ALZ-NET Data User Code of Conduct

I) Overview

The following Code of Conduct outlines the principles and responsibilities for the ethical and lawful use of Alzheimer's Network for Treatment and Diagnostics (ALZ-NET) data. Sponsored by the Alzheimer's Association and managed by the American College of Radiology, ALZ-NET collects longitudinal data from patients being evaluated for or treated with novel FDA-approved therapies for Alzheimer's disease (AD), and tracks patient health outcomes (clinical response and safety), associated with use in real-world settings.

ALZ-NET data can be accessed from multiple sources, each offering varying levels of detail. Some sources provide publicly available aggregate data, while others offer site-specific or network-wide datasets, depending on the level of access and the intended use.

- Data Dashboard: Publicly available, aggregate ALZ-NET data that may be viewed and used in accordance with permitted uses herein. Data users with verified log in access may view, download and analyze site-specific data without formal permission from the ALZ-NET Leadership Team.
- Data Access Request Process/Affiliated Studies: Requests must follow the formal request process as outlined in the ALZ-NET Data Access and Use Policy.

Recipients of ALZ-NET data, including data accessed or received through the ALZ-NET Data Dashboard, the Data Access and Request Process, or affiliated studies, acknowledge and agree that the data received are in an "as-is" condition without any warranties, representations, or guarantees, either expressed or implied, of any nature whatsoever from or on behalf of ACR, including without limitation, those of fitness for a particular purpose and use.

II) Guiding Principles

These guiding principles, developed by the ALZ-NET Leadership Team, articulate ethical and operational standards to ensure ALZ-NET data user's use of data upholds the integrity and success of ALZ-NET.

- **Transparency**: Data usage and sharing practices must comply with ALZ-NET's principles of Acceptable Use defined herein.
- **Privacy**: Personal and sensitive data must be protected in accordance with applicable privacy laws and regulations.
- **Security**: Appropriate administrative, physical and technical safeguards and organizational measures are in place to prevent unauthorized access, alteration, or destruction other than as described.
- **Fairness**: Data must not be used in ways that discriminate, harm, or disadvantage individuals or groups.
- **Accountability**: All individuals accessing and/or handling data are responsible for complying with this Code and applicable laws.

III) Acceptable Use

With permission to use data, ALZ-NET expects that the ALZ-NET data user is transparent in their use of the data and adheres to the following acceptable cases for use:

- Use data only for legitimate business, clinical, research, marketing, operational purposes, scientific investigation, teaching, or the planning of clinical research studies.
- Ensure data accuracy and correct errors when identified.
- Share data only with authorized individuals or entities, and only when necessary or educational in nature.
- Maintain the confidentiality of the data.

IV) Prohibited Use

In support of our commitment to ethical and responsible data stewardship, the following uses of data are prohibited:

- Do not attempt to download or otherwise capture a view of ALZ-NET data for use or disclosure to any entity or individual beyond the reasons described as Acceptable Use.
- Do not redistribute data to anyone else.
- Do not use data for personal gain or unauthorized purposes.
- Do not attempt to re-identify anonymized or pseudonymized individuals or communities associated with ALZ-NET.
- Do not generate information that could allow individual identities to be readily ascertained.
- Do not attempt to contact individuals, their relatives or relevant groups from whom data represented within the ALZ-NET data was collected.
- Do not bypass security controls or access restrictions.
- Do not share the data with a third party without written permission from the ALZ-NET Leadership Team. Requests may be made to alz-net@acr.org.

V) Data Governance

To ensure that our data practices are consistent, compliant, and aligned with organizational goals, all data users must adhere to the following data governance standards:

- Comply with any applicable local, state, federal or tribal laws, regulations or policies with regard to data use, data privacy and data security and exercise responsible stewardship of data, software or other tools provided through and in collaboration with ALZ-NET.
- Follow data classification and data retention policies.
- Document data sources, transformations, and usage.
- Participate in training and awareness programs related to data ethics and compliance.

VI) Material Review: Publications, Presentations and Recruitment

ALZ-NET data may be used in various professional settings, including but not limited to medical or scientific conferences, site presentations, or community events as well as used in the development of marketing or recruitment materials. Data users must comply with the ALZ-NET Advertising Policy for all marketing materials that use or reference ALZ-NET data.

If data are obtained through the Data Use and Request Process or through affiliated study collaborations, the ALZ-NET Leadership Team requires notice to alz-net@acr.org two weeks in advance of use as otherwise written in the Data Use Agreement (DUA) entered into by the requestor. Authors are encouraged to share data uses if presenting public-facing aggregate data from the Data Dashboard or post-log in site-level data, but formal disclosure is not required.

Authors will be required to include acknowledgement statements, including the date of data access, and relevant ALZ-NET project details, in accordance with the ALZ-NET Data Use Policy.

Example Acknowledgement Statement:

"The analyses described in this [publication/report/presentation] were conducted with ALZ-NET data (LINK) accessed on X/XX/XXXX. ALZ-NET is sponsored by the Alzheimer's Association, who has contracted with the American College of Radiology (ACR) to provide for the management and operations of ALZ-NET. ALZ-NET is advised by a group of leading clinicians and researchers, as well as partner organizations. This research was made possible because of the patients who provided their consent to share their information and the providers and organizations (www.alz-net.org) who contributed to the real-world patient data of ALZ-NET."

Recommended Citation for the Use of ALZ-NET Data:

The Alzheimer's Association. (2025). The Alzheimer's Network for Treatment and Diagnostics (ALZ-NET) (Data Accessed) [Data set]. ALZ-NET. www.alz-net.org.

VII) Reporting and Enforcement

This section establishes formal procedures for reporting potential violations of the Code of Conduct, ensuring that all concerns are addressed with confidentiality, impartiality, and a commitment to non-retaliation, thereby upholding the integrity and fairness of our enforcement and monitoring of processes and user access.

- Report any suspected data misuse, breaches, or violations to the ALZ-NET Operations Team at alz-net@acr.org.
- Violations of the Code of Conduct may result in disciplinary action, including suspension or termination of participation in ALZ-NET as deemed appropriate by ALZ-NET Leadership.
- Data misuse or failure to notify the ALZ-NET Leadership of intended data usage may compromise the data user's collaboration opportunities on future projects, and/or incur other sanctions.
- Failure to comply with the requirements outlined in this Code may result in termination of access to the registered ALZ-NET Data Dashboard account, if applicable.
- Dormant and inactive accounts will be evaluated annually for restricted access or deactivation per ACR's standard data security, compliance, and operational efficiency standard operating procedures.

VIII) Review and Updates

This Code of Conduct will be reviewed annually and updated as needed to reflect changes in laws, technologies, and organizational practices. For additional information, please contact the ALZ-NET Operations Team at alz-net@acr.org.