

RESIDRAS is a patient-partnered national platform for longitudinal phenotyping, treatment monitoring, safety surveillance and trial-ready research in SCN1A- and PCDH19-related epilepsies.

	Dravet S. SCN1A + tot. 397		Dravet S. SCN1A - tot. 25		Other S. SCN1A + tot. 143		PCDH19 tot. 77	
	Female n. 201	Male n. 196	Female n. 18	Male n. 7	Female n. 86	Male n. 57	Female n. 74	Male n. 3
Age distribution at last follow-up								
0-5 y	34	43	1	0	14	12	11	0
6-12 y	46	46	2	0	21	15	17	0
13-17 y	41	34	0	3	21	10	23	2
18 y	10	5	5	0	2	2	6	0
+19 y	70	68	10	4	28	18	17	1

Longitudinal coverage: 8,333 epilepsy follow-up records

8,333

Longitudinal coverage
epilepsy follow-up records

9.9 y

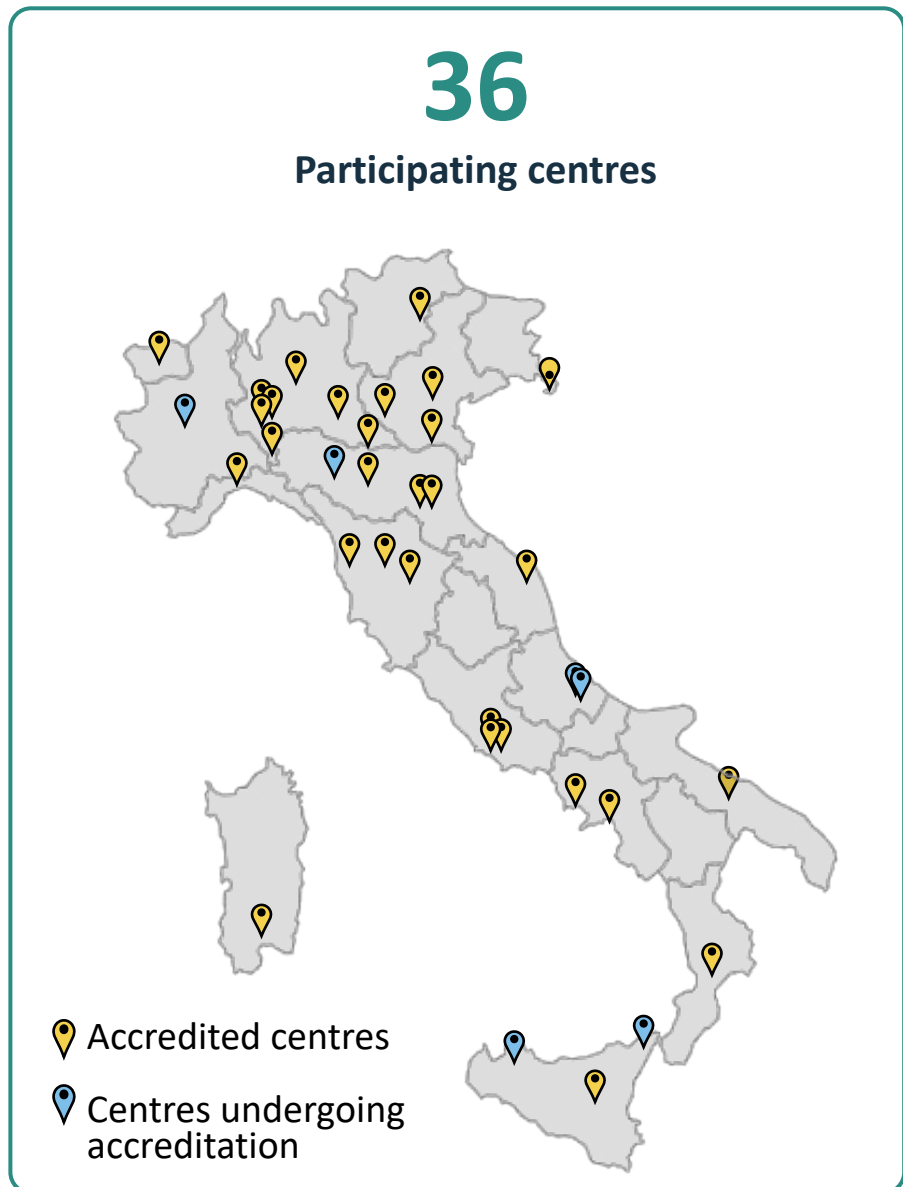
Median registry follow-up

19.5 y

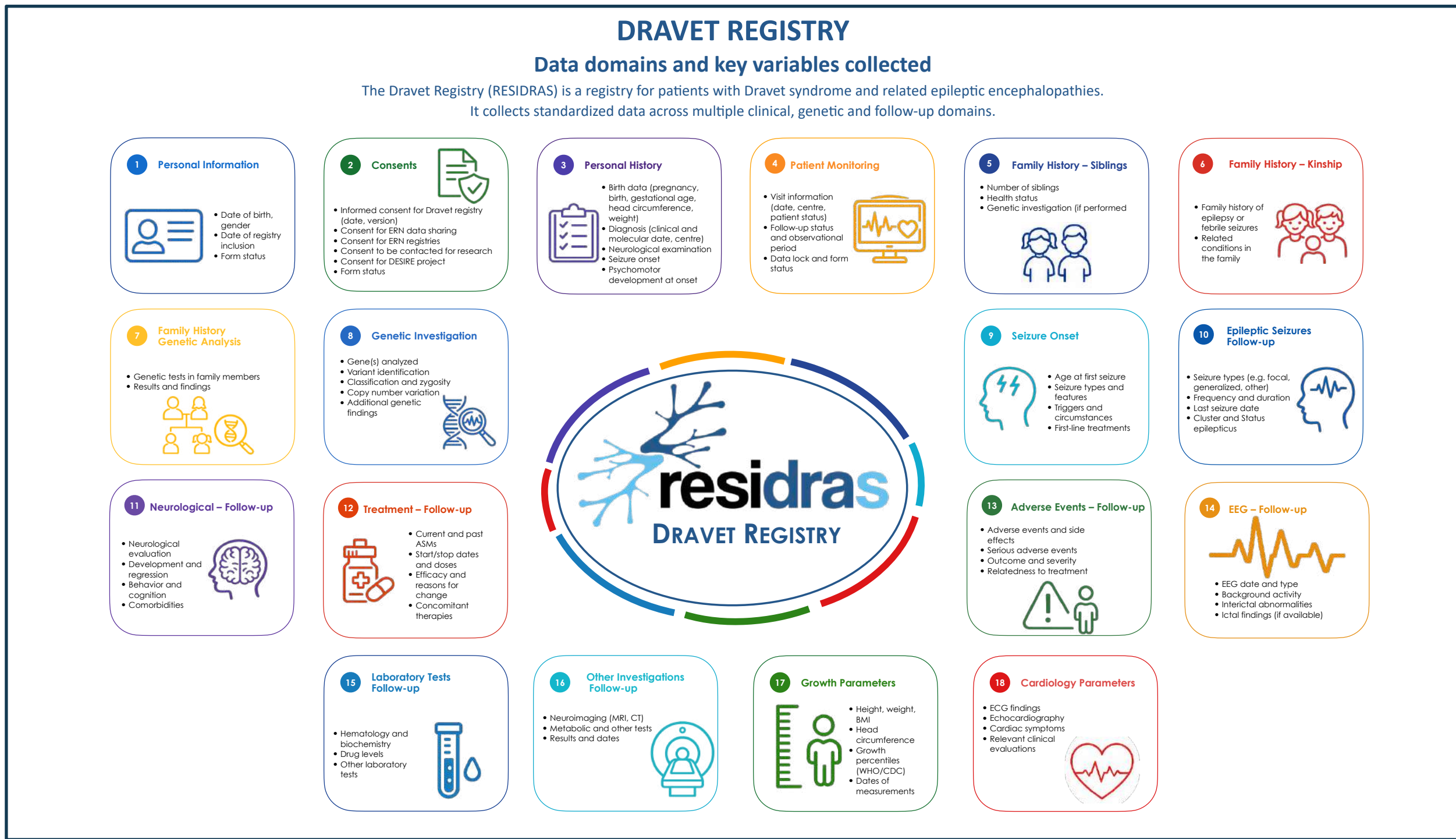
Median age at last follow-up
(range: 6 months–77 years)

1.1 y

median age at first
recorded follow-up



Key data available



Completed and ongoing projects based on registry data evidence:

1

A registry for Dravet syndrome: The Italian experience

Epilepsia Open®

2

Orphanet Journal of Rare Diseases

POSITION STATEMENT

Istore: a project on innovative statistical methodologies to improve rare diseases clinical trials in limited populations

3

DESIRE

Development to Epilepsy

Strategies for Innovative Research to Improve Diagnosis, Prevention and Treatment in Children with Difficult to Treat Epilepsy

4

Ministero della Salute

Finanziato dall'Unione europea

Precision medicine: from a national registry to neuronal modeling based on individual genome data

5

Post-authorisation safety study

A Registry of Patients Treated with Fintepla (TAPESTRY Registry)

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REFERENCES

Balestrini S, et al. A registry for Dravet syndrome: The Italian experience. Epilepsia Open. 2023;8:575–588. doi:10.1002/epi4.12730.

Schoenen S, et al. ISTORE. Orphanet J Rare Dis. 2024;19:153. doi:10.1186/s13023-024-03103-2.

DESIRE: <https://www.epilepsydesireproject.eu/>

PNNR Precision medicine: from a national registry to neuronal modeling based on individual genome data

TAPERSTRY PASS: EMA Catalogue of RWD Studies, <https://catalogues.ema.europa.eu/node/3746>. Registry metrics: RESIDRAS extract, July 2026.

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EEC2026 ilae.org/eec2026

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