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AI models, bias and data sharing efforts to tackle Alzheimer's disease and related dementias

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ABSTRACT

Artificial intelligence (AI), often seen as a harbinger of future innovation, also presents a dilemma: it can perpetuate existing human biases. However, this issue is not novel or unique to AI. Humans have long been the progenitors of biases, and AI, as a product of human creation, often mirrors these inherent tendencies. Here, we present a perspective on the development and use of AI, recognizing it as a tool influenced by human input and societal norms, rather than an autonomous entity. Modern efforts to technologically enabled data collection approaches and model development, particularly in the context of Alzheimer's disease and related dementias, can potentially reduce bias in AI. We also highlight the importance of data sharing from existing legacy cohorts to help accelerate ongoing AI model development efforts for greater scientific good and clinical care.

1. Introduction

The study of biases, specifically perceptual biases, which are systematic patterns of deviation from normative or rational judgment, has been a significant area of research for centuries, spanning disciplines like psychology, sociology, and behavioral economics. These biases manifest in various forms, ranging from those characterized by noise to motivational biases influenced by experientially reinforced associations. B.F. Skinner famously put forward the notion that positive and negative reinforcements shaped human behavior [1–4]. Divergent from Skinner's supposition is the premise that this shaping process leads to intrinsic bias that influences human judgments and decisions simultaneously. In the context of artificial intelligence (AI), the challenge lies not within its own inherent nature but in how it reflects and amplifies our own prejudices. This realization makes necessary a balanced perspective that neither blindly dismisses AI as fundamentally flawed nor uncritically heralds it as an unblemished force for good.

Bias in AI predominantly originates from the data that these systems are trained on. This data is generated through humanly designed methods and sources, leading to permeation of the prevailing prejudices and disparities that have historically always shaped human societies. In the context of Alzheimer's disease (AD) and related dementias (ADRD), these biases can manifest in cohort selection, diagnostic labeling, and access to healthcare resources, potentially skewing the development and performance of AI models intended to detect or monitor cognitive impairment [5,6]. For instance, imbalanced diagnostic imaging datasets that lack population representation may lead to underdiagnosis in underrepresented groups, delaying treatment and worsening prognosis, as seen in models that perform poorly on non-White populations. Similarly, in biomarker analysis, AI might overestimate risk based on genetic factors like APOE4 that vary by ethnicity, leading to inequitable treatment planning. In cognitive testing, biased algorithms could misclassify symptoms in diverse linguistic or socioeconomic groups, impacting early intervention and clinical outcomes. If left unaddressed, such biases risk perpetuating disparities in diagnosis and treatment, especially among underrepresented populations. When AI algorithms process and interpret this data, they risk not only adopting these biases but also amplifying them, inadvertently reinforcing societal inequalities they might be employed to mitigate. This amplification is particularly concerning given AI's wide-reaching impact and its role in decision-making

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processes across various sectors. It is important to note that the presence of bias in AI outcomes does not necessarily indicate that AI systems are themselves inherently biased. Instead, it reflects the biases that are already embedded in the data sources used for training AI. These biases may arise from a range of sources: from skewed sampling methods that overlook different segments of the population to historical data that inherently carries the biases of past societies. The recognition of AI's tendency to reflect and magnify existing biases presents a paradoxical yet unique opportunity. AI, with its advanced data analysis capabilities, can serve as a powerful tool in identifying and dissecting the biases embedded within our systems and decision-making processes [7,8]. AI can process vast quantities of data, identify patterns and correlations that might be imperceptible to human analysis, and provide an objective view of systemic biases.

AI's potential extends beyond merely reflecting human biases; it also possesses the capacity to challenge and rectify them. For example, in the context of ADRD research and care delivery, AI can identify diagnostic disparities, such as lower accuracy in detecting AD among Hispanic populations in the Health and Retirement Study (HRS) [9], and propose adjustments to clinical algorithms to enhance equity in cognitive screening and referrals. Additionally, by analyzing longitudinal data, AI can reveal racial biases, like overestimating dementia risk in African American cohorts due to unrepresentative training data. It can also examine loan approval rates to detect biases in financial services that are barriers to long-term economic growth [10]. By bringing these insights to the forefront, AI can enable organizations and societies to confront and address these biases more effectively. In the context of science, AI can serve as a catalyst for positive transformation but realizing this opportunity hinges on developing and steering AI with ethical considerations at its core. AI as a catalyst for positive transformation of science is contingent upon the development and guidance of AI with a strong emphasis on ethical considerations. Precision medicine heralds a new era of personalized healthcare but can only happen if the data that is used to generate solutions is sufficiently reflective of the population it seeks to serve. By embedding these principles of ethics and representativeness at the core of AI's design and application, we can harness its transformative capabilities for greater scientific good. To facilitate user comprehension, we present a list of technical terms with brief explanations in Table 1.

Table 1
Glossary of technical terms.

Adversarial debiasing	A technique in AI training where an opposing model component removes correlations with biased attributes (like race or gender) to make predictions fairer.
Algorithmic transparency	The practice of making AI decision-making processes clear and understandable, so users can see how outcomes are reached.
Bias in AI	Systematic errors in AI models that lead to unfair outcomes, often reflecting prejudices in the training data.
CRediT taxonomy	A system for crediting contributors to research based on their specific roles, like data collection or analysis.
Data sovereignty	The right of individuals or communities to control how their data is used and shared.
Demographic distributions	Statistics showing how a dataset is divided by factors like age, gender, race, or location.
Differential privacy	A method to protect individual data by adding noise to outputs, allowing analysis without revealing personal information.
Explainability	The ability to understand and explain how an AI model arrives at its conclusions.
FAIR principles	Guidelines for data management: Findable, Accessible, Interoperable, and Reusable, to improve sharing and reuse.
Federated learning	A method where AI models are trained across multiple locations without sharing raw data, to protect privacy.
General Data Protection Regulation (GDPR)	A European law that sets rules for handling personal data to ensure privacy.
International Committee of Medical Journal Editors (ICMJE)	A group that sets guidelines for ethical publishing in medical journals, including authorship rules.
Missingness patterns	Trends in a dataset showing where data is incomplete or absent, which can indicate biases.
Privacy-preserving architectures	Systems designed to protect personal information while allowing data analysis, like federated learning.
Secure multi-party computation	A technique allowing multiple groups to compute results together without revealing their private data.
SHAP (Shapley Additive exPlanations)	A method to explain AI predictions by assigning importance values to each input feature.

2. The value and challenges of data sharing

Public data sharing as an expedient solution. Institutions, researchers, and stakeholders worldwide are increasingly recognizing the crucial role of data diversity in AI development [11]. They are raising awareness about how AI models trained on biased data can inadvertently perpetuate scientific insights that are limited in scope and utility [12]. This understanding has led to a concerted effort to collect data from diverse sources, encourage the recruitment of people from various backgrounds, and promote open-source data sharing of newly collected data. Programs like the All of Us Research Program exemplify these efforts by prioritizing representativeness of the U.S. population to create a more comprehensive and less biased dataset for further development [13–15]. However, while progress is being made in gathering and disseminating diverse datasets for future AI models, a significant challenge persists in the context of existing or legacy data. The underutilization of data collected over decades across many studies remains hindered by various barriers to current data sharing approaches. To realize the promise of these initiatives, practical limitations in current data sharing practices must be addressed.

Importance of legacy data. The inclusion of existing or legacy data in AI development is critical for advancing ADRD research. First, legacy datasets, such as those from the Alzheimer's Disease Neuroimaging Initiative (ADNI), [16] serve as a valuable source from which to identify historical biases and disparities and then correct them, enabling researchers to prevent perpetuation of inaccurate presumptions in AI models, which is essential to ensure AI fairness and neutrality. For instance, ADNI cohorts predominantly feature White participants, with biases including skewed educational status toward higher-status individuals, gender imbalances, genetic overrepresentation (e.g., of APOE4+ carriers), clinical preferences for MCI/dementia cases with fewer comorbidities, and selection/analytical flaws that overestimate performance. Second, integrating these datasets with diverse, newly collected data, e.g., from the AMP-AD multi-omics hub, [17] provides a comprehensive view, enabling AI to better reflect and serve underrepresented groups by illuminating long-term disease trajectories and evolving diagnostic thresholds. Third, decades-long prospective follow-up data, such as ADNI's verified incident outcomes, are invaluable for training prognostic models essential for ADRD prevention when combined with new collections. Fourth, combining legacy data with modern datasets fosters innovation, uncovering unique correlations, e.g., imaging-neuropsychology links in ADNI, that drive improved ADRD outcomes. Fifth, leveraging existing data optimizes resources by maximizing past investments reduces waste in data collection efforts. Finally, revisiting and managing legacy data ensures compliance with evolving privacy standards, safeguarding trust and mitigating legal risks, which is critical for datasets like ADNI. Together, these elements underscore the critical role of legacy data in building fairer, more informed, and efficient AI systems for ADRD.

3. Barriers to reuse of existing data

Resource constraints. In healthcare research and other fields, effective data sharing is frequently impeded by various factors including limited funding for data management infrastructure [18]. In research, there is a funding bias for the collection of new data relative to the funding of restructuring and reconstructing data collected using long-outdated measurement tools and stored in less secure and outdated useable formats. This financial scarcity impacts the ability to manage and share invaluable existing data effectively. Research funding also often prioritizes projects with immediate, tangible outcomes over more effortful and time-consuming infrastructural needs, such as updating old data management systems or developing more state-of-the art data sharing platforms. Additionally, the technical requirements for bringing secure and accessible data repositories to contemporary standards necessitate significant, sustained investments, often out of reach for smaller or under-funded projects. To overcome this, we recommend adopting FAIR (Findable, Accessible, Interoperable, Reusable) principles as a framework for data management, [19–24] which can guide efficient resource allocation and standardization. Funders could prioritize grants for FAIR-compliant infrastructure upgrades.

Direct access barriers. Another challenge in data sharing is the lack of incentives for researchers and institutions. Currently, career advancement and recognition are largely based on metrics like high-impact publications, grant funding, and individual contributions, often reflected in authorship position [25]. Sharing data, which involves significant effort to curate and maintain datasets, typically receives little comparable recognition, discouraging participation [26]. Additionally, even when data sharing initiatives are available, they often include restrictive conditions that pose obstacles. For example, contributors to data repositories may require researchers to navigate a multi-step permission process. Since approval often depends on human judgment beyond just data use agreements signed to ensure ethical use, it can reflect societal norms about acceptable science. Some researchers also hesitate to share datasets, treating them as valuable intellectual capital to maintain a competitive edge. The reliance on human-in-the-loop decisions for data access can further delay approvals, ultimately slowing scientific progress. Best practices include implementing automated, standardized access protocols aligned with FAIR principles, such as metadata templates for quick evaluation, and institutional policies that reward data sharing through metrics like data citation indices.

Data contributor recognition barriers. Many research groups that provide data also require authorship recognition. This stipulation typically takes two forms. First, the data access approval process may stipulate that contributing researchers be included as collaborators, and by extension, authors on any resulting publication. Second, some groups mandate pre-specified authorship inclusion, often requiring that all individuals involved in data collection be listed as co-authors, regardless of their involvement in conceptualization, study design, or analysis. In the first scenario, including data contributors may unintentionally perpetuate their scientific perspectives, particularly in hypothesis-driven research where investigators tend to pursue questions aligned with their prior beliefs. The second scenario reflects a broad authorship policy that conflicts with established standards [16]. Such practices run counter to the International Committee of Medical Journal Editors (ICMJE) authorship criteria, which require substantial contributions to the conception, design, analysis, or interpretation of data. Moreover, ethical authorship guidelines emphasize the importance of review and approval of the final manuscript, which can further reinforce the biases noted above. While recognizing contributions is important, these authorship requirements can complicate and deter broader use of the data. To address this, we propose adopting the CRediT taxonomy, ORCID-linked dataset DOIs, and data-citation indices to acknowledge data providers' efforts without mandating co-authorship, fostering equitable recognition and encouraging data sharing.

Platform utilization costs. Certain data repositories, such as the UK Biobank (UKBB), prohibit downloading data altogether, requiring researchers to use their platforms for analysis, [27] where high fees or limited functionality often monetize access and stifle open collaboration. However, the UKBB's new subsidized cloud-credit program now supports enhanced access, offering a step toward improvement. These practices, despite the subsidy, can still hinder the accessibility and equitable utilization of shared data, particularly for researchers in low resourced research environments, ultimately slowing the collective progress of AI in healthcare that will impact all. To address these challenges, it is essential to implement structural changes in the academic recognition system and establish clear, fair data-sharing policies that balance acknowledgment with usability. We suggest policies like open-access subsidies and standardized metadata reporting under FAIR guidelines to reduce costs and enhance interoperability across platforms.

4. Ethics, legal and social considerations

The data sharing process is further complicated by privacy and ethical considerations. Protecting participant/patient confidentiality while ensuring informed consent for data usage presents intricate challenges, particularly when maintaining the research utility of anonymized data. With the increasing capabilities of AI and other analytical tools, it is becoming more difficult to guarantee absolute privacy, and a residual risk of re-identification remains even with de-identified data [28]. Efforts are underway to enable data access while obfuscating identities; [29] however, this remains an ongoing and inherently imperfect process that may never fully eliminate the risk. Privacy-preserving architectures such as federated learning and secure multi-party computation offer promising solutions to mitigate these risks. Specifically, federated learning allows collaborative model training across decentralized datasets without exchanging raw participant/patient data, enabling institutions to contribute to AI development while keeping sensitive information local and secure. For example, the Alzheimer's Disease Data Initiative (ADDI) Workbench employs federated data sharing through its Federated Data Sharing Appliance, [30] facilitating ADRD research by aggregating model parameters rather than centralizing data, thus enhancing privacy and data sovereignty. Similarly, EU-funded projects like TRUMPET advance federated learning in healthcare ensuring compliance with GDPR and promoting equitable global collaboration [31]. To build on this, differential privacy can be integrated into federated setups by adding controlled noise to model updates, preserving individual data while maintaining utility [32, 33]. Federated multi-site training further enables cross-institutional collaboration for ADRD prediction, such as quantifying the extent of hippocampal atrophy in AD from MRI data across hospitals without data transfer, improving model generalizability and reducing bias amplification [34]. These methods have shown practical success, e.g., achieving comparable accuracy to centralized models while ensuring compliance in dementia cohorts [35]. Informed consent for reuse of data in the future, either in its raw or derived form, must include data analysis for scientific objectives that are unknown at the time of consent. Data sovereignty is a crucial factor in research involving marginalized communities, demanding ethical practices that respect these groups' participation and decision-making regarding their data. Navigating these ethical complexities alongside the goals of broad data sharing requires adherence to robust ethical guidelines and careful consideration. This is particularly relevant in ADRD research involving groups who may be underrepresented in neuroimaging and biomarker studies. Ensuring their inclusion in shared datasets must go together with ethical safeguards and community engagement to promote trust and transparency.

5. Designing equitable and transparent platforms

Equitable data collection, technological accessibility for global

reach. To promote inclusive and impactful research, platforms for participant data collection and data sharing must be guided by principles of accessibility, global reach, explainability, and transparency. Ensuring usability across diverse settings, especially in low- and middle-income countries, requires support for multi-lingual, multi-region, and low-literacy use cases that support equitable data collection and inclusion of underrepresented populations globally.

Technological accessibility can be strengthened by designing open-access platforms with no-code interfaces that lower technical barriers and broaden participation. Strategic partnerships and community engagement are critical to extending these platforms to underrepresented researchers and populations, thereby helping democratize AI and data tools. Equally important is embedding explainability and transparency into system design. AI outputs must be auditable and reproducible, particularly in sensitive domains like biomedical research, to identify and reduce bias. Platforms should also integrate metrics and evaluation tools that track inclusivity, equity, and diversity throughout their development and deployment. Together, these design principles support a more equitable and trustworthy research infrastructure.

Importance of transparency and responsible use of data during data sharing. As AI models increasingly rely on multimodal datasets for ADRD research, ensuring transparency and detailed documentation demonstrating responsible use during data sharing becomes critical to uncover and mitigate potential biases. Many datasets, particularly legacy cohorts, may contain imbalances related to gender, race and ethnicity, socioeconomic status, and geographic representation. Without explicit documentation of these attributes, there is a substantial risk that AI models will unknowingly perpetuate or even amplify these historical inequities. To promote transparency, datasets should be accompanied by comprehensive summary statistics and demographic distributions. Key variables to report include gender breakdown, race and ethnicity composition, age ranges, socioeconomic indicators when available, and geographic distribution across urban, rural, and regional settings. In addition, repositories should document missingness patterns across critical modalities such as neuroimaging, cognitive assessments, and biomarker data. By providing these metrics upfront, researchers can critically assess the diversity, strengths, and limitations of datasets before proceeding with model development, allowing for more informed decisions about data use, subgroup analyses, and fairness evaluations.

Importantly, transparency efforts should extend beyond the data level to the modeling process itself to address explainability. AI developers should carry forward demographic metadata into training, validation, and testing stages, systematically reporting model performance across key subgroups. This practice enables the identification of differential error rates, highlights potential disparities and strengthens the interpretability and fairness of model outcomes and makes the models explainable. Embedding demographic transparency throughout the data-to-model pipeline will not only improve scientific rigor but also foster the development of AI systems that are equitable, generalizable, and clinically responsible. Ultimately, addressing explainability at the outset of data sharing lays the foundation for developing AI models that better reflect and serve diverse populations. As the ADRD field embraces increasingly complex and heterogeneous datasets, maintaining visibility of underlying biases throughout the research lifecycle will be essential to ensure that technological advances translate into meaningful, equitable clinical improvements.

6. Towards ethical AI: addressing bias through better practices

The criticism aimed at AI for propagating bias underscores the necessity of comprehending its multidimensional role. AI's efficacy and fairness are contingent on the quality of the data it learns from and the intent behind its creation and application. Consequently, developing and implementing AI demands a deliberate focus on ensuring data representativeness, algorithmic transparency, and constant vigilance for biases. Confronting AI's complexities necessitates a collaborative effort encompassing a broad spectrum of stakeholders, including technologists, ethicists, policymakers, and the communities they impact. Jointly, these groups can establish ethical AI standards, advocate for diverse and inclusive data practices, and implement ongoing evaluation mechanisms to detect and mitigate biases.

While upstream data practices (e.g., representative data collection and low barrier data access) are essential, biases can persist or emerge during model training and deployment. To mitigate this, targeted techniques that intervene directly in the AI pipeline include: (a) Adjusting the influence of underrepresented groups in training data. For instance, oversampling minority cohorts (e.g., non-White participants in ADRD datasets) or assigning higher weights to their samples can balance model learning and reduce disparities in prediction accuracy. (b) Training models with an adversary component that penalizes predictions correlated with protected attributes (e.g., race, sex). This encourages the model to focus on disease-relevant features, such as neuroimaging patterns, rather than demographic proxies [36]. (c) Incorporating fairness metrics directly into the loss function during training, such as enforcing equalized odds (ensuring similar true positive rates across groups) or demographic parity (equal prediction rates across groups). These methods build on general data equity but are tailored to AI's iterative learning process, helping prevent amplification of historical biases in legacy ADRD cohorts.

To assess whether mitigation efforts are effective, rigorous evaluation is key. Post-training audits can include: (a) Quantitative measures like disparate impact (ratio of favorable outcomes between groups, ideally close to 1.0) or equalized odds/error rates to quantify bias. For example, in an ADRD diagnostic model, evaluate if false negative rates are higher for underrepresented ethnic groups. (b) Stratify performance by demographics (e.g., via confusion matrices per race/ethnicity) and test robustness to perturbations in input data, revealing hidden biases. (c) Employ techniques like SHAP (SHapley Additive exPlanations) to interpret feature importance, [37,38] identifying if biased variables (e.g., socioeconomic proxies in HRS data) unduly influence ADRD risk predictions.

To demonstrate how mitigation can lead to better clinical outcomes, such as earlier accurate diagnoses and equitable treatment planning, consider the following ADRD-specific examples:

- *Racial bias in diagnostic models:* In models trained on predominantly White cohorts (e.g., ADNI), algorithms may overestimate dementia risk in African American individuals due to unrepresentative biomarkers like APOE4 prevalence. One way to address this is to apply reweighting during training and evaluate with equalized odds [39].
- *Sex/gender bias in prognostic models:* Female participants might be underrepresented in neuroimaging subsets, leading to poorer prediction of outputs for women [40,41]. A strategy to address is via adversarial training to decorrelate gender from outputs, combined with subgroup analysis to ensure balanced sensitivity/specificity.
- *Socioeconomic bias in screening tools:* AI relying on electronic health records may underperform for low-socioeconomic status groups due to access disparities. To address this aspect, one could integrate fairness constraints and test with disparate impact metrics, then refine via federated learning across diverse institutions [42].

Understanding the dual nature of AI, both as a reflector of human biases and a potential tool for overcoming them, is crucial in shaping its future trajectory. Rejecting AI as inherently flawed or uncritically accepting it as a universal solution oversimplifies its impact. Instead, recognizing AI as a human-crafted tool with the dual capacity to both mirror and amend our biases is key. By embracing the complexity and potential of AI, we can steer its evolution towards a future where it serves not only as a technological advancement but to foster equity and deeper understanding, aligning with our aspirations for a fairer and more insightful society. We commend the recent initiatives undertaken by various agencies to encourage the sharing of diverse datasets.

Additionally, we advocate for institutions, researchers, and other stakeholders to actively support the sharing of historical data. This collaboration is crucial for meaningful contributions to the development of AI models, both ongoing and future. This comprehensive approach to data sharing, encompassing both contemporary and legacy datasets, is essential for creating AI models that are robust, representative, and effective [7].

7. Conclusion

As AI continues to transform scientific discovery and healthcare delivery, particularly in the context of ADRD, the way we collect, document and then share data will profoundly shape its fairness and utility. The study of bias that is rooted in centuries of behavioral research reminds us of these cognitive distortions, once solely considered human, are now embedded in the datasets that train machine intelligence. While AI has the potential to reflect and reinforce longstanding inequities, it also offers a powerful mechanism for identifying and correcting them, if developed with intention, transparency, and inclusive design. Moving forward, a core requirement for ethically sound AI will be transparency in data sharing. Publishing summary statistics on key demographic and geographic variables, alongside detailed documentation of data completeness and structure, is no longer optional. It is foundational. Equally, ensuring that these metadata persist through the full modeling lifecycle will allow for subgroup-specific performance analysis, surfacing hidden inequities and enabling their mitigation. This level of transparency not only enhances model generalizability and interpretability but also builds public trust in AI systems used in high-stakes contexts such as ADRD. The path ahead requires collaborative leadership. Institutions, funders, and researchers must work together to remove disincentives for sharing well-annotated, diverse datasets including legacy data, and develop clear standards that reward openness and fairness. Ethical AI will not emerge by default; it will result from deliberate choices made at every level of the data and model pipeline. By confronting the structural origins of bias and embedding equity as a design principle, the field can move toward an AI-enabled future that serves all populations accurately, responsibly, and justly.

8. Ethics declarations

V.B.K. is a co-founder and equity holder of deepPath Inc., and Cognimark, Inc. He also serves on the scientific advisory board of Altoida Inc. R.A. is a scientific advisor to Signant Health and NovoNordisk. The remaining author declares no competing interests.

Declaration of competing interest

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