Data Dictionary Codebook

CIFASD External Request Review (PID: 11965)

06/12/2024 1:32pm

	Instruments

	#	**Variable / Field Name**	**Field Label** *Field Note*	**Field Attributes (Field Type, Validation, Choices, Calculations, etc.)**
		Instrument: CIFASD Data Access Request Form (cifasd_data_access_request_form) **⮐ Enabled as survey**		
	1	[request_no]	Request No	text
	2	[date_entered]	Date of Initial Request	text (date_mdy), Required Custom alignment: RH Field Annotation: @NOW @READONLY
	3	[responsible_yn]	Are you the person who is authorized to act as the Qualified Investigator on behalf of your institution? For example, if you are a graduate student, you should select "No."	yesno, Required 1 Yes 0 No
	4	[rep_name] Show the field ONLY if: [responsible_yn]='0'	Name: *This should be the name of the person who is authorized to act for the Qualified Investigator on behalf of his/her institution*	text, Required, Identifier Custom alignment: RH
	5	[rep_title] Show the field ONLY if: [responsible_yn]='0'	Position/Title: *This should be the position of the person who is authorized to act for the Qualified Investigator on behalf of his/her institution, for example, "VP for Research Administration"*	text, Required Custom alignment: RH
	6	[rep_institution] Show the field ONLY if: [responsible_yn]='0'	Institution/Organization or Affiliation: *The institution of the qualified investigator and authorized representative*	text, Required Custom alignment: RH
	7	[rep_phone] Show the field ONLY if: [responsible_yn]='0'	Phone No: *This should be the telephone of the person who is authorized to act for the Qualified Investigator on behalf of his/her institution.*	text, Required, Identifier Custom alignment: RH
	8	[rep_email] Show the field ONLY if: [responsible_yn]='0'	Email Address: *This should be the email of the person who is authorized to act for the Qualified Investigator on behalf of his/her institution*	text (email), Required, Identifier Custom alignment: RH
	9	[bar2]	Completed: | 5%	descriptive

10	[rep_qi] Show the field ONLY if: [responsible_yn]='1'	Section Header: *Qualified Investigator (QI)* Name: *This should be the name of the person responsible for the research and data.*	text, Required, Identifier Custom alignment: RH
11	[qi_title] Show the field ONLY if: [responsible_yn]='1'	Position/Title:	text, Required Custom alignment: RH
12	[cv_upload] Show the field ONLY if: [responsible_yn]='1'	Please upload your Biosketch or CV	file, Required, Identifier
13	[qi_institution] Show the field ONLY if: [responsible_yn]='1'	Institution/Organization or Affiliation:	text, Required Custom alignment: RH
14	[qi_address] Show the field ONLY if: [responsible_yn]='1'	Mailing Address:	text, Required, Identifier Custom alignment: RH
15	[qi_phone] Show the field ONLY if: [responsible_yn]='1'	Phone No:	text, Required, Identifier Custom alignment: RH
16	[qi_email] Show the field ONLY if: [responsible_yn]='1'	Email Address:	text (email), Required, Identifier Custom alignment: RH
17	[bar3]	Completed: | 10%	descriptive
18	[research_title]	Section Header: *Research Project Description* Title of QI's Research Project:	notes, Required Custom alignment: RH
19	[funding]	Relevant Funding (if applicable): *List grant number and sponsoring agency for each funding source.*	text Custom alignment: RH Field Annotation: @HIDDEN-SURVEY
20	[other_access] Show the field ONLY if: [date_entered] <> ''	Other IRB-approved Individuals who will Access the Data: *List name, institution and email address for each individual or n/a if not applicable.*	notes, Identifier Custom alignment: LH Field Annotation: @HIDDEN-SURVEY
21	[collaborators]	List all Collaborators Involved in the Project (Name and Role), if applicable. *Describe any planned data sharing among these collaborators. Please note that collaborators from other institutions who wish to have access to CIFASD*	notes Custom alignment: LH

		data are required to submit their own DAR to the CIFASD DAC.	
22	[bar4]	Completed: | 20%	descriptive
23	[irb_approval_yn]	Does the QI have current IRB or appropriate Ethics approval for this research project? *Projects must have IRB or Ethics approval for the project to be reviewed by the DAC.*	yesno, Required 1 | Yes 0 | No Custom alignment: LH
24	[approval_upload] Show the field ONLY if: [irb_approval_yn] = '1'	Please upload documentation of approval.	file
25	[bar8]	Completed: | 40%	descriptive
26	[irb_no] Show the field ONLY if: [date_entered] <> ''	IRB Protocol No:	text, Identifier Custom alignment: RH Field Annotation: @HIDDEN-SURVEY
27	[irb_start] Show the field ONLY if: [date_entered] <> ''	Start Date of Approval: *YYYY-MM-DD format*	text (date_mdy) Custom alignment: RH Field Annotation: @HIDDEN-SURVEY
28	[irb_end] Show the field ONLY if: [date_entered] <> ''	End Date of Approval: *YYYY-MM-DD format*	text (date_mdy) Custom alignment: RH Field Annotation: @HIDDEN-SURVEY
29	[fwa] Show the field ONLY if: [date_entered] <> ''	Federal Wide Assurance Number (FWA#): *Federal Wide Assurance Number (FWA#) for the Institution Overseeing the IRB that Granted Approval for this Project*	text Custom alignment: RH Field Annotation: @HIDDEN-SURVEY
30	[request_birth_data]	Section Header: *I am requesting access to the following CIFASD Research Data:* Birth-related data	yesno, Required 1 | Yes 0 | No Custom alignment: RH
31	[request_birth_data_phases] Show the field ONLY if: [request_birth_data] = '1'	Birth-related data	checkbox, Required 2 | request_birth_data_phases___2 | Phase 2 3 | request_birth_data_phases___3 | Phase 3 Custom alignment: LV
32	[request_dysmo]	Dysmorphology	yesno, Required

			1 Yes	
			0 No	

Custom alignment: RH

33	[`request_dysmo_phases`] Show the field ONLY if: [request_dysmo] = '1'	Dysmorphology	checkbox, Required

1	request_dysmo_phases___1	Phase 1
2	request_dysmo_phases___2	Phase 2
3	request_dysmo_phases___3	Phase 3

Custom alignment: LV

34	[`request_neuro`]	Neurobehavior	yesno, Required

1	Yes
0	No

Custom alignment: RH

35	[`request_neuro_phases`] Show the field ONLY if: [request_neuro] = '1'	Neurobehavior	checkbox, Required

1	request_neuro_phases___1	Phase 1
2	request_neuro_phases___2	Phase 2
3	request_neuro_phases___3	Phase 3
4	request_neuro_phases___4	Phase 4

Custom alignment: LV
Field Annotation: @HIDECHOICE='1'

36	[`request_brain`]	MRI	yesno, Required

1	Yes
0	No

Custom alignment: RH

37	[`request_brain_phases`] Show the field ONLY if: [request_brain] = '1'	MRI	checkbox, Required

1	request_brain_phases___1	Phase 1
2	request_brain_phases___2	Phase 2
3	request_brain_phases___3	Phase 3

Custom alignment: LV

			Field Annotation: @HIDECHOICE='1'
38	[request_face]	3D Facial Imaging	yesno, Required 1 Yes 0 No Custom alignment: RH
39	[request_face_phases] Show the field ONLY if: [request_face] = '1'	3D Facial Imaging	checkbox, Required 1 request_face_phases___1 Phase 1 2 request_face_phases___2 Phase 2 3 request_face_phases___3 Phase 3 Custom alignment: LV
40	[request_genetics]	Genetic Data	yesno, Required 1 Yes 0 No Custom alignment: RH
41	[request_genetics_type] Show the field ONLY if: [request_genetics] = '1'	Genetic Data:	checkbox, Required 1 request_genetics_type___1 PLINK files for GWAS Data 2 request_genetics_type___2 VCF files for WES Data Custom alignment: LV
42	[request_usa] Show the field ONLY if: [date_entered] <> ''	Phase 1 - All Data from the USA	yesno 1 Yes 0 No Custom alignment: RH Field Annotation: @HIDDEN
43	[request_ukraine_russia] Show the field ONLY if: [date_entered] <> ''	Phase 1 - Ukraine Prospective Data	yesno 1 Yes 0 No Custom alignment: RH
44	[request_ukraine_phases]	3D Facial Imaging	checkbox, Required 2 request_ukraine_phases___2 Phase 2

					3	request_ukraine_phases___3	Phase 3

	Show the field ONLY if: [request_ukraine_russia] = '1'				4	request_ukraine_phases___4	Phase 4
					Custom alignment: LV		

45	[research_strategy_download]	Describe the Project's Research Strategy (4 page limit; for details see Appendix 1.)	descriptive (Attachment: Appendix 1.docx, Display format: Link), Required
46	[project_aims] Show the field ONLY if: [date_entered] <> ''	Describe the Proposed Research Project, its Goals/Specific Aims, and why CIFASD Data are Necessary. *Roughly 500 words.*	notes Custom alignment: LH Field Annotation: @HIDDEN-SURVEY
47	[project_analysis]	Upload your Research Strategy Form here.	file, Required Custom alignment: LV
48	[elements_desc] Show the field ONLY if: [date_entered] <> ''	List the data elements you propose to collect. We encourage consultation with CIFASD investigators. *For more information on data elements see cifasd.org/data-sharing*	notes Custom alignment: LH Field Annotation: @HIDDEN-SURVEY
49	[project_start] Show the field ONLY if: [date_entered] <> ''	Proposed Start Date of CIFASD Data Use: *YYYY-MM-DD format*	text (date_mdy) Custom alignment: RH Field Annotation: @HIDDEN-SURVEY
50	[project_end] Show the field ONLY if: [date_entered] <> ''	Proposed End Date of CIFASD Data Use: *YYYY-MM-DD format*	text (date_mdy) Custom alignment: RH Field Annotation: @HIDDEN-SURVEY
51	[data_protection] Show the field ONLY if: [date_entered] <> ''	Explain how the Data will be Managed and Protected as Part of this Research. *Roughly 200 words*	notes Custom alignment: LH Field Annotation: @HIDDEN-SURVEY
52	[it_director] Show the field ONLY if: [date_entered] <> ''	Name and Email of IT Director	notes, Identifier Custom alignment: RH Field Annotation: @HIDDEN-SURVEY
53	[data_disposal] Show the field ONLY if: [date_entered] <> ''	Explain how the Data will be Disposed of Following your Research. *Roughly 200 words*	notes Custom alignment: LH Field Annotation: @HIDDEN-SURVEY
54	[add_docs]	Upload any additional documents relevant to your request *Please use a zip file format if uploading several files*	file
55	[letter_of_support]	Letter of Support Please note that CIFASD does not issue	yesno, Required 1 Yes

		funding. If the QI has yet to obtain funding for this study, the DAC will issue a letter to the applicant documenting provisional access to the data. This letter could be used to support a funding application. If you require a letter of support, please provide a grant title and the date for the grant submission. Letters of support will be sent within two weeks of the review date associated with the submission window. Will you require a letter of support?	0 No Custom alignment: LV
56	[bar5]	Completed: | 60%	descriptive
57	[name_sign]	Section Header: *Signature* As Qualified Investigator, sign your name here to confirm you have read and will abide by the posted CIFASD Data Use Agreement and that you have emailed that signed agreement to dac@cifasd.org. This request cannot be reviewed without receipt of that signed agreement. *Your signature as evidence of your submission. Draw signature with mouse or finger.*	file (signature), Required Custom alignment: RH
58	[signature]	Section Header: *Use of CIFASD Research Data will be cited as follows, "Data obtained from the Collaborative Initiative on Fetal Alcohol Spectrum Disorders (CIFASD, www.cifasd.org), which receives government support awarded by the National Institute on Alcohol Abuse and Alcoholism (NIAAA), were used in this study."* Enter your signature here to confirm that you, and all who use CIFASD data as part of this research, agree to appropriately cite CIFASD and CIFASD projects in resulting publications. *Draw signature with mouse or finger*	file (signature), Required, Identifier Custom alignment: RH
59	[sponsor_list]	If a CIFASD Investigator Sponsors this Proposal, List them here:	notes Custom alignment: LV
60	[bar6]	Completed: | 80%	descriptive
61	[review_answers]	Section Header: *Review answers* Review your answers below: Name of Qualified Investigator: [rep_qi] Qualified Investigator email: [qi_email] I am requesting access to the following CIFASD Research Data: Dysmorphology: [request_dysmo] Dysmorphology Phase 1: [request_dysmo_phases(1)]	descriptive

		Dysmorphology Phase 2: [request_dysmo_phases(2)] Dysmorphology Phase 3: [request_dysmo_phases(3)] Neurobehavior: [request_neuro] Neurobehavior Phase 1: [request_neuro_phases(1)] Neurobehavior Phase 2: [request_neuro_phases(2)] Neurobehavior Phase 3: [request_neuro_phases(3)] MRI: [request_brain] MRI Phase 1: [request_brain_phases(1)] MRI Phase 2: [request_brain_phases(2)] MRI Phase 3: [request_brain_phases(3)] 3D Facial Imaging : [request_face] 3D Facial Imaging Phase 2: [request_face_phases(2)] 3D Facial Imaging Phase 3: [request_face_phases(3)] Genetic Data: [request_genetics] Genetic Data Phase 1: [request_genetics_type(1)] Genetic Data Phase 2: [request_genetics_type(2)] If all your responses look correct and you did not leave any blank, then click the Submit button below.	
62	[bar7]	Completed: | 100%	descriptive
63	[test_entry]	Test/blank entry?	yesno 1 Yes 0 No
64	[cifasd_data_access_request_form_complete]	Section Header: *Form Status* Complete?	dropdown 0 Incomplete 1 Unverified 2 Complete
Instrument: CIFASD Data Access Request Review (cifasd_data_access_request_review)			
65	[institutional_review_fwa]	Section Header: *Proposal title: [research_title] PI: [rep_name]Institutional Review.* There is an Active Federal Wide Assurance number (FWA): [fwa]	truefalse, Required 1 True 0 False

			Custom alignment: RH
66	[signing_official]	There is an appropriate Institutional Signing Official *Representative: [rep_name]*	truefalse, Required 1 | True 0 | False Custom alignment: RH
67	[pi_qualified]	The proposing PI is qualified	truefalse, Required 1 | True 0 | False Custom alignment: RH
68	[institution_qualified]	The Institution is qualified as a research institution *QI Institution: [qi_institution]*	truefalse, Required 1 | True 0 | False Custom alignment: RH
69	[request_each]	There is a Data Access Request from EACH institution for this proposal *List of Collaborators: [collaborators]*	truefalse, Required 1 | True 0 | False Custom alignment: RH
70	[pi_signed]	Section Header: *Data Use Agreement review.* The Data Use Agreement has been signed by the PI.	truefalse, Required 1 | True 0 | False Custom alignment: RH
71	[sa_signed]	The Data Use Agreement has been signed by the Signing Official	truefalse, Required 1 | True 0 | False Custom alignment: RH
72	[it_director_included]	The Data Use Agreement includes name and email of the IT Director	truefalse, Required 1 | True 0 | False Custom alignment: RH
73	[assertions_made]	Appropriate use and security assertions have been made *[data_protection]*	truefalse, Required 1 | True 0 | False Custom alignment: RH

74	[request_complete]	Section Header: *Data Access Request review.* The Data Access Request is complete	truefalse, Required 1 | True 0 | False Custom alignment: RH
75	[request_signed]	The Data Access Request has been signed by the Qualified Investigator	truefalse, Required 1 | True 0 | False Custom alignment: RH
76	[data_available]	CIFASD can respond to The Data Access Request with data it has.	truefalse, Required 1 | True 0 | False Custom alignment: RH
77	[irb_review]	IRB Review	radio, Required 0 | The requesting Institution has provided a statement that IRB is not required. 1 | IRB Approval is provided: IRB Approval No.: [irb_no] , IRB Approval expires on [irb_end] Custom alignment: LV
78	[reviewed_by]	Reviewed by:	radio, Required 1 | William K. Barnett, Director, Informatics Core 2 | Helen Yezerets, Data Manager, Informatics Core Custom alignment: LV
79	[date_reviewed]	Date Request Reviewed:	text (date_ymd), Required Custom alignment: LV
80	[cifasd_data_access_request_review_complete]	Section Header: *Form Status* Complete?	dropdown 0 | Incomplete 1 | Unverified 2 | Complete

Instrument: CIFASD Data Access Decision (cifasd_data_access_decision)

81	[info_request]	Requested Additional Information from [rep_name]	radio, Required 1 | Yes 0 | No

82	[date_add_info] Show the field ONLY if: [info_request] = '1'	Date of Additional Information Request *YYYY-MM-DD format*	text (date_ymd), Required Custom alignment: LV
83	[responded_info] Show the field ONLY if: [info_request] = '1'	Requestor Responded with Required Information	radio | 1	Yes
0	No	
84	[comm_file]	Communication with Requestors *please create a file with your emails to requestors*	file
85	[decision_type_fin]	Data Access Committee (DAC) final decision	radio, Required | 0	Disapproved
1	Approved to receive data
2	Approved to receive LOS
9998	Withdrawn
9999	Requestor Failed to Follow-up	
86	[disapprove_reason] Show the field ONLY if: [decision_type_fin] = '0'	Reason for Disapproval	text Custom alignment: LV
87	[date_emailed_fin]	Date of Final Email to Requestor *YYYY-MM-DD format*	text (date_ymd) Custom alignment: LV
88	[annual_update_start_date]	If approved to receive data, please indicate the date that the researcher should receive the first email asking for an annual update:Please enter 01-15-XXXX where XXXX is the year following the year the researcher was approved to receive data.Example, if a researcher was approved to receive data on 4/17/2025, then you should enter 01-15-2026 into this field.	text (date_mdy) Field Annotation: @HIDEBUTTON
89	[cifasd_data_access_decision_complete]	Section Header: *Form Status* Complete?	dropdown | 0	Incomplete
1	Unverified
2	Complete	

Instrument: **CIFASD Access Current Status** (cifasd_access_current_status)

90	[status_header]	CIFASD Data Access - Current Status After each 1 year update, please update the responses to the fields below.	descriptive
91	[project_overview]	General Request Information: [research_title] Name of Qualified	descriptive

			Investigator: [rep_qi], [rep_name]Qualified Investigator Email: [qi_email], [rep_email], [rep_email_internal] Institution: [qui_institution], [rep_institution] DAC Final Decision: [decision_type_fin] Date of Final Email to Requestor: [date_email_fin] Annual Update Start Date: [annual_update_start_date]	
	92	[rep_email_internal]	Responsible Party EmailThis is the email that will receive automated emails to complete the "Yearly Data Access Update" Survey. *if the project has ever been transferred, ensure this email field is updated*	text (email)
	93	[current_status]	Based on the responses to the most recent "Yearly Data Access Update" survey, what is the current status of the project?	radio 0 Continuation 1 Close 2 Transfer 3 Non compliant - access to data terminated
	94	[cifasd_access_current_status_complete]	Section Header: *Form Status* Complete?	dropdown 0 Incomplete 1 Unverified 2 Complete

Instrument: CIFASD External Request Yearly Update (cifasd_external_request_yearly_update)

Enabled as survey

	95	[current_date]	Today's date	text (date_mdy), Required Field Annotation: @HIDDEN-SURVEY @TODAY @READONLY
	96	[current_year]	Current year	calc, Required Calculation: right([current_date], 4) Field Annotation: @HIDDEN-SURVEY @READONLY
	97	[collaborator_name]	Name of collaborator	text, Required
	98	[project_title]	Project Title	notes, Required
	99	[data_use_upload]	Please upload a document with a brief description of CIFASD data use in past year	file, Required
	100	[manuscripts_yn]	Are there any manuscripts that we can report?	yesno, Required 1 Yes 0 No
	101	[manuscript_references]	Please provide references to the manuscripts that we can report in APA format.	notes, Required

		Show the field ONLY if: [manuscripts_yn]='1'		
102	[presentations_yn]	Are there any presentations that we can report?	yesno, Required 1 Yes 0 No
103	[presenation_references] Show the field ONLY if: [presentations_yn]='1'	Please provide references to the presentations that we can report in APA format.	notes, Required
104	[patents_yn]	Are there any patents that we can report?	yesno, Required 1 Yes 0 No
105	[patent_references] Show the field ONLY if: [patents_yn]='1'	Please provide references to the patents that we can report.	notes, Required
106	[other_references]	Please provide anything else we can report as a result of CIFASD data use.(Reference in APA format)	notes
107	[departures_yn]	Were there any departures from the original research plan? (includes previous, current, or proposed departures)	yesno, Required 1 Yes 0 No
108	[departures_notes]	Describe the departure(s) from the original research plan:(includes previous, current, or proposed departures)	notes, Required
109	[next_year_status] Show the field ONLY if: [next_year_status]='0'	Please select the correct status for your project for the coming year:	radio, Required 0 Continuation 1 Close 2 Transfer
110	[security_changes_yn]	Were there any changes to data security measures?	yesno, Required 1 Yes 0 No
111	[security_changes_notes] Show the field ONLY if: [security_changes_yn]='1'	Describe changes to data security measures:	notes, Required
112	[transfer_upload]	Provide documentation that Approved User is using the data under an active	file, Required

	Show the field ONLY if: [next_year_status]='2'	CIFASD Data Access Committee approved research project:	
113	[transfer_security_yn] Show the field ONLY if: [next_year_status]='2'	Will there be any changes to data security measures resulting from part of the transfer:	yesno, Required 1 Yes 0 No
114	[transfer_security_notes] Show the field ONLY if: [transfer_security_yn]='1'	Describe any changes to data security measures that will result as part of the transfer:	notes, Required
115	[collaborator_changes_yn] Show the field ONLY if: [next_year_status]='0' or [next_year_status]='2'	Will there be any changes to collaborators who have access to data?	yesno, Required 1 Yes 0 No
116	[collaborator_changes_notes] Show the field ONLY if: [collaborator_changes_yn]='1'	Describe changes to collaborators who have access to data:	notes, Required
117	[irb_review_upload] Show the field ONLY if: [next_year_status]='0' or [next_year_status]='2'	Provide evidence of review of renewal request by your institutional IRB (if applicable):	file
118	[destroy_attestation] Show the field ONLY if: [next_year_status]='1'	By signing below, I attest to destroy all copies of the data, except as required by publication practices or law to retain them.	file (signature), Required
119	[misc_info]	Miscellaneous Information	notes Custom alignment: LV
120	[misc_upload]	Please upload any additional information that needs to be reported	file Custom alignment: LV
121	[cifasd_external_request_yearly_update_complete]	Section Header: *Form Status* Complete?	dropdown 0 Incomplete 1 Unverified

				2	Complete