

Supplementary Information

Table 1: Average number of months and entries from ARC participants by data type.

Data Type	Participants Included	Duration of data entries (months)			Total number of data entries		
	<i>Count</i>	<i>Average</i>	<i>Stdev</i>	<i>Median</i>	<i>Average</i>	<i>Stdev</i>	<i>Median</i>
ALSFRS-R	1463	18.5	25.3	9.2	16.5	23.6	8
Voice	938	19.1	24.1	11.2	16.6	21.3	9
Accelerometer	534	20.3	25.9	11.4	16.6	20.6	9
Blood	329	11.8	13.9	8.0	3.7	2.9	3

Table 2: Banked fibroblast and iPS cells from ARC Study participants

C9orf72 Status	iPSCs Available	Age At Collection	Onset Age	Family with Als	Sex	Als Frs Slope per Month
2/10	Yes	56	53	false	male	-0.478144922
8/10	Yes	31	29	false	male	-0.303132335
2/2	Yes	28	19	false	male	-0.081597802
2/2	Yes	55	52	false	female	-0.380300869
2/18	Yes	54	53	false	male	-1.003614556
2/8	Yes	72	68	false	female	-0.728787714
2/8	Yes	59	57	false	male	-0.741822252
2/2	Yes	39	38	true	female	-0.40849394
2/5	Yes	38	36	false	male	-0.492178848
5/Expanded	Yes	51	50	false	male	-1.04124962
2/8	Yes	31	28	false	male	-0.649553727
6/9	Yes	50	49	false	male	-1.691330896
2/2	Yes	30	28	false	male	-0.337935701
6/6	Yes	59	59	false	male	-0.50439328
2/8	Yes	27		true	male	-0.001130429
2/6	Yes	54	52	false	male	-0.127114221
2/2	Yes	63	59	false	female	-0.287790769
2/6	Yes	50	44	true	female	-0.060067063
2/2	Yes	42	42	false	male	-0.438198809

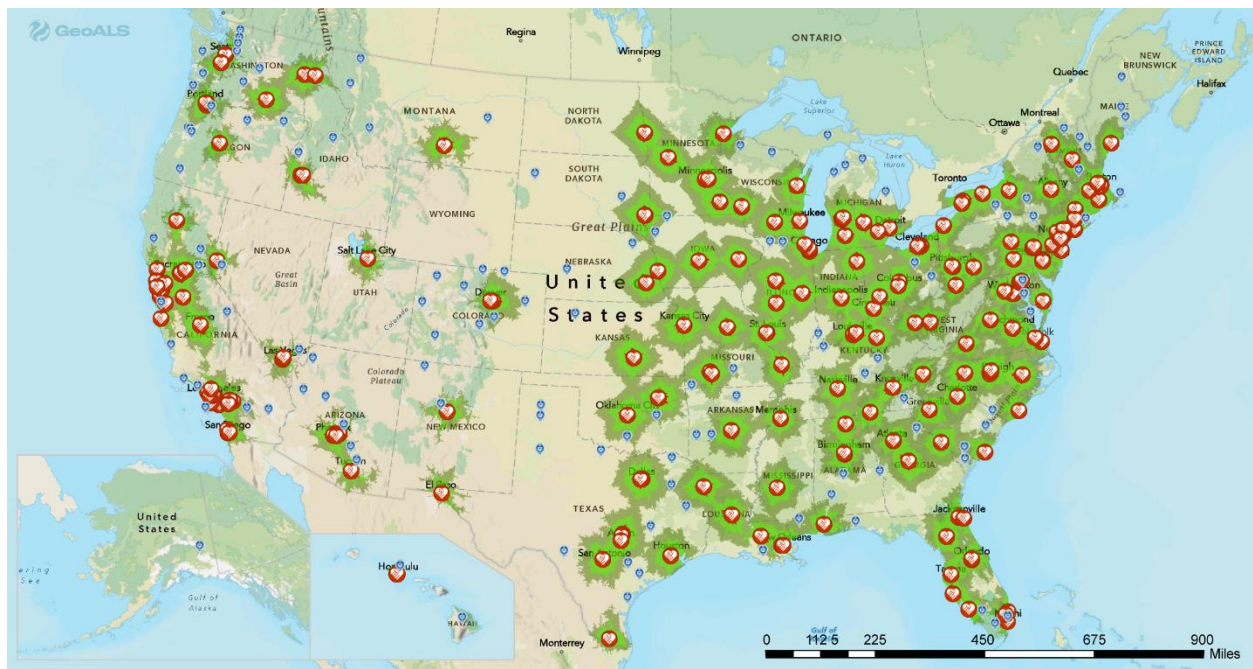
-/Expanded	Yes	50	49	false	male	-1.137188191
6/7	Yes	49	47	false	female	-0.32256945
7/8	Yes	37	35	false	male	-0.276326557
2/2	Yes	34	32	false	female	-0.030462205
2/2	Yes	48	47	false	male	-1.233664359
5/6	Yes	45	42	false	male	-1.202454572
2/2	Yes	69	69	false	male	-1.089696821
2/5	Yes	58	56	true	female	-0.598747711
6/6	Yes	28		true	female	0
2/9	Yes	49	47	false	female	-0.364094234
2/9	Yes	59	57	false	male	-1.494586555
5/11	Yes	50	47	false	female	-0.819727792
2/2	Yes	59	51	false	male	-0.042012827
2/5	Yes	53	51	false	male	-0.684854644
2/2	Yes	51	51	false	female	-0.358189377
2/5	Yes	38	34	true	female	-0.084335792
10/10	Yes	61	59	false	male	-0.849905266
6/13	Yes	27	24	true	female	-0.126819373
5/10	Yes	46		true	male	0
14/14	Yes	52		true	male	0
2/5	Yes	50		true	male	-0.000108984
2/8	Yes	48	45	false	male	-0.301641606
-/Expanded		56	55	true	male	-1.237523025
5/8		46	44	false	male	-1.844113142
2/5		62	61	false	male	-3.011854171
2/7		62	57	false	female	-0.014918806
5/5		47	44	false	male	-0.998180108
2/2		57	55	false	male	-1.436338829
2/4		53	51	false	male	-0.049116894
4/6		60	57	false	male	-1.249711689
2/8		53	51	false	male	-2.62483258
2/2		51	48	false	female	-0.981949651

5/5	58	57	false	male	-0.731302263
2/6	59	53	false	male	-1.28657709
13/Expanded	64	60	false	female	-0.612058835
2/8	49	47	false	male	-0.587760067
2/4	61	58	false	female	-0.174345435
2/2	62	53	false	male	-0.646760425
2/2	31	30	false	male	-1.976470555
2/2	43	42	false	male	-0.99541518
2/8	59	54	false	male	-0.093738782
2/8	41	37	true	female	-0.346187983
-/-	40	36	false	male	-0.23460382
2/2	52	47	false	female	-0.237301186
2/8	74	60	false	female	0.151512685
2/10	58	56	false	male	-0.279670338
2/5	61	57	true	female	-0.961166258
5/5	60	57	false	male	-0.28372233
7/12	28	25	true	male	-0.426897055
2/2	61	58	false	female	-1.54118576
2/2	45	37	false	female	-0.037206501
2/2	65	64	false	female	-2.100553501
7/8	34	34	false	male	0
2/2	59	56	false	male	-0.139201655
2/2	53	50	false	male	-0.112043712
2/2	65	63	false	male	-0.75590344
2/8	70	69	false	male	-1.064241389
5/5	43	42	false	female	-0.882132654
2/10	62	52	false	male	-0.037873142
2/3	55	53	false	female	-0.013312478
2/8	65	60	false	female	-0.529450608
2/11	39	36	false	female	-1.219684776
2/8	68	62	false	male	-0.091032763
2/2	54	49	false	female	-0.240699646

2/9	73	71	false	male	-1.442949103
2/2	46	43	false	male	-0.249281161
2/2	44	40	false	male	-0.0504148
2/3	54	52	false	male	-1.011727073
2/7	61	53	false	male	-0.541964292
2/4	58	57	false	female	0.002078944
2/4	26	25	false	male	-1.523590816
2/7	56		true	female	0
2/7	50	46	false	male	0.002498589
2/2	63	60	false	male	-1.569071614
2/2	61	53	false	male	-0.180023012
2/10	30		true	male	0
2/3	66	57	false	male	-0.062859155
-/Expanded	59	58	true	female	-0.095385034
4/5	29		true	female	0
2/6	65		true	male	0.000457734
2/2	52	50	false	male	-1.254664786
5/8	61	57	false	male	-0.455216884
3/8	68		true	male	0
2/2	56	53	false	female	-1.025836125
6/8	36	35	false	male	0.022902104
2/5	54	49	false	male	0.39514067
2/2	47	46	false	female	-0.393056849
2/8	53	52	false	male	-1.769082023
2/8	47	46	true	male	-0.620574776
2/2	68	66	false	male	-0.529774515
2/Expanded 62	40		true	female	0
2/2	40		true	male	0
2/2	61	58	false	male	-1.569191791
2/11	62		true	female	0
5/6	61	55	false	male	-0.052285795
2/2	66		true	female	0

2/10	55	54	false	male	-1.680300994
2/2	33	32	false	male	-0.260587811
2/5	54	53	false	male	-1.211088805
5/Expanded	48	47	false	female	-0.327954091
2/2	70	67	false	male	-0.335518144
2/2	71	68	false	male	-1.140476631
-/-	67	66	false	female	-1.294795377
2/4	60	58	false	female	-0.854405328
2/Expanded	45		true	male	0
5/8	30	27	false	female	-0.129285524
2/5	41	39	false	male	-0.08609622
2/8	35	27	false	female	0.133547549
8/8	53	48	false	male	-0.434516367
4/13	59	56	false	male	-0.433015809
2/Expanded	58	55	true	male	-0.225493872
2/10	33	31	false	male	-0.302987505
2/Expanded	59	56	false	male	-0.943654913
6/10	61	60	true	female	-0.720851839
2/5	58	52	false	male	-0.530294543
2/8	65	63	false	male	-0.269084393
2/13	63	61	false	male	-0.289277423
2/2	39	35	false	male	-0.794119116
2/6	47	46	true	male	0.595654521
6/15	51	49	false	male	-0.816485657

Figure 1: Map of ALS clinics and drive time from ARC participants



This summary view of a data map shows the 30, 60, and 90 minute drive times to ALS clinics and the ARC participants that are 90 minutes or more from an ALS clinic. Only 172 (13%) of ARC participants are 90 minutes or more from an ALS clinic.

- 30-min drive time
- 60-min drive time
- 90-min drive time

- 📍 ARC participants with a drive time > 90 min
- ❤️ ALS clinics

June 23, 2025

Figure 2: Esri Tapestry segments and ARC participant geographic areas



This map shows the dominant tapestry segments of ARC participants. Tapestry segments are Esri categories that identify US neighborhoods by market segments such as baby boomers (Boomburbs) and city dwellers who rent (Metro Renters). The categories are based on shared demographic and socioeconomic characteristics that can help you gain an understanding of a population being studied, such as ARC participants.

Top Tier	Green Acres	Up and Coming Families
Savvy Suburbanites	Workday Drive	Metro Renters
Boomburbs	Salt of the Earth	Professional Pride
Pleasantville		

June 23, 2025