 11 If this FII is correct, you can submit it using the menu option "Create Multiple GUIDs (No Close Match Checking)" Download Results	



NOTES: 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.

GUID Tool GUID Overview Create GUIDs	Create GUIDs In order to protect the privacy of study participants, the GUID tool is run locally. By selecting the link below, the GUID tool will be downloaded and executed automatically from your computer. The GUID tool requires a version of Java to be installed on your computer. Helpful Documentation
My GUIDs	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) Functions About Select a file in the file input below to begin batch processing
	Select a life in the multiple provide using to be sing sources file. No file chosen Source file: Choose File No file chosen Status: Finished GUID batch request for C:\fakepath\GUID_BATCH_TEMPLATE.csv Status: Finished GUID batch request for C:\fakepath\GUID_BATCH_TEMPLATE.csv GUID Number of subjects processed with errors: 0 Reference ID Error(s) Download Results

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

GUID Tool	Create GUIDs In order to protect the privacy of study participants, the GUID tool is run locally. By selecting the link below, the GUID tool will be downloaded and executed automatically from your computer. The GUID tool requires a version of Java to be installed on your computer.
GUID Overview Create GUIDs My GUIDs	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)
_	Functions About Select a file in the file input below to begin batch processing Source File: Choose File: Choose File: Status: Finished GUID batch request for C:\fakepath\GUID_BATCH_TEMPLATE_im.csv Number of subjects successfully processed: 3 Reference ID GUID Status: Finished GUID batch request for C:\fakepath\GUID_BATCH_TEMPLATE_im.csv 2 TEiHP337FWXVC 3 TEiHP206FYKXZ Status: Finished GUID batch request for C:\fakepath\GUID_BATCH_TEMPLATE_im.csv Number of subjects processed with errors: 1 Reference Error(s) Aclose match was found. Month of Bith. Current value: 11 If this PII is correct, you can submit it using the menu option "Create Multiple GUIDs (No Close Match Checking)" Download Results

15. 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
referenceld	guid	serverShortName	notes
1			A close match was found: Month of Birth. Current value: 11
2	TBIHP337FWXVC	FITBIR	
3	TBIHU206FYKXZ	FITBIR	
4	TBINE514UGTLP	FITBIR	



NOTE: 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 **GUID Client**. (For instructions navigating to the GUID Client refer to <u>Section 6.4</u> above). In the GUID Client, Select **Functions** to open the drop-down menu.

lome	Workspace	ProFoRMS	GUID Data Dictionary	Data Repository	Query	Meta Study	Account Management	
GUID	(Global	Unique Id	entifier)					
GUID Too					n locally. By s	electing the link be	low, the GUID tool will be down	nloaded and executed automatically from your computer. The GUIE
Create GU			cumentation					
My GUIDs			started and need help? Downloa generate multiple GUIDs at one			mplate (csv)		
wy GOID'S	· · · · · ·	Functions	About					
		 Does the Complete Complete Day of bin Month of 	legal given (first) name of the s subject have a middle name? additional (middle) name or nar legal family (last) name of subje th [1-31] Birth	ubject at birth nes at birth	Please Enter	Subject's Informat	ion (PII)	Please Confirm (Re-Enter) the Subject's Information
			city/municipality in which subject	was born				
		 Country o Optional Field Physical 			[• • • • • • • • • • • • • • • • • • •	
		11. Governm 12. Country I	ent Issued or National ID ssuing Government-Issued or N	lational ID			• ए	
		GUID		Generate GUI	D Сору	GUID Copy	GUID and PII Clear/New	



2. Select Generate Pseudo GUID as shown below.

GUID Tool GUID Overview Create GUIDs My GUIDs	Create GUIDS In order to protect the privacy of study participants, the GUID to tool requires a version of Java to be installed on your computer Helpful Documentation . Getting started and need help? Download the GUID Use . Need to generate multiple GUIDs at one time? Download	r. er Guide (pdf)	ill be download	led and executed automatically from y	our computer. The GUID
	Functions About				
_	Create GUID Convert PseudoGuid to GUID Create Multiple GUIDs (With Close Match Checking) Create Multiple GUIDs (No Close Match Checking) Generate Pseudo GUID Search if GUID (or PseudoGUID) exists in the system	Please Enter Subject's Information (PII) No	v	Please Confirm (Re-Enler) the Subje	tect's Information ▼
	 Name of city/municipality in which subject was born Country of Birth Optional Fields Dehysical sex of subject at birth [M/F] 		•		•
	11. Government Issued or National ID 12. Country Issuing Government-Issued or National ID GUID	ate GUID Copy GUID Copy GUID and PII C	V Clear/New		• •

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.

GUID Tool	Create GUIDs In order to protect the privacy of study particip	
	tool requires a version of Java to be installed	Generate Pseudo GUID
GUID Overview	Helpful Documentation	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
Create GUIDs	Getting started and need help? Downlo	generate a Pseudo GUID?
My GUIDs	 Need to generate multiple GUIDs at on 	
	Functions About	Yes No

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.

GUID Tool	Create GUIDs In order to protect the privacy of study particips tool requires a version of Java to be installed	ants, the GUID tool is run locally. By selecting the link below, the GUID tool will be downloade an
GUID Overview Create GUIDs My GUIDs	Helpful Documentation Getting started and need help? Downlc Need to generate multiple GUIDs at on	Get Pseudo GUID PSEUDO_GUID: TBI_INVFU017XDNGD
	Functions About	



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

GUID Tool	Create GUIDs In order to protect the privacy of study particip tool requires a version of Java to be installed of	ants, the GUID tool is run locally. By selecting the link below, the GUID tool will be downloade in a
GUID Overview Create GUIDs My GUIDs	Helpful Documentation Getting started and need help? Downlo Need to generate multiple GUIDs at on	Get Pseudo GUID PSEUDO_GUID: TBI_INVFU017XDNGD
	Functions About	

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 **GUID Client.** (For instructions navigating to the GUID Client Dialog Box refer to <u>Section 6.4</u> above). In the GUID Client, Select **Functions** to open the drop-down menu.

f Home Workspace	ProFoRMS GUID Data Dictionary Data Repository Query Meta Study Account Management
GUID (Global I	Unique Identifier)
GUID Tool GUID Overview Create GUIDs My GUIDs	Create GUIDs In order to protect the privacy of study participants, the GUID tool is run locally. By selecting the link below, the GUID tool will be downloaded and executed automatically from your computer. The GUID tool requires a version of Java to be installed on your computer. 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) Functions About
	Required Fields Complete legal given (first) name of the subject at birth Does the subject have a middle name? Complete legal family (last) name of subject at birth Complete legal family (last) name of subject at birth Day of birth [1-31] Month of Birth Year of Birth [####] Name of citly/municipality in which subject was born Country of Birth Country of Birth Country of Birth Scompted alex or National ID Country tissuing Government-Issued or National ID Country issuing Government-Issued or National ID Generale GUD Copy GUID and PII Clear/New Please Confirm (Re-Enter) the Subject's Information



2. Select the Convert Pseudo GUID to GUID option.

ff Home Workspace	ce ProFoRMS GUID Data Dictionary Data Repository Query Meta Study Account Management
GUID (Glob	al Unique Identifier)
GUID Tool	Create GUIDs In order to protect the privacy of study participants, the GUID tool is run locally. By selecting the link below, the GUID tool will be downloaded and executed automatically from your computer. The GUID tool requires a version of Java to be installed on your computer.
GUID Overview Create GUIDs	Helpful Documentation Getting started and need help? Download the GUID User Guide (pdf)
My GUIDs	Need to generate multiple GUIDs at one time? Download the GUID Batch Template (csv) Functions About
	Create GUID Convert PseudoGuid to GUID Create Multiple GUIDs (With Close Match Checking) Generate Pseudo GUID Search if GUID (or PseudoGUID) exists in the system 8. Name of city/municipality in which 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 Generate GUID Copy GUID Copy GUID and PII Clear/New

3. The **Convert Pseudo GUID to GUID** dialog box appears. Notice that the **Generate GUID** button is de-activated and a **Convert Pseudo GUID** activated.

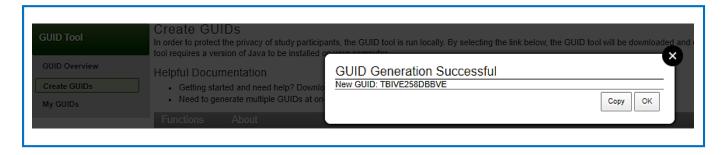
GUID Tool GUID Overview Create GUIDs My GUIDs	Create GUIDs In order to protect the privacy of study participants, the GUID tool tool requires a version of Java to be installed on your computer. Helpful Documentation Getting started and need help? Download the GUID User G Need to generate multiple GUIDs at one time? Download the Functions About	Suide (pdf)	vnload	ed and executed automatically from your computer. The GUID
-		Please Enter Subject's Information (PII) No	,	Please Confirm (Re-Enter) the Subject's Information
	5. Day of birth [1-31] 6. Month of Birth 7. Year of Birth [#####] 8. Name of city/municipality in which 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 Convert P	seudo GUID Copy GUID Copy GUID and PII Cle	7 ear/Net	



4. To convert a **Pseudo-GUID** to a valid **GUID**, enter the Pseudo-GUID and the participant's information. Click the **Convert Pseudo GUID** button. This process is similar to the process of entering participant information to generate a new/valid GUID. If any of the required fields are missing, an error will appear.

GUID Tool GUID Overview Create GUIDs My GUIDs	Create GUIDS In order to protect the privacy of study participants, the GUID tool is run locally. By selecting the link below, the GUID tool will be downloaded and executed automatically from your computer. The GUID tool rour expression of Java to be installed on your computer. The GUID tool requires a version of Java to be installed on your computer. The GUID tool requires a version of Java to be installed on your computer. The GUID tool started and need help? Download the GUID USER Guide (pdf) • Getting started and need help? Download the GUID Batch Template (csv) Functions About						
	Required Fields Input Pseudo GUID ID 1. Complete legal given (first) name of the subject at birth 2. Does the subject have a middle name? 3. Complete legal family (last) name of subject at birth 4. Complete legal family (last) name of subject at birth 5. Day of birth [1-31] 6. Month of Birth 7. Year of Birth [####] 8. Name of citly/municipality in which subject was born 9. Country of Birth Coptional 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	Please Enter Subject's Information (PII) TBI_INVFU017XDNGD John No Doe 1 January 1981 Bethesda UNITED STATES Male seudo GUID Copy GUID Copy GUID and I	V V V V V V V	Please Confirm (Re-Enter) the Subject's Information TBLINFU017XDNGD John No V Doe 1 January Y 1961 Bethesda UNITED STATES V Male V			

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.



<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.



GUID Tool	Create GUIDs In order to protect the privacy of study participants, the GUID tool tool requires a version of Java to be installed on your computer.	is run locally. By selecting the link below, the GUID too	ol will be downlo	aded and executed automatically from your comput	er. The GUID
GUID Overview Create GUIDs My GUIDs	Helpful Documentation Getting started and need help? Download the GUID User G Need to generate multiple GUIDs at one time? Download the				
	Functions About				
	Required Fields Input Pseudo GUID ID	Please Enter Subject's Information (PII) TBI INVFU017XDNGD		Please Confirm (Re-Enter) the Subject's Informa TBI_INVFU017XDNGD	ation
	1. Complete legal given (first) name of the subject at birth	John		John	
	2. Does the subject have a middle name?	No	Ψ.	No	Ψ
	3. Complete additional (middle) name or names at birth				
	4. Complete legal family (last) name of subject at birth	Doe		Doe	
	5. Day of birth [1-31]	1		1	
	6. Month of Birth	January	Ψ.	January	Ŧ
	 Year of Birth [####] 	1961		1961	
	Name of city/municipality in which subject was born	Bethesda		Bethesda	
	9. Country of Birth	UNITED STATES	Ψ.	UNITED STATES	Ŧ
	Optional Fields				
	10. Physical sex of subject at birth [M/F]	Male	Ψ	Male	Ψ
	11. Government Issued or National ID				
	12. Country Issuing Government-Issued or National ID		Ŧ		Ŧ
I	GUID TBIVE258DBBVE	Pseudo GUID Copy GUID Copy GUID and	PII Clear/I	New	
	Converte	Copy GOID Copy GOID and	Cicalin	10W	

6.4.5 My GUIDs

To View My GUIDs: 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 **GUID** module to enter the GUID Tool.

ff Home Workspace	ProFoRMS GUID	Data Dictionary	Data Repository	Query	Meta Study	Account Management			
Workspace Workspace Module Overview	There are a variety of	hality and downloadable	comprising this system tools that support dat	. These modules	support the visio	n of interconnectivity and collaborat data access throughout the researc	ih lífe cycle.	communities, as well as, prov	ide a combination
	Query		Meta	Study		Account Management			



3. On the **GUID Overview** page click the "**My GUIDs**" link in the left-hand GUID Tool navigation. The "**My GUIDs**" page displays a table list of all GUIDs and Pseudo GUIDs that you have registered.

4. By default, the table is filtered to display "Mine Only" which are GUIDs that have been registered by you. You can change the filter to "Show All" which will display GUIDs registered to your account and those registered to your Organization.

lome	Workspace	ProFoRMS	GUID	Data Dictionary	Data Repository	Query Meta	Study Account Manager	nent		
SUID) (Global	Unique I	dentifi	er)						
GUID T	lool	My GU The table		vs a list of all GUIDs that	at vou have registered f	rom the one-way has	hed PII information as well as F	seudoGUIDs your organiza	tion has registered.	
GUID C	Overview	Download	-		•				Sear	ch: -
Create										
My GU		••			TYPE	♦ ENTITY	REGISTERED BY	♦ BY	DATE REGISTERED	LINKED TO
my GO	105	TBIHP3	37FWXVC		GUID	FITBIR	NIH	Meckley, Jon	2019-03-11	
		TBIHU2	06FYKXZ		GUID	FITBIR	NIH	Meckley, Jon	2019-03-11	
		TBINE5	14UGTLP		GUID	FITBIR	NIH	Meckley, Jon	2019-03-11	
		TBIVE2	58DBBVE		GUID	FITBIR	NIH	Meckley, Jon	2019-03-11	TBI_INVFU017XDNGD
		TBIXYO	80ATARJ		GUID	FITBIR	NIH	Meckley, Jon	2019-03-11	
			FU017XDN	GD	PseudoGUID	FITBIR	NIH	Meckley, Jon	2019-03-11	TBIVE258DBBVE



NOTE: The following filters are available on the "My GUIDs" table:

- Mine Only GUIDs and Pseudo GUIDs that you have registered (User Registered By)
- Show All GUIDs and Pseudo GUIDs that you have registered and/or have been registered by your Organization (Organization Registered By)
- **GUIDs** Filters the table (Type column) to only show valid GUIDs
- **Pseudo GUIDs** Filters the table (Type column) to only show Pseudo GUIDs
- **Converted Pseudo GUIDs** Filters the table to only show Pseudo GUIDs that have been converted into valid GUIDs. The valid GUID will be displayed in the "Linked To" column.
- **Unconverted Pseudo GUIDs** Filters the table to only show Pseudo GUIDs that have not been converted to valid GUIDs; there will be no value in the "Linked To" column.
- 5. For users with access to the Multi-Tenant GUID, "matching" or "linked" GUIDs will be identified with an "(i)" icon: NHAG610HYEMT³. This is an indicator that the registered GUID is linked to an existing GUID within the Multi-Tenant GUID server. Clicking the icon will provide additional details including the [Entity], [User], and [Date Registered] that is associated with the linked GUID. Note: No study data and/or dataset information is provided.

ID Tool	My GUIDs The table below displays a list of all GUID:	s that you have registered fr	om the one-way hash	ed PII information as well as P	seudoGUIDs your organizati	on has registered.
ID Overview	Download Mine Only ▼ All	٣				Search: 🗸
eate GUIDs	D	▲ ТҮРЕ	\$ ENTITY	ORGANIZATION REGISTERED BY	♦ USER REGISTERED BY	DATE REGISTERED 🝦 LINKED TO
GUIDs	NIADEMOHR393KVU	GUID	NIA	NIH	Meckley, Jon	2018-02-16
ID Admin	NIADEMOJZ994CH4	GUID	NIA	NIH	Meckley, Jon	2018-02-16
	NIADEMOJZ994CH4	GUID	NIA	NIH	Meckley, Jon	2018-10-01
	NIADEMO INVUK774FC1	PseudoGUID	NIA	NIH	Meckley, Jon	2018-02-16
	NIHAG610HYEMT	GUID	NIA	NIH	Meckley, Jon	2018-12-06
	NIHJE855KLZCA	GUID	NIA	NIH	Meckley, Jon	2018-12-06



6.4.6 Searching if GUID (or Pseudo GUID) Exists

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

 Navigate to the GUID Client. (For instructions navigating to the GUID Client refer to Section 6.4 above). The GUID Client opens. Select Functions to open the drop-down menu.

lome	Workspace	ProFoRMS	GUID	Data Dictionary	Data Repository	Query	Meta Study	Account Manag	ement	
SUID	(Global	Unique lo	lentifi	ər)						
GUID To	ool		otect the priv	racy of study particip Java to be installed o		run locally. By s	selecting the link b	elow, the GUID tool w	vill be download	ded and executed automatically from your computer. The
GUID Ov	verview	Helpful Do	cumenta	tion						
Create 0	GUIDs				ad the GUID User Gu	ide (pdf)				
My GUIE)s	 Need t 	o generate i	multiple GUIDs at on	e time? Download the	GUID Batch Te	emplate (csv)			
		Functions	Abo	ut						
		2. Does the 3. Complet 4. Complet 5. Day of b 6. Month o 7. Year of f 8. Name o 9. Country Optional Fil 10. Physica 11. Governm	e legal give e subject ha e additional e legal fami irth [1-31] f Birth Birth [####] f city/munici of Birth elds il sex of sub ment Issued	n (first) name of the s e a middle name? (middle) name or na y (last) name of subj pality in which subjec ect at birth [M/F] or National ID vernment-Issued or t	mes at birth ect at birth t was born	No	Subject's Informa		V V V V Clear/New	Please Confirm (Re-Enter) the Subject's Information No

2. Select Search if GUID (or Pseudo GUID) exists in the system as shown below.

GOID (Globa	al Unique Identifier)				
GUID Tool	Create GUIDs In order to protect the privacy of study participants, the GUID t		ik below, the GUID tool will be down	loaded and executed automatically from your c	omputer. The GU
GUID Overview	tool requires a version of Java to be installed on your compute				
Create GUIDs	Helpful Documentation Getting started and need help? Download the GUID Us	ar Guida (adf)			
My GUIDs	Need to generate multiple GUIDs at one time? Download				
my conos	Functions About				
	Create GUID Convert PseudoGuid to GUID	Please Enter Subject's Info	rmation (PII)	Please Confirm (Re-Enter) the Subject's I	nformation
	Create Multiple GUIDs (With Close Match Checking)	No	۲	No	
	Create Multiple GUIDs (No Close Match Checking) Generate Pseudo GUID				
	Search if GUID (or PseudoGUID) exists in the system		T		
	8. Name of city/municipality in which subject was born 9. Country of Birth		T		
	Optional Fields 10. Physical sex of subject at birth [M/F]		•		

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3. 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.

GUID Tool	Create GUIDs In order to protect the privacy of study particip	Check if GUID E	vists	
GUID Overview	Helpful Documentation Getting started and need help? Downlo		TBIHJ226FYKXZ	check
Create GUIDs My GUIDs	Need to generate multiple GUIDs at on Functions About	Result:	The GUID TBIHJ226FYKXZ does	n't exist.
	Required Fields 1 Complete legal given (first) name of the s			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	BH
BANGLADESH	BD
BARBADOS	BB
BELARUS	BY
BELGIUM	BE
BELIZE	BZ
BENIN	BJ
BERMUDA	BM
BHUTAN	ВТ
BOLIVIA	во
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	CC
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	CY
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	HT
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	IT
JAMAICA	JM



Country	Country Code
JAPAN	JP
JERSEY	JE
JORDAN	OL
KAZAKHSTAN	KZ
KENYA	KE
KIRIBATI	КІ
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	MO
MACEDONIA, THE FORMER YUGOSLAV REPUBLIC OF	МК
MADAGASCAR	MG
MALAWI	MW
MALAYSIA	MY
MALDIVES	MV
MALI	ML
MALTA	MT
MARSHALL ISLANDS	MH
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	OM
PAKISTAN	РК
PALAU	PW
PALESTINIAN TERRITORY, OCCUPIED	PS
PANAMA	PA
PAPUA NEW GUINEA	PG
PARAGUAY	PY
PERU	PE
PHILIPPINES	PH
PITCAIRN	PN
POLAND	PL
PORTUGAL	PT
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	LT
TANZANIA, UNITED REPUBLIC OF	TZ
THAILAND	TH
TIMOR-LESTE	TL
TOGO	TG
TOKELAU	ТК



Country	Country Code
TONGA	то
TRINIDAD AND TOBAGO	ТТ
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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