

Variable / Form Name	Section Header	Field Type	Field Label	Choices, Categories	Field Note	Text Valid	Text Valid
record_id	survey_1	text	Record ID				
survey_date	survey_1	text	Date survey completed			date_mdy	
age	survey_1	text	My current age is...				
anxiety	survey_1	text	I have been diagnosed with Anxiety				
aortic_dissection	survey_1	text	I have been diagnosed with Aortic Dissection				
aortic_enlargement	survey_1	text	I have been diagnosed with Aortic enlargement				
arthritis	survey_1	text	I have been diagnosed with Arthritis				
asian	survey_1	text	I am Asian				
attention_deficit_disorder	survey_1	text	I have been diagnosed with Attention Deficit Disorder (with or without hyperactivity)				
autism_spectrum_disorder	survey_1	text	I have been diagnosed with Autism Spectrum Disorder				
bisexual	survey_1	text	My sexual orientation is bisexual				
black	survey_1	text	I am Black or African American				
bondy_research_registry	survey_1	text	I have previously participated in the bondy research registry				
cheek_swab	survey_1	text	In addition to blood testing, I have had a cheek swab				
chromosomal_makeup	survey_1	text	My genetic/chromosomal makeup is...				
chronic_ear_infections	survey_1	text	I have been diagnosed with Chronic ear infections				
chronic_kidney_disease	survey_1	text	I have been diagnosed with Chronic kidney disease				
coronary_artery_disease	survey_1	text	I have been diagnosed with Coronary artery disease				
craniofacial_or_dental_abnormality	survey_1	text	I have been diagnosed with Craniofacial or dental abnormality				
curvature_of_the_spine_scoliosis	survey_1	text	I have been diagnosed with Curvature of the spine (Scoliosis)				
depression	survey_1	text	I have been diagnosed with Depression				
developmental_coordination_disorder	survey_1	text	I have been diagnosed with Developmental Coordination Disorder				
diabetes	survey_1	text	I have been diagnosed with Diabetes				
diagnosis_age_turner_syndrome	survey_1	text	I was ____ years old when I was diagnosed with Turner syndrome				
ear_abnormality	survey_1	text	I have been diagnosed with Ear abnormality				
estrogen_replacement_therapy_start_age	survey_1	text	I was ____ years old when I started estrogen replacement therapy				
estrogen_replacement_therapy_currently_receiving	survey_1	text	I am currently receiving estrogen replacement therapy				
estrogen_replacement_therapy_treated	survey_1	text	I have been treated with estrogen replacement therapy (I was never treated)				
gastrointestinal_stomach_issues	survey_1	text	I have been diagnosed with Gastrointestinal (stomach) issues				
gay	survey_1	text	My sexual orientation is gay or lesbian				
gender	survey_1	text	My self-identified gender is...				
gentac_research_registry	survey_1	text	I have previously participated in the GenTAC research registry				
gh_treat	survey_1	text	I have been treated with growth hormone therapy				
give_sample	survey_1	text	I am interested in giving a blood sample that would be used for research				
glucose_intolerance	survey_1	text	I have been diagnosed with Glucose intolerance				
hearing_impairment	survey_1	text	I have been diagnosed with Hearing impairment				
heart_abnormality	survey_1	text	I have been diagnosed with Heart abnormality				
height	survey_1	text	My current height is approximately...				
high_blood_pressure	survey_1	text	I have been diagnosed with High blood pressure				
high_cholesterol	survey_1	text	I have been diagnosed with High cholesterol				
indian	survey_1	text	I am Native American or an Alaskan Native				
informed_general_ts_care_knowledge	survey_1	text	My doctor that oversees my general TS care is knowledgeable				
informed_about_managing_turner_syndrome	survey_1	text	I feel informed about managing Turner syndrome.				
informed_about_managing_my_daughter	survey_1	text	As a parent, I feel informed about managing my daughter				
intellectual_disability_mental_retardation	survey_1	text	I have been diagnosed with Intellectual Disability (Mental Retardation)				
interested_in_research_in_general	survey_1	text	I am interested in taking part in research in general...				

karyotype_survey_1	text	According to my karyotype, I am...
kidney_abr_survey_1	text	I have been diagnosed with Kidney abnormality
latino_survey_1	text	I am Hispanic or Latino
learning_di_survey_1	text	I have been diagnosed with Learning Disorder (such as Nc
liver_disea:survey_1	text	I have been diagnosed with Liver disease
low_bone_survey_1	text	I have been diagnosed with Low bone mineral density
lympheden_survey_1	text	I have been diagnosed with Lymphedema
none_of_th:survey_1	text	I have been diagnosed with None of the above conditions
osteoporos_survey_1	text	I have been diagnosed with Osteoporosis
other_rese_survey_1	text	Aside from this survey, I have taken part in research proje
ovarian_fai_survey_1	text	I have been diagnosed with Ovarian failure (requires estr
pacific_survey_1	text	I am Native Hawaiian or Other Pacific Islander
parent_for_survey_1	text	Are you a parent completing registry data on behalf of yo
preferred_survey_1	text	My preferred method of contact is email
preferred_survey_1	text	My preferred method of contact is phone call
preferred_survey_1	text	My preferred method of contact is postal mail
preferred_survey_1	text	My preferred method of contact is text message
pregnancy_survey_1	text	I have been diagnosed with Pregnancy
satisfied_survey_1	text	I am satisfied with the care I am receiving from the docto
seizures_survey_1	text	I have been diagnosed with Seizures
short_statu_survey_1	text	I have been diagnosed with Short stature or Growth failur
skin_chrom_survey_1	text	In addition to blood testing, I have had skin chromosome
social_com_survey_1	text	I have been diagnosed with Social-Communicative Disord
straight_survey_1	text	My sexual orientation is straight
stroke_survey_1	text	I have been diagnosed with Stroke
thyroid_dis_survey_1	text	I have been diagnosed with Thyroid disease
update_me_survey_1	text	If it was quick and easy to do, I would be willing to update
update_prc_survey_1	text	If I could control who saw the information, I would be wil
visual_imp:survey_1	text	I have been diagnosed with Visual impairment
vitamin_d_survey_1	text	I have been diagnosed with Vitamin D deficiency
weight_survey_1	text	My current weight is approximately...
white_survey_1	text	I am White
completer_survey_2	radio	Please sele 1, I am an adult with Turner syndrome   2, I a
cardiovasc:survey_2	checkbox	I have beer 1, Bicuspid aortic valve   2, Coarctation or nar
skeletal_survey_2	checkbox	I have beer 1, Low bone mineral density or osteoporosis c
digestive_survey_2	checkbox	I have beer 1, Gluten sensitivity or Celiac disease   2, Infla
skin_survey_2	checkbox	I have beer 1, Swelling of my hands or feet or lymphedem
endocrine_survey_2	checkbox	I have beer 1, Thyroid disease or thyroiditis or hypothyroi
growth_ho_survey_2	radio	I have beer 1, Yes, for less than 10 years   2, Yes, for more
estrogen_survey_2	radio	I have beer 1, Yes, for less than 10 years   2, Yes, for more
pregnant_survey_2	radio	I have beer 1, Yes, spontaneously (without medical assista
physical_he:survey_2	radio	I have beer 1, Kidney condition: horseshoe shape or dupli
ear_health_survey_2	radio	I have beer 1, Hearing loss   2, Frequent ear infections or
mental_he:survey_2	radio	I have beer 1, Anxiety disorder   2, Depressive disorder
mental_de:survey_2	radio	I have beer 1, Intellectual disability   2, Autism spectrum
learning_cc_survey_2	radio	I have beer 1, Difficulties with understanding numbers an
diagnosis_:survey_2	radio	I was diagn 1, Before birth   2, Less than 1 year   3, 1-5

karyotype2	survey_2	radio	According to 1, Mosaic, or more than one type of cell   2, N
physical_fu	survey_2	radio	I am able to 1, Without any difficulty   2, With a little diffic
fatigue	survey_2	radio	I feel fatigu 1, Not at all   2, A little bit   3, Somewhat   4,
race2	survey_2	checkbox	My race or 1, American Indian or Alaskan Native   2, Asia
asian2	survey_2	checkbox	More speci 1, Asian Indian   2, Chinese   3, Filipino   4, Ja
hispanic	survey_2	checkbox	More speci 1, Mexican   2, Puerto Rican   3, Cuban   4, C
pacific2	survey_2	checkbox	More speci 1, Native Hawaiian   2, Guamanian   3, Cham
other_back	survey_2	text	More specifically, my "Other" background is:
height2	survey_2	text	My current height is:
height_me:	survey_2	radio	Height me: 1, Feet and inches   2, Meters and centimeter
weight2	survey_2	text	My current weight is: integer 1
weight_me	survey_2	radio	Weight me 1, Pounds   2, Kilograms
heardfrom	survey_2	text	I heard about the Turner Syndrome Research Registry fro
ts_clinic	survey_2	yesno	In the last two years, have you received medical care at a
which_clini	survey_2	notes	Where was the clinic and/or which doctor did you see?
email	global_unique_identifi	text	Email email
guid	global_unique_identifi	text	Global Unique Identifier (GUID):

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or osteopenia or fragile bones   2, i	y
mmatary bowel disease or Chroh	y
ia   2, Dry skin or flaky skin or scaly	y
dism or hyperthyroidism   2, Diab	y
≥ than 10 years   3, No   4, Not sur	y
≥ than 10 years   3, No   4, Not sur	y
ance)   2, Yes, with assisted reprody	y
cated kidney or absent kidney or multicy	y
stic kidney or ectopic kidney   2, Lung condition: asthma or chr	y
otitis media   3, Deafness   4, Cole	y
3, Personality disorder   4, Sleep/v	y
disorder   3, Global developmenta	y
d learning math facts   2, Difficulti	y
4, 6-10   5, 11-15   6, 16 or older   y	y

Non-mosaic | 3, Not sure/Don't know | y  
Cult | 3, With some difficulty | 4, \ | y  
Quite a bit | 5, Very much | y  
n | 3, Black or African American | 4 | y  
panese | 5, Korean | 6, [race2(2)] = y  
Central American | 5, So [race2(4)] = y  
orro | 4, Samoan | 5, Fi [race2(5)] = y  
[race2(8)] = y  
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clinic that is specialized for people | y  
[ts\_clinic] = y  
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onic bronchitis or emphysema | 3, Tumors or cancer | 4, Another physical health condition | 5, I have n







ever been diagnosed with any condition listed | 7, Don't remember/don't know