DOI: *http://dx.doi.org/10.18502/cjn.v25i1.???*

Current Journal of Neurology

Review Paper

Curr J Neurol 2026; 25(1): 65-79

Podcast

Scoping review of ALS databases: Opportunity for multimodal machine learning

Received: 09 Sep. 2025
Accepted: 03 Nov. 2025

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Keywords
Amyotrophic Lateral Sclerosis; Diagnostic Imaging; Genomics; Facial Expression; Voice; Scoping Review

Abstract

Background: Amyotrophic lateral sclerosis (ALS) is a progressive, incurable neurodegenerative disease. ALS databases play a critical role in supporting research, decision-making, and the development of generative machine learning (ML) applications. This scoping review aims to explore genetic/imaging/facial expression/voice databases that can inform ALS disease research, supporting future multimodal ML applications.

Methods: A literature search was conducted across PubMed, Scopus, Web of Science, Cochrane Library, and grey literature, covering publications up to September 2025. The Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) guidelines were followed. Two reviewers independently screened titles, abstracts, and full texts. Databases were included if they provided ALS-specific data on genomics, medical imaging, voice, or facial expression. Extracted information included data type, accessibility, demographic details, key features, limitations, and database link. This review identifies gaps in the current database landscape. The Newcastle-Ottawa Scale (NOS) was used for evaluating study quality.

Results: Twenty-four ALS databases were identified, accounting for twenty studies of moderate quality. Most resources were single-modality, with only a few [e.g., Sporadic ALS Australia Systems Genomics Consortium (SALSA-SGC), Answer ALS, Canadian ALS Neuroimaging Consortium (CALSNIC)] offering multidimensional data. Common limitations included restricted demographic diversity, small sample sizes in digital cohorts, limited longitudinal follow-up, and insufficient cross-modal integration.

How to cite this article: Yazdanian T, Azimi P. Scoping review of ALS databases: Opportunity for multimodal machine learning. Curr J Neurol 2026; 25(1): 65-79.

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Published by Tehran University of Medical Sciences

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Data gaps limit the development of accurate ML models in ALS.

Conclusion: This scoping review provides a comprehensive understanding of ALS databases for future multimodal deep learning research. Research gaps were highlighted, and recommendations for future directions were stated.

Introduction

Amyotrophic lateral sclerosis (ALS) is a progressive and fatal neurodegenerative disease that primarily affects motor neurons in the brain and spinal cord, leading to muscle weakness, paralysis, and ultimately respiratory failure. Despite extensive research efforts, the exact causes of ALS remain largely unknown, and effective treatments capable of halting or reversing disease progression are still lacking.[1] ALS presents with varied clinical features, including differences in disease onset, progression speed, and survival outcomes among patients.[2] This variability poses significant challenges for early diagnosis, prognosis, and the development of personalized treatment strategies.

In recent years, artificial intelligence (AI) and machine learning (ML) techniques have shown great promise in addressing complex biomedical problems, including disease prediction and patient stratification.[3] However, the success of ML-driven models heavily depends on the availability of large, high-quality, and well-annotated databases. In the case of ALS, diverse data modalities, including medical imaging, genetic profiles, speech and facial expression recordings, and detailed clinical records, are essential for comprehensively capturing the multifaceted nature of the disease.[4-6]

The establishment of comprehensive and accessible ALS databases is therefore crucial to support ML-based prediction systems. Such databases can facilitate the development of robust algorithms capable of early diagnosis, progression prediction, and identification of potential therapeutic targets.[7] Up to now, single-modal-based approaches have led to significant progress in ML-based diagnosis/prognosis of ALS. Integrating multimodal data from various sources can improve the accuracy and reliability of predictive models, ultimately contributing to better clinical decision-making and personalized care for patients with ALS.[8,9]

No review has previously evaluated this exact topic. Therefore, the present study aims to conduct a comprehensive scoping review of the existing databases related to ALS, with a particular focus on those containing medical imaging, genetic data, speech data, and facial expression recordings. The review seeks to identify, categorize, and evaluate the characteristics of these datasets to support the development of ML-based predictive models for ALS diagnosis and prognosis. By systematically mapping the available resources, this study aims to highlight current gaps, opportunities for data integration, and recommendations for future database development to enhance ML-driven research in the field of ALS.

The selection of genetic, neuroimaging, speech, and facial expression data in this scoping review was guided by their established relevance to ALS pathophysiology and their demonstrated utility in computational and ML-based research. Genetic data provide insights into disease susceptibility and underlying molecular mechanisms; neuroimaging captures structural and functional neurodegeneration; speech data reflect bulbar motor impairment; and facial expression recordings enable objective assessment of orofacial motor dysfunction. Together, these modalities represent complementary biological and digital biomarkers that are increasingly used in ALS research and are well-suited for multimodal ML applications.[1,4-9]

Materials and Methods

Protocol: The protocol for this scoping review was drafted in accordance with the guidelines of the Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for scoping reviews (PRISMA-ScR).[10]

Eligibility criteria: The inclusion criteria were peer-reviewed articles, grey literature from official websites, and documentation describing publicly or institutionally available ALS-related datasets. Only English-language studies evaluating ALS databases were included. Exclusion criteria comprised studies that, upon full-text review, did not align with the precise aims of the scoping review. Additionally, datasets that were purely computational or descriptive and not derived from experimental patient samples were excluded from this study.

Search strategy: We performed a comprehensive literature search using four major databases: PubMed, Scopus, Web of Science, and Cochrane Library. We also reviewed grey literature and official project pages for ALS datasets. Records were identified from various online data repositories, including Mendeley Data

(https://data.mendeley.com/), Kaggle (https://www.kaggle.com/datasets), and Google Dataset Search (https://datasetsearch.research.google.com/). Two authors (PA and TY) independently searched all records published up to August 2025. Disagreements were resolved through discussion. The key search terms were structured as follows: ("ALS" OR "Amyotrophic Lateral Sclerosis" OR ALS*) AND ("genetic" OR "genomics" OR "neuroimaging" OR "MRI" OR "PET" OR "DTI" OR "voice" OR "speech" OR "facial expression" OR genetic* OR neuroimaging*) AND ("registry" OR "registries" OR "database" OR "dataset" OR "library" OR "record" OR "archive"). We adapted the search strategy to the search requirements of the remaining databases mentioned above. The reference lists of relevant studies were also screened. Details of the search strategy are provided in table 1.

Risk of bias (quality) evaluation: Two independent reviewers evaluated the methodological quality of all included studies using a modified Newcastle-Ottawa Scale (NOS).[11] The NOS assesses case-control and cohort studies across three domains: selection (up to 4 points), comparability (up to 2 points), and outcome (up to 3 points). Since none of the studies were randomized controlled trials (RCTs), scores of 7–9 indicate high quality, 5–6 indicate moderate quality, and 0–4 indicate poor quality. A summary of the quality assessment method is provided in table 2. Although a formal risk-of-bias assessment is not a mandatory component of scoping reviews, quality appraisal may be conducted when it aligns with the objectives of the review. In the present study, a modified NOS was applied descriptively to characterize the methodological features of ALS databases, including representativeness, data completeness, follow-up duration, and data-type diversity. The NOS scores were not used to exclude databases or to draw comparative effectiveness conclusions, but rather to contextualize database readiness for multimodal ML research.

Data extraction: Two reviewers independently extracted the data from the included studies. Relevant data were compiled in a table. From each included resource, we extracted the following information: database name and year of publication; country or organizing institution; modality of data (e.g., genetic, imaging, voice, facial expression); database information; sample size (ALS and control group if available); age and gender (if reported); accessibility status (public, restricted, on-request); key findings; limitations; and web address. The extracted data were revised accordingly.

All extracted data were summarized descriptively in a structured table. Databases were categorized based on data modality, and key gaps in availability, integration, and accessibility were identified. No statistical meta-analysis was performed.

Table 1. Search strategy

Database	Search strategy	Filters and date of search
PubMed	((ALS [Title/Abstract]) OR (Amyotrophic Lateral Sclerosis [Title/Abstract])) AND ((genomics [Title/Abstract]) OR (genetic [Title/Abstract]) OR (gene expression [Title/Abstract]) OR (neuroimaging [Title/Abstract]) OR (MRI [Title/Abstract]) OR (voice [Title/Abstract]) OR (speech [Title/Abstract]) OR (facial expression [Title/Abstract])) AND ((registry [Title/Abstract]) OR (dataset [Title/Abstract]) OR (database [Title/Abstract]) OR (library [Title/Abstract]) OR (archive [Title/Abstract]) OR (record [Title/Abstract]))	Publication date up to September 18, 2025; Field: Title/Abstract. 356
Scopus	(TITLE-ABS-KEY(ALS) AND (TITLE-ABS-KEY(neuroimaging) OR TITLE-ABS-KEY(genetic) OR TITLE-ABS-KEY(voice) OR TITLE-ABS-KEY(facial expression)) AND (TITLE-ABS-KEY(database) OR TITLE-ABS-KEY(dataset)))	Publication date up to September 22, 2025
Web of Science	TS=("Amyotrophic Lateral Sclerosis") AND (TS=(genetic)) OR TS=(neuroimaging)) OR TS=(voice) OR TS=(facial expression)) AND (TS=(database) OR TS=(dataset)) https://www.webofscience.com/wos/woscc/summary/f5827074-504a-4abe-8dc8-e0ed9bd256c0-017ec16301/relevance/1	Publication date up to September 26, 2025
Cochrane Library	(ALS):ti,ab,kw AND (neuroimaging OR genetic OR voice OR speech OR facial expression):ti,ab,kw AND (database OR dataset OR registry):ti,ab,kw	Publication date up to September 19, 2025 (Word variations included)

Table 2. Checklist for quality assessment and scoring of studies using the Newcastle-Ottawa Scale (NOS)

Checklist	Definition	Point
Selection		Maximum: 4
1. Representativeness of patients with ALS	a) Database broadly representing the ALS population	1
	b) Narrow or biased sample	0
2. Control/comparator group	a) Controls from the same population as patients	1
	b) Controls absent or from different populations	0
3. Data quality and validation	a) Data collected by standardized and validated methods	1
	b) Unclear or non-standard methods	0
4. Sample size	a) > 100	1
	b) ≤ 100	0
Comparability		Maximum: 2
1. Control for key confounders (age, sex)	a) Yes	1
	b) No	0
2. Database accounting for major ALS subtypes (e.g., bulbar, limb onset) and demographic factors, such as ethnicity, in data collection	a) Yes	1
	b) No	0
Outcome		Maximum: 3
1. Outcome definition and completeness	a) Clear outcomes; low missing data (< 10%)	1
	b) Unclear outcomes; high missing data (≥ 10%)	0
2. Adequacy of follow-up period	a) Follow-up time sufficient to capture ALS progression (≥ 12 months)	1
	b) Insufficient or absent follow-up	0
3. Diversity of data type	a) ≥ 2 data types (e.g., genetics, imaging, voice, or facial)	1
	b) < 2 data types	0

ALS: Amyotrophic lateral sclerosis

Results

A total of 24 ALS databases were included in this scoping review (Figure 1, Table 3).[12-35] Collectively, these resources encompass data from approximately 63270 patients,[12-20,23-28,32-35] with mean ages ranging from 59 to 65 years. The majority of patients were women, and most datasets were affiliated with research institutions. Notably, about half of the identified databases (n = 13) originated from the United States (US). The NOS for each study is detailed in table 3, with a comprehensive description of the measurement methods provided in table 4. Most studies received NOS scores of 5 (n = 7) or 6 (n = 13), which correspond to moderate quality, while only four studies achieved a high-quality score of 7.

The databases were categorized into four main modalities: genetics, neuroimaging, voice, and facial expression. Large-scale initiatives such as Project MinE and Answer ALS primarily focus on genomics, whereas other resources specialize in neuroimaging [e.g., Canadian ALS Neuroimaging Consortium (CALSNIC)], voice (e.g., VOC-ALS), or facial movement data (e.g., Toronto NeuroFace). Sample sizes vary substantially across modalities: genetic cohorts often include more than 10000 patients, while voice and facial datasets are typically limited to fewer than 200 participants. Only a small proportion of resources (e.g., VOC-ALS, Answer ALS) integrate both clinical and omics-level metadata.

To date, no dataset has combined genetic, imaging, voice, and facial expression data from the same group of patients simultaneously. Most remain unimodal, lack longitudinal follow-up, and vary in accessibility, ranging from open access [e.g., Pooled Resource Open-Access ALS Clinical Trials (PRO-ACT), VOC-ALS] to restricted or consortium-based availability [e.g., CALSNIC, New York Genome Center's ALS Consortium (NYGC)].

Discussion

The included ALS databases encompass diverse and complementary data modalities. Genetic resources include multi-omics data, such as whole-genome sequencing (WGS), genome-wide association studies (GWAS), methylation, and transcriptomic profiles, providing insights into disease susceptibility and underlying molecular mechanisms. Neuroimaging datasets primarily rely on magnetic resonance imaging (MRI)-based techniques, including structural imaging, diffusion tensor imaging (DTI), functional MRI (fMRI), and magnetic resonance spectroscopy (MRS), enabling the assessment of neurodegeneration at both structural and functional levels.

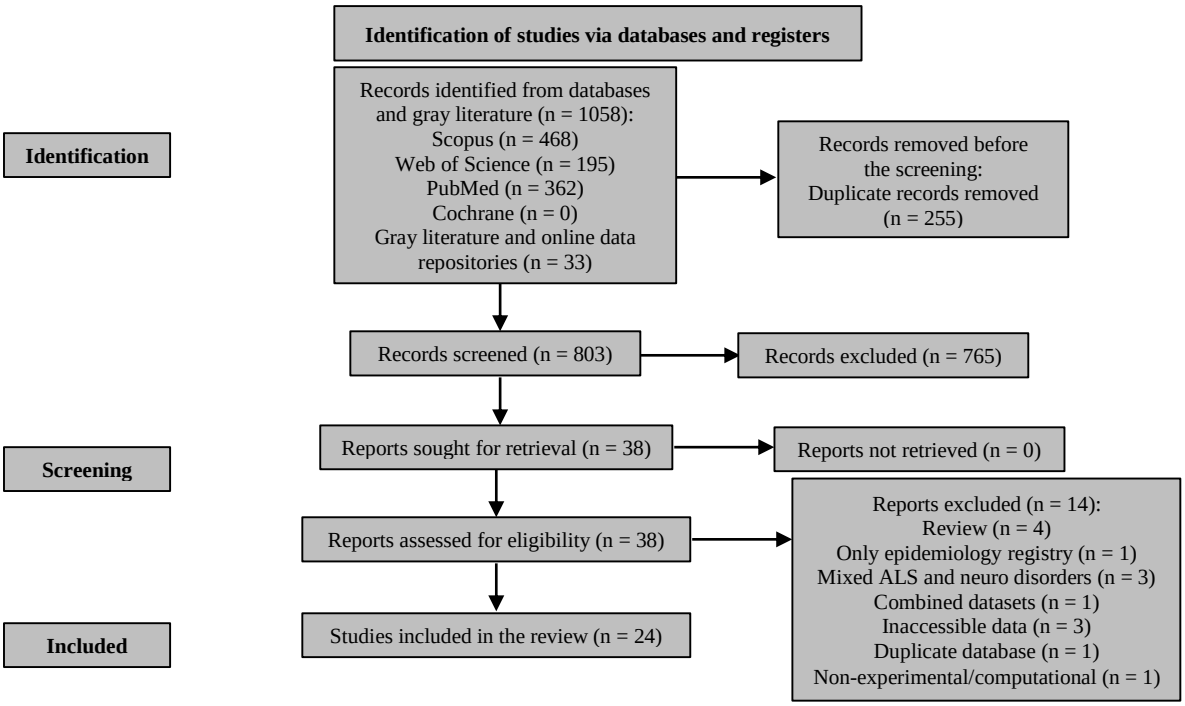


Figure 1. Flowchart of the selection process for amyotrophic lateral sclerosis (ALS) studies

Speech datasets consist of acoustic recordings from standardized tasks, allowing quantitative evaluation of bulbar motor impairment, while facial expression databases use video-based landmark analysis to objectively assess orofacial motor dysfunction. Together, these modalities offer rich feature spaces that support the development of multimodal ML models for ALS research. The scoping review identified that existing ALS databases were primarily modality-specific, lacking integration of genetic, imaging, voice, and facial data from the same individuals. This deficiency in multimodal, longitudinal, and demographically diverse datasets considerably limits the development of robust and generalizable ML models for ALS. Furthermore, the NOS evaluations revealed that the majority of studies were of moderate quality, emphasizing the critical need to develop standardized, high-quality, and comprehensive databases. Addressing these gaps is essential, not only to improve the reliability and validity of ALS research but also to fulfill the increasing requirements of advanced AI systems for high-precision predictive modeling and personalized medicine.

Recent advancements in technology have facilitated the precise quantification of individual variability in ALS across multiple domains, including genomics, neuroimaging, vocal characteristics, facial expressions, and clinical data. The increasing availability of high-resolution, multimodal datasets offers substantial opportunities for advancing research on ALS as well as on healthy control populations. However, this rapid expansion in data availability presents several challenges, including concerns related to data sharing and governance, the need for novel analytical methodologies and software tools, and growing demands for storage capacity and computational resources. In this context, and to support researchers, we begin by presenting a detailed overview of the different data formats and their associated file sizes across various data modalities (Table 3).

There is a growing scientific and ethical discussion about the representativeness of the datasets being used in research. Researchers should be aware of the biases present in certain datasets, which need to be considered during study design, for example, when analyzing diverse ancestries in genetic research, as well as when reporting results and evaluating algorithms. Smartphones and sensors allow for the unobtrusive collection of physiological data. For instance, smartphones are commonly used in real-time assessment of participant symptoms. In addition, smartphones and tablets can utilize their built-in microphones and touchscreens to record both speech and movement.[36]

Table 3. List of identified databases for the amyotrophic lateral sclerosis (ALS) disease study (Part I)

Author(s)	Country	Database name	Data type	Database information	Database main affiliations (organization, government, institution, or company)	Sample size (n, ALS/control)	Age*	
							ALS	Control
Stephen et al.[12] Thacker CDC Library. USA	USA (CDC)	National ALS Registry	Clinical/ epidemiological	National surveillance database of ALS incidence, prevalence, risk factors, and progression (ALSFRS-R)	Government (CDC)	~34290 people in the USA (2025)	60-69	NR
Lill et al.[13]	UK	ALSoD	Genetic (mutations)	Curated gene mutations, age of onset, and basic clinical descriptors	King's College London	419 (343 with age-of-onset)	NR	NR
Atassi et al.[14]	Multiple (Europe/ Canada/USA)	PRO-ACT	Clinical trial datasets (limited genetic indicators may be present in some trials)	Records of patients with ALS from 23 clinical trials; time and site of disease onset; ALSFRS questionnaire scores; respirator, motor, and laboratory assessments; treatment arms; and genetic data	Amylyx Pharmaceuticals, Inc.; Cytokinetics, Inc.; Knopp Biosciences; Neuraltus Pharmaceuticals, Inc.; Neurological Clinical Research Institute, Massachusetts General Hospital; Northeast ALS Consortium; Novartis; Orion Corporation; Regeneron Pharmaceuticals, Inc.; Sanofi; Teva Pharmaceutical Industries, Ltd.	8635	59	NR
Project MinE ALS Sequencing Consortium[15]	International	Project MinE	Genomic (WGS)	Genome data	Led by the ALS Center Netherlands and UMC Utrecht; Project MinE Consortium (21 countries)	11176/7398	On request	On request
Kalra et al.[16]	Canada	CALSNIC	MRI (T1, DTI, MRS, fMRI)	CALSNIC database including multimodal MRI data (structural, diffusion, functional) alongside clinical assessments of patients with ALS, collected across multiple Canadian research centers	University of Alberta	250/190	On request	NR
NYGC ALS Web[17]	USA/ international	NYGC ALS Consortium	Clinical/genomic data	A partnership of clinicians, basic scientists, geneticists, and computational biologists from 45 institutions across the globe	NYGC	Only 400 patients per year, 4359 whole genomes, and 2348 RNA samples	On request	NR

Table 3. List of identified databases for the amyotrophic lateral sclerosis (ALS) disease study (continue) (Part I)

Author(s)	Country	Database name	Data type	Database information	Database main affiliations (organization, government, institution, or company)	Sample size (n, ALS/control)	Age*	
							ALS	Control
ALS Therapy Development Institute[18]	USA	ARC Data Commons	Clinical, genetic, accelerometry, speech, and ALSFRS-R scores	Over 8.5 trillion data points; data visualization and analytic tools	ALS TDI	Over 840 patients/on request	On request	NR
Baxi et al.[19]	USA	Answer ALS	Clinical/genomic/multi-omics multimodal dataset combining clinical, iPSC, RNA-sequencing, speech, and digital biomarker data	Multi-omics (genomic, epigenomic, transcriptomic, proteomic), speech, longitudinal clinical, and smartphone-derived functional data	Johns Hopkins (Packard Center); Cedars-Sinai; and Massachusetts General Hospital	1100/-	On request	NR
Nabais et al.[20]	Australia	SALSA-SGC	Clinical/genomic data	Case–control cohort of Australian sporadic patients with ALS and healthy controls with genome-wide genotyping (GWAS), DNA methylation (MWAS), and WGS data	University of Queensland, Macquarie University, University of Sydney, and the MND Research Institute of Australia	596/223	62	59
ENCALS Web[21]	Europe	ENCALS	Clinical/genetic data	Registry for ALS epidemiological and genetic data across Europe	ENCALS	On request	On request	NR
TRICALS Web[22]	Europe	TRICALS	Clinical/genetic in some centers	Largest European clinical trial network for ALS	The TRICALS consortium (consisting of over 60 top ALS research centers across Europe)	On request	On request	NR
Target ALS Web[23]	USA	Target ALS	Clinical/multi-omics data	Supporting integrated multi-omics analysis to identify biomarkers and disease mechanisms.	Target ALS (in collaboration with DNAstack and Verily)	260/on request	On request	On request
Bede et al.[24]	Ireland	Brainstem pathology in ALS: A longitudinal neuroimaging study	MRI neuroimaging	Detailed, longitudinal MRI data focused on brainstem pathology in ALS for studying disease progression	University College Dublin and the National University of Ireland	100/100	59.8 ± 11.2	59.7 ± 11.9
Fotini and Bede[25]	Greece	Mesial temporal lobe metrics in ALS	MRI neuroimaging	Neuroimaging metrics of the mesial temporal lobe in patients with ALS and healthy controls	National and Kapodistrian University of Athens, Greece	50/40	60.7 ± 11.6	65.5 ± 9.2

Table 3. List of identified databases for the amyotrophic lateral sclerosis (ALS) disease study (continue) (Part I)

Author(s)	Country	Database name	Data type	Database information	Database main affiliations (organization, government, institution, or company)	Sample size (n, ALS/control)	Age*	
							ALS	Control
Vashkevich and Rushkevich[26]	Belarus	Minsk2020_ALS_dataset	Voice	Dataset of vowel phonations and syllable repetition recorded in healthy controls and patients with ALS	Belarusian State University of Informatics and Radioelectronics	31/33	59.4 ± 7.7	53.7 ± 11.3
Schreiber[27]	Germany	Dataset for the evaluation of tongue alterations in ALS by sonographic and 3T-MRI imaging	Clinical/HRUS (coronal cross-sections) of the tongue/3T MRI of the head	Comparing structural differences in tongue anatomy/function in patients with ALS vs. controls	Ulm University	206/104	61.1	-
Bandini et al.[28]	Canada	Toronto NeuroFace dataset	Facial video	Orofacial videos with landmarks and clinical scores	University of Toronto	11/11	61.5 ± 8.0	63.2 ± 14.3
Noori et al.[29]	USA	Atlas of differential expressions	Genetic	Differential expression analyses and data quality reports for 60 individual datasets	Harvard College, Harvard Medical School, Massachusetts General Hospital	NR	NR	NR
Li[30]	USA	ALS_Leaf_Info	Genetic	Identifying genes or genomic regions potentially associated with ALS	Duke University	NR/-	NR	Li[30]
ALS United Greater New York Web[31]	USA	ALS United Greater New York	Clinical/patient-reported	ALS awareness and patient-reported symptoms database and registry	ALS United Greater New York	On request	On request	On request
National Institutes of Health[32]	USA	The ALL ALS Clinical Research Consortium	Clinical/biomarker data	Records of patients with ALS from 35 research sites, conducting a combined longitudinal natural history study and biomarker (blood and CSF sample) collection study for ALS	Government (NIH)	632/-	On request	On request
Dubbioso et al.[33]	Italy	VOC-ALS	Voice (speech)	Dataset of vowel phonations and syllable repetition recorded in healthy controls and patients with ALS	Federico II University Hospital of Naples, Italy	102/51	65.0	62.9

Table 3. List of identified databases for the amyotrophic lateral sclerosis (ALS) disease study (continue) (Part I)

Author(s)	Country	Database name	Data type	Database information	Database main affiliations (organization, government, institution, or company)	Sample size (n, ALS/control)	Age*	
							ALS	Control
Segerstrom and Kasarskis[34]	USA	SALSPPD	Clinical/patient-reported	Information on both exposures and outcomes	University of Washington, Oregon State University, University of Kentucky	143/NR	NR	NR
Hernandez[35]	USA	JPS2024_ALS_dataset	Voice (speech)	Dataset of vowel phonations and syllable repetition recorded in healthy controls and patients with ALS	University of South Carolina	69/on request	56.7	On request

Table 3. List of identified databases for the amyotrophic lateral sclerosis (ALS) disease study (Part II)

Author(s)	Gender, women (%, ALS/control)	Accessibility	Key features	Limitations	Database link	Study quality
Stephen et al.[12] Thacker CDC Library. USA	43.5/NR	Public (data accessible via controlled registration)	Nationwide registry with risk factor data	Lacking biological/imaging data	https://www.cdc.gov/als	6
Lill et al.[13]	NR	Public	Curated mutation and phenotype data	No patient-level data; not frequently updated	http://alsod.iop.kcl.ac.uk	6
Atassi et al.[14]	39.3/NR	Semi-public	Longitudinal clinical trial data with ALSFRS-R scores, treatments, and demographics	No imaging or omics (no genomic data; limited genetic indicators may be present in some trials)	https://nctu.partners.org/ProACT	6
Project MinE ALS Sequencing Consortium[15]	On request	Semi-public	Global genetic database; > 300 research centers; Open-access browser	No multimodal data; limited clinical linkage	https://www.projectmine.com	7
Kalra et al.[16]	35.0/NR	Restricted	Standardized imaging; longitudinal	No genomic or audio/visual data	https://www.calsnic.org	6
NYGC ALS Web[17]	On request	Restricted (data accessible via controlled registration)	WGS + transcriptomics; identification of novel ALS-associated mutations; multi-institutional	Not publicly accessible	https://www.nygenome.org/science-technology/collaborative-research-programs/neurodegenerative-disease-research/als-consortium	7
ALS Therapy Development Institute[18]	On request	Public (data accessible via controlled registration)	Large-scale longitudinal natural history data; multimodal data; global research collaboration from 110+ groups	Usage restricted by fee structure (commercial); dynamic/evolving data platform	https://www.als.net/arc/	7

Table 3. List of identified databases for the amyotrophic lateral sclerosis (ALS) disease study (continue) (Part II)

Author(s)	Gender, women (%, ALS/control)	Accessibility	Key features	Limitations	Database link	Study quality
Baxi et al.[19]	On request	Public (data accessible via controlled registration)	Omics + clinical + imaging+ digital biomarker data	No brain imaging and facial data	https://www.answerals.org	6
Nabais et al.[20]	-/54.0	Restricted (data accessible via controlled registration)	Multi-omic data (genotype + methylation) linked to clinical phenotypes in Australian patients with ALS	Insufficient ancestry quality control; limited MWAS normalization (shared IDAT/ image data only)	https://www.ncbi.nlm.nih.gov/projects/gap/cgi-bin/study.cgi?study_id=phs002068.v1.p1	6
ENCALS Web[21]	On request	Public (data accessible via controlled registration)	European network collaboration	Limited cross-modality integration	https://encals.eu/centres	6
TRICALS Web[22]	On request	Restricted	European network collaboration	Limited cross-modality integration	https://www.tricals.org/	6
Target ALS Web[23]	On request	Public (data accessible via controlled registration)	Multimodal datasets, including post-mortem tissue, longitudinal biofluids, and stem cells; data are updated approximately every 4-6 months.	Sample size variability due to ongoing data updates; limited geographic diversity	https://www.targetals.org/resource/genomic-datasets/	7
Bede et al.[24]	38.0/46.0	Public, on request	T1-weighted 3D MRI, brainstem volumetry, demographic data, and longitudinal ALS scans at 4-month intervals	Small sample size, and lack of validation across multiple centers	https://data.mendeley.com/datasets/4t8c4bmw5p/3	5
Fotini and Bede[25]	36.0/42.5	Public	Structural MRI (for volumetric analysis); DTI (for white matter microstructure)	Cross-sectional imaging only, no longitudinal follow-up; limited clinical variables	https://data.mendeley.com/datasets/d4crz2cg2x/1	5
Vashkevich and Rushkevich[26]	45.2/60.6	Public	131 acoustic features of sustained /a/ and /i/ vowel phonations, as used in the study	Reduced audio fidelity and increased background noise (due to smartphone/headset use)	https://www.kaggle.com/datasets/daniilkrasnoproshin/amyotrophic-lateral-sclerosis-als/data	5
Schreiber[27]	52.9/-	Public	Longitudinal tongue morphology and surface texture progression	Single-center design and limited modalities (HRUS and 3T MRI only; no electrophysiological or functional data)	https://data.mendeley.com/datasets/8d939wvc7r/1	6
Bandini et al.[28]	63.6/36.4	Publicly available (on request)	261 facial expression recordings with annotated facial landmarks	Single-center design and small sample size	https://bmi.toronto.edu	5
Noori et al.[29]	NR	Public	A differential expression atlas highlighting both disease-specific and shared pathways in ALS	Heterogeneity of data sources; limited clinical information; non-uniform analysis methods	https://data.mendeley.com/datasets/752nd4w7pd/2	6

Table 3. List of identified databases for the amyotrophic lateral sclerosis (ALS) disease study (continue) (Part II)

Author(s)	Gender, women (%, ALS/control)	Accessibility	Key features	Limitations	Database link	Study quality
Li[30]	NR/-	Public	Large-scale genomic dataset (263k rows) containing genomic locations, gene names, and statistical associations measures	Absence of patient information and imaging data; requirement for advanced bioinformatics and statistical expertise	https://data.mendeley.com/datasets/gvykg8pwyw/1	5
ALS United Greater New York Web[31]	On request	Publicly available (on request)	Identification of early ALS symptoms, useful for early trial recruitment and symptom monitoring	Lack of structured research design and standardized data collection	https://als-ny.org/very-early-als-symptoms-what-to-look-out-for/#ref9	6
National Institutes of Health[32]	On request	Restricted	Longitudinal clinical and biospecimen data from patients with ALS, at-risk individuals, and controls	No public sample size or demographic data; limited access to information	https://www.all-als.org/about/	6
Dubbioso et al.[33]	56.9/59.4	Public	Dysarthria severity + some metadata	Only vowel/consonant tasks; Italian only	https://www.synapse.org/vocals	6
Segerstrom and Kasarskis[34]	NR	Public	Characterization of the psychosocial and physical natural history of ALS and their interactions	Only exposures and outcomes reported	https://data.mendeley.com/datasets/stcztggnnp/2	5
Hernandez[35]	53.6/on request	Public	A valuable resource for ML models, acoustic analysis, and medical diagnostics related to ALS	Restricted phonetic coverage (vowels /a/ and /i/ only; other ALS-related speech impairments not captured)	https://data.mendeley.com/datasets/fbhc38zzm9/2	5

*Data are presented as mean ± standard deviation (SD), mean, or range, as indicated.

ALS: Amyotrophic lateral sclerosis; ALS TDI: ALS Therapy Development Institute; ALSFRS-R: ALS Functional Rating Scale–Revised; ARC: ALS Research Collaborative; CSF: Cerebrospinal fluid; DTI: Diffusion tensor imaging; GWAS: Genome-wide association studies; HRUS: High-resolution ultrasound; iPSC: Induced pluripotent stem cells; MRI: Magnetic resonance imaging; MRS: Magnetic resonance spectroscopy; fMRI: Functional magnetic resonance imaging; NIH: National Institutes of Health; NR: Not reported; VOC-ALS: Voice signals acquired in ALS patients; ALSoD: ALS Online Genetics Database; PRO-ACT: Pooled Resource Open-Access ALS Clinical Trials; Project MinE; National ALS Registry (CDC/USA); Answer ALS; ALS United Greater New York; The ALL ALS Clinical Research Consortium; TRICALS: Treatment Research Initiative to Cure ALS; RNA: Ribonucleic acid; ENCALS: European Network for the Cure of ALS; CALSNIC: Canadian ALS Neuroimaging Consortium; CDC: Centers for Disease Control and Prevention; NYGC: New York Genome Center's ALS Consortium; SALSA-SGC: Sporadic ALS Australia Systems Genomics Consortium; MWAS: Methylome-wide association studies; SALSPPD: Seattle ALS Patient Profile Database; UK: United Kingdom; USA: United States of America; WGS: Whole-genome sequencing; 3D: Three-dimensional

Table 4. The quality assessment score for studies under review based on the Newcastle-Ottawa Scale (NOS)

List of studies	Selection (Maximum: 4 points)				Comparability (Maximum: 2 points)		Assessment of the outcome (Maximum: 3 points)			Total score
	Representativeness of patients with ALS	Control/ comparator group	Data quality and validation	Sample size	Control for key confounders (age, sex)	Database accounting for major ALS subtypes (e.g., bulbar, limb onset) and demographic factors like ethnicity in data collection	Outcome definition and completeness	Adequate follow-up period	Data type diversity	
Stephen et al.[12] Thacker CDC Library. USA	1	0	1	1	1	0	1	1	0	6
Lill et al.[13]	1	0	1	1	1	0	1	1	0	6
Atassi et al.[14]	1	0	1	1	1	0	1	1	0	6
Project MinE ALS Sequencing Consortium[15]	1	1	1	1	1	0	1	1	0	7
Kalra et al.[16]	1	1	1	1	1	0	1	0	0	6
NYGC ALS Web[17]	1	0	1	1	1	0	1	1	1	7
ALS Therapy Development Institute[18]	1	1	1	1	1	0	1	1	0	7
Baxi et al.[19]	1	0	1	1	1	0	1	1	0	6
Nabais et al.[20]	1	1	1	1	1	0	1	0	0	6
ENCALS Web[21]	1	0	1	1	1	0	1	1	0	6
TRICALS Web[22]	1	0	1	1	1	0	1	1	0	6
Target ALS Web[23]	1	1	1	1	1	0	1	1	0	7
Bede et al.[24]	1	1	1	0	1	0	1	0	0	5
Fotini and Bede[25]	1	1	1	0	1	0	1	0	0	5
Vashkevich and Rushkevich[26]	1	1	1	0	1	0	1	0	0	5
Schreiber[27]	1	1	1	1	1	0	1	0	0	6
Bandini et al.[28]	1	1	1	0	1	0	1	0	0	5
Noori et al.[29]	1	0	1	1	1	0	1	1	0	6
Li[30]	1	0	1	1	1	0	1	0	0	5
ALS United Greater New York Web[31]	1	1	1	1	1	0	1	0	0	6
National Institutes of Health[32]	1	0	1	1	1	0	1	1	0	6
Dubbioso et al.[33]	1	1	1	1	1	0	1	0	0	6
Segerstrom and Kasarskis[34]	1	0	1	1	1	0	1	0	0	5
Hernandez[35]	1	1	1	0	1	0	1	0	0	5

Wells GA, Shea B, O'Connell D et al. The Newcastle-Ottawa Scale (NOS) for assessing the quality of nonrandomized studies in meta-analyses. http://www.ohri.ca/ programs/clinical_epidemiology/nosgen.pdf. Accessed on May 11, 2020.

ALS: Amyotrophic lateral sclerosis; ENCALS: European Network for the Cure of ALS; NYGC: New York Genome Center's ALS Consortium; TRICALS: Treatment Research Initiative to Cure ALS

ML methods have been widely used to analyze data collected from smartphones and sensor devices.

Although existing ALS databases serve as valuable resources for clinical and translational research, their limitations restrict their effective application in advanced multimodal ML. A critical issue is the fragmentation and heterogeneity of data sources, where neuroimaging, genetic profiles, speech recordings, and facial expression data are often collected independently, using varied acquisition protocols across different centers and patient cohorts. This lack of standardization and synchronized multimodal data from the same individuals complicates data integration, limits interoperability, and reduces the potential for building robust multimodal ML systems.[6,33] Moreover, existing resources such as VOC-ALS, Project MinE, and small-scale MRI cohorts are frequently limited by small sample sizes and insufficient demographic diversity, particularly with respect to early-onset cases and individuals of non-European and non-American ancestries.[15,33] These limitations impair the external validity and clinical generalizability of ML models derived from such data, restricting their applicability to broader, real-world ALS populations. To address these issues, it is essential to establish large-scale, multicenter, longitudinal databases that concurrently acquire standardized neuroimaging, genetic, voice, and facial expression data from the same patients. Coordinated efforts adhering to harmonized protocols such as those developed by the CALSNIC consortium for neuroimaging, along with emerging international initiatives in ALS genomics and digital phenotyping, are critical for generating high-quality, multimodal datasets suitable for ML-based diagnostic, prognostic, and disease-monitoring applications.[9,37-39] To address these identified gaps and guide future ALS database initiatives, we propose the following recommendations:

a) Utilize the existing databases listed in table 3 as benchmark models for designing new, comprehensive, and internationally collaborative ALS databases.

b) Conduct dataset-quality assessments to assist researchers in understanding the strengths and limitations of the dataset.

c) Detailed documentation of dataset usage is required in published methodologies.

d) Prioritize multi-center and international collaborations to improve demographic diversity within datasets.

e) Develop fully integrated, multimodal datasets that link imaging, genetic, voice, and facial data.

f) Implement globally standardized protocols for data acquisition and annotation to enhance interoperability.[16]

g) Increase dataset sample sizes and incorporate longitudinal follow-up data.

h) Expand representation to cover age groups that are currently over- or under-represented in existing datasets.

i) For voice modality data, use standardized recording devices to minimize technical variability.

j) Invest in innovative, multimodal ML frameworks to improve the efficiency and accuracy of early ALS diagnosis and disease monitoring.[6]

k) Recognize the current absence of fully integrated four-modal datasets (genetic, imaging, speech, and facial data) and prioritize addressing this critical limitation.

l) Clinical assessments and validated functional scales, particularly the ALS Functional Rating Scale–Revised (ALSFRS-R), remain central to ALS research and clinical trials. ALSFRS-R provides a standardized measure of disease severity and progression across motor, bulbar, and respiratory domains and is frequently used as a reference outcome for validating imaging, genetic, and digital biomarkers. Integration of ALSFRS-R with multimodal datasets enables supervised ML models to learn clinically meaningful patterns, and enhances the translational relevance of computational findings.[14]

m) Beyond motor and functional impairment, ALS has a profound impact on patients' quality of life (QoL) and daily functioning. ALS-specific instruments, such as the ALS Assessment Questionnaire (ALSAQ-40), capture physical mobility, emotional well-being, social interaction, and communication. Incorporating QoL measures into ALS databases is essential for developing patient-centered ML models and for evaluating the real-world impact of disease progression and therapeutic interventions.[40]

During our scoping review of all datasets, we identified a critical gap: none of them integrated all four types of datasets (genetic, neuroimaging, speech, and facial data) required for a multimodal ML approach. Given the inherent complexity of ALS diagnosis, the majority of investigations have been confined to clinical settings, thereby hindering the construction of large-scale, multimodal datasets essential for developing robust early detection models.

This review has significant limitations. First, databases analyzed across many included studies were relatively small. Such limited sample sizes may not fully represent the diversity of ALS symptoms and can lead to overfitting in ML models. Expanding the dataset size and diversity, perhaps through multi-center collaborations, would enhance ML-driven research in the field of ALS. Second, this review was restricted to articles published in English, which may introduce language bias. Third, although scoping reviews primarily aim to map existing evidence rather than assess methodological quality, some published scoping reviews have employed structured appraisal tools, such as the NOS, to enhance transparency.[41-43] In the present study, the descriptive quality assessment revealed limitations in dataset completeness, longitudinal coverage, and multimodal integration. These limitations should be taken into account when interpreting the findings and planning future ALS database development. Fourth, the majority of included papers were from Europe and North America, which could have affected the generalizability of findings to other geographical regions. Lastly, enhancing dataset variability is crucial. Confirming that the four databases include diverse recordings from different individuals and across various stages of ALS will lead to more robust and generalizable data for use in ML models. Despite these limitations, the review provides a comprehensive overview of all the ALS databases worldwide. Compared with previous reviews in neurology and ALS, which have largely focused on clinical characteristics, epidemiology, or single-modality biomarkers, the present review uniquely emphasizes database readiness for multimodal ML applications. By systematically mapping genetic, imaging, speech, and facial expression datasets, this study highlights critical gaps in data harmonization, longitudinal integration, and demographic diversity. These findings underscore the need for next-generation ALS databases specifically designed to support ML-driven diagnosis, prognosis, and personalized disease monitoring.

Conclusion

This scoping review highlights the current state of researcher-accessible ALS databases, identifying several critical gaps and serving as a practical guide for finding new data sources to advance future clinical trials. Furthermore, the review emphasizes the urgent need for large-scale, multicenter, harmonized databases that collect multimodal data synchronously from the same patients over time. Coordinated international collaborations and emerging federated learning frameworks could address data-sharing and privacy challenges, enabling the development of clinically robust, multimodal ML tools for ALS diagnosis, monitoring, and personalized care.

Acknowledgments

The authors gratefully acknowledge the Clinical Research Development Unit of Shahid Madani Hospital, Karaj, Iran, for their invaluable cooperation and support.

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