

Requesting Human Subjects Data

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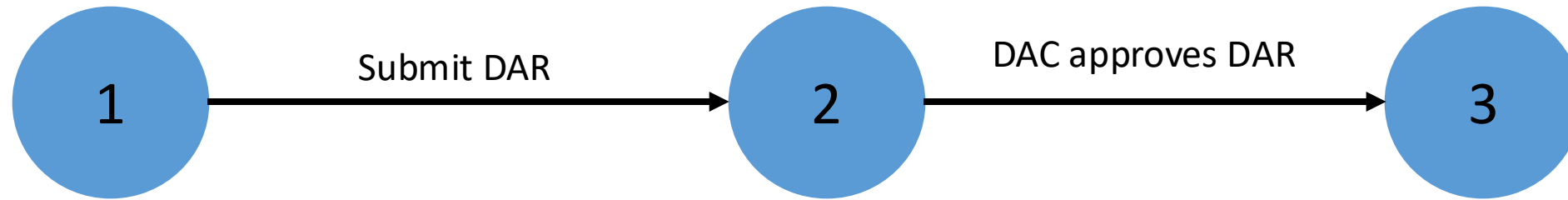
FaceBase Bootcamp (Nov. 5th 2025)

Why request Human-Subject Data from FaceBase?

1. FaceBase has a very large (~50,000 participants), comprehensive and diverse collection of human-subject *controlled access* data
2. Wide-ranging set of syndromes and data modalities
 - Examples:
 - About 4000 facial scans from a Tanzania population (<https://doi.org/10.25550/TX4>)
 - About 1000 facial scans of North American Children (<https://doi.org/10.25550/TK0>)
 - About 100 facial scan of Phelan-McDermid Syndrome (<https://doi.org/10.25550/1A-BWJ8>)
 - RNA-seq, ChIP-seq and ATAC-seq analysis of human fetal tissue (<https://doi.org/10.25550/3C-4G62>)
 - Oral health study of northern Appalachian households (<https://doi.org/10.25550/2Q-M86G>, <https://doi.org/10.25550/4Y-4SK4>)
 - Whole exome sequencing assay of female with Robin sequence, microglossia, microstomia structure of the oropharynx (<https://doi.org/10.25550/1-415T>)
 - Pittsburgh Oral Facial Cleft Studies (<https://doi.org/10.25550/5A-FJBJ>, <https://doi.org/10.25550/56-ES6P>)
3. 3x increase in number of subjects in FaceBase data during 2025
4. Expected to grow even more in 2026 with large-scale comprehensive studies on craniosynostosis, temporal bone database and TMD, with focus on AI readiness
5. Access to this data is free and publicly available but *CONTROLLED*
6. To access this data, users need to submit a Data Access Request (DAR)

Requesting FaceBase Controlled Access Data

(<https://docs.facebase.org/docs/human-data>)



- Gather institutional documentation
- Complete Data Access Request (DAR) form

NIDCR Data Access Committee (DAC) reviews submission

- User downloads data
- Valid for 1 year
- Can renew/revise to extend access

Completing the Data Access Request (DAR) form

(<https://docs.facebook.org/docs/dar>)

1. Complete the Data Use Certificate Agreement (DUC)
 - <https://www.facebook.org/policies/data-use-certification>
 - Requires institutional signatures: Information Technology (IT) Director, Principal Investigator and Institutional Signing Official.
2. Login as FaceBase user (create new account if don't have one)
3. Go to <https://docs.facebook.org/docs/dar> and create new DAR
 1. Complete fields 1 to 14 of the DAR form
 2. If IRB required upload copy of IRB letter and Approved IRB Protocol
 3. Upload DUC document
 4. Save the form
4. Select list of requested datasets
5. Upload public encryption key file

From Submission Request to a New Dataset

1. Request to Submit data
 - <https://www.facebase.org/contributing/submitting/form.html>
2. Once Approved you'll receive email with:
 1. Link to join the authentication group (Globus) to access your new Project page
 2. Request to setup an intro Zoom call with the FaceBase Hub
3. New Project is not *public* by default so you first need to Login
4. Find your new Project
5. Navigate to Datasets and click "+ Add Record"
6. Step-by-step documentation:
 - <https://docs.facebase.org/docs/Data-Submission-Key-Concepts>