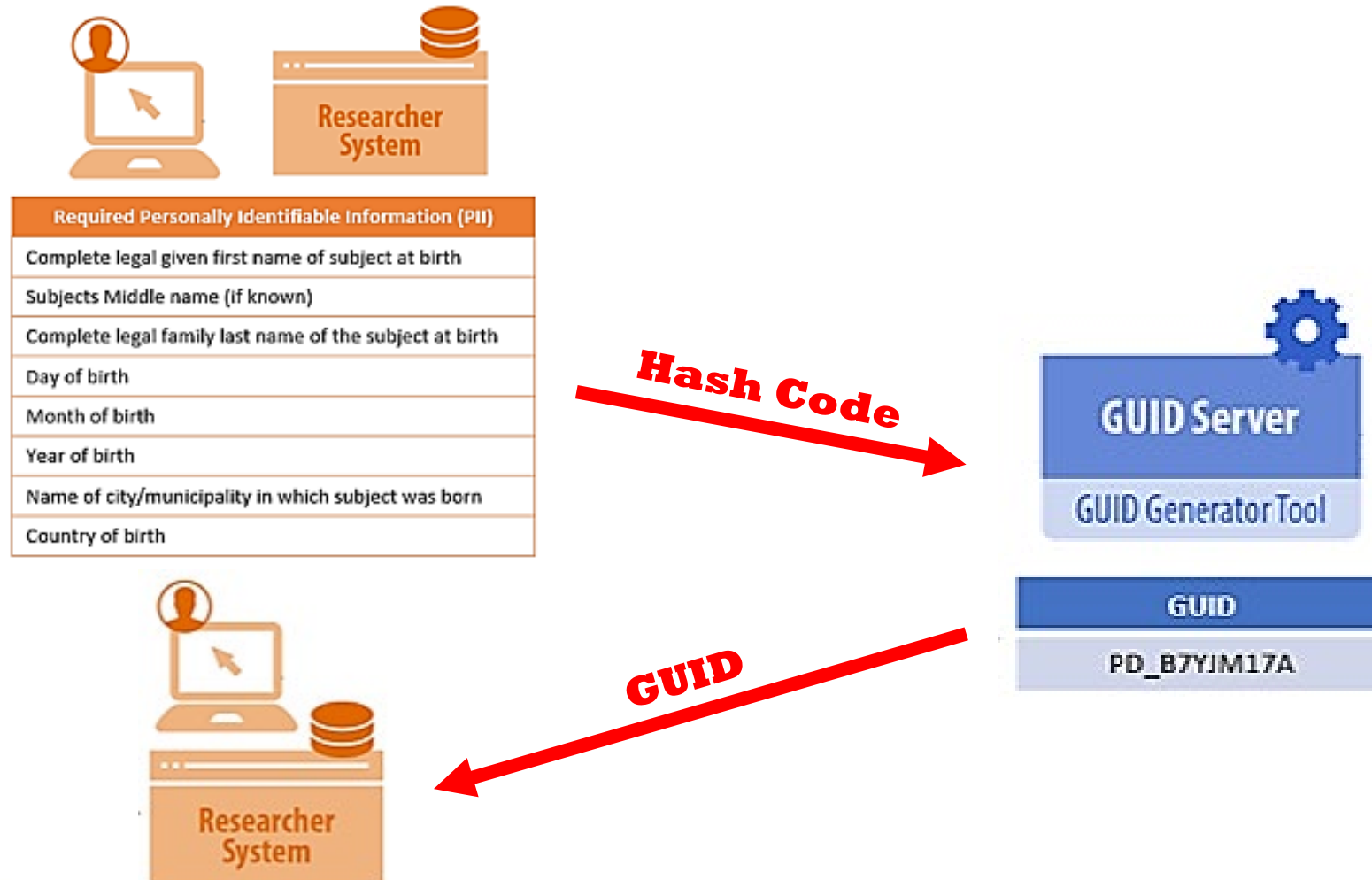


The Role of GUIDs in Data Sharing

(and data security)

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NIH GUID Basics



GUID Users at NIH

- NINDS
 - Parkinson's Disease Biomarker Program (PDPB)
 - Federal Interagency Traumatic Brain Injury Repository (FITBIR)
- NIMH Data Archive (NDA: houses NIMH, NIDA, NIAAA and NIAMS research)
 - Adolescent Brain Cognitive Development Study
 - Human Connectome Projects
- NIA
- NCATS

NIA, NIH and NINDS GUIDs can currently be cross-mapped by hash code

NIH GUIDs: Linking Across Studies

1. A user requests access to multiple data sets.

Can the user link GUIDs between them?

YES—If the data sets use the same GUID server
e.g., any study that uses the NIH GUID server
will generate the same GUID for the
same subject

NO—If the data sets use different GUID servers
e.g., one study uses the NIA GUID server
while the second study uses the NIH
GUID server.

| GUID | TYPE |
|-----------------------|------|
| <u>NIH_876YH45300</u> | GUID |
| <u>NIH_876YH45300</u> | GUID |
| <u>NIA_MQ9U4BH5</u> | GUID |
| <u>NIH_876YH45300</u> | GUID |

NIH GUIDs: Linking Across Studies

2. A user requests access to the GUID server, and enters a GUID. Can the user link GUIDs?

YES—If the user is a registered user for BOTH data repositories.

| GUID | TYPE | REGISTERED ENTITY | SUBJECT MATCH* |
|---------------------|------|-------------------|----------------|
| <u>NIA MQ9U4BH5</u> | GUID | NIA | PD_79N45BYS |

NO— If the user is registered for only ONE repository, they cannot link GUIDs, but will know that the subject exists in multiple repositories

| | | | |
|---------------------|------|------|--|
| <u>NIA MQ9U4BH5</u> | GUID | NIA | |
| <u>XXXXXXXX</u> | GUID | PDBP | |

GUID Benefits & Risks

- Benefits
 - Can maximize information gathered by being able to link individuals across research studies
 - Facilitates tracking subjects and their data over time—longitudinal research
 - Cost and time effective (same data is not gathered twice)
- Risks
 - The more you know, the more you know (re-identification)
 - Security is only as strong as the weakest link (data base security)

Recommendations

- Good Data Security Practices Always!
- Report Misconduct!

https://grants.nih.gov/policy/research_integrity/process.htm