# **Research Integrity**

## **Our Statement on Research Integrity**

As the world's largest not-for-profit funder of Alzheimer's and dementia research and the leading voice for Alzheimer's disease advocacy, the Alzheimer's Association is committed to upholding high standards of research integrity. Integrity and rigor in research are foundational to building and maintaining the public's trust in the scientific process and the medical community. As a patient advocacy group committed to advancing transformative outcomes for those we serve, we hold ourselves to principles of research integrity. Additionally, we actively take steps to ensure all funders, researchers, industries, and other entities that conduct, fund or communicate about Alzheimer's and dementia research and/or related findings, or create products for consumers living with or facing this disease, are also acting in accordance with these principles below.

The four principles of research integrity include transparency, disclosure of conflicts of interest, utilization of scientific discourse to establish direction, and commitment to communication and disclosure to participants involved in research studies.

#### Transparency

For the purposes of this document, transparency refers to the sharing of appropriate aspects of a research study — including the questions being asked, the methods to answer these questions, the data collected, the analysis conducted, and the conclusions from the study — to allow others to fully evaluate and potentially validate the process and the findings. Sharing should be in a timely manner, and should follow best practices for the given type of data. For instance, Alzheimer's Association clinical studies are required to adhere to the CAP (Collaboration for Alzheimer's Prevention) principles.<sup>1</sup> Study designs and methods should be shared at the earliest time point, and should include website and other public facing information, as applicable for the study.

Transparency is a key principle of open science, promoting reproducibility and accountability within the scientific community. This also includes transparency of our grant review process and our funding programs. The Alzheimer's Association includes detailed information on our review process on our website at <u>alz.org/grants</u>, publishes lay language abstracts of all funded projects, and participates in the International

<sup>&</sup>lt;sup>1</sup> <u>https://pubmed.ncbi.nlm.nih.gov/27157073/</u>

Alzheimer's disease and Related Dementias Research Portfolio (IADRP)<sup>2</sup> to publicly share funded research through a common ontology.

Transparency also applies to the Alzheimer's Association-owned publications, including the *Alzheimer's & Dementia* journal family. The Association's publisher, Wiley, uses specific guidelines published on their website: "Best Practice Guidelines on Research Integrity and Publishing Ethics<sup>3</sup>" for "researchers, in their various roles as editors, authors and peer reviewers; societies; librarians; funders; corporations; publishers; and journalists."

#### **Disclosure of conflicts of interest**

A conflict of interest is defined as any financial, personal or professional relationship that may compromise or appear to compromise an individual's or group's decisions or opinions. The Alzheimer's Association expects the full research community as well as all our staff and board members to disclose conflicts of interest, real or perceived, to ensure the integrity of the work being conducted in any workstream, scientific presentation, publication or other venue and/or to ensure that relevant audiences are aware of any real or perceived conflict, and appropriate actions are taken to protect the research integrity.

In instances of financial conflict, the Alzheimer's Association has a strict policy for staff-related interactions that ensures no contribution impacts the organization's decision-making. For researchers funded by the Alzheimer's Association, those working with the Association across a variety of workstreams, or those in the field broadly who present or publish their research to various audiences — including but not limited to media, health care professionals and the general population — we expect a similar commitment to disclosure of relevant conflicts that align with Association policies or federal guidelines on identification, reporting and management of financial conflicts of interest.

The Alzheimer's Association engages numerous volunteers for scientific advising, study-specific scientific advising, peer-review input for potential funding, conferences and journal publications, development of systematic reviews and clinical practice guidelines, as well as other scientific input more broadly. In each of these instances, the Association collects detailed conflict of interest information following best practices for the purpose. For instance:

• The Associations' journals require all authors to submit forms designed by the International Committee of Journal Medical Editors (ICJME); similar forms are

<sup>&</sup>lt;sup>2</sup> https://iadrp.nia.nih.gov/

<sup>&</sup>lt;sup>3</sup> <u>https://authorservices.wiley.com/ethics-guidelines/index.html</u>

used for various scientific committees of the Alzheimer's Association. In addition, the Association mandates the senior editorial board of the journals to provide COI forms, and these disclosures are listed on the journals' websites.

- All clinical practice guidelines (hereafter, "guideline") panel nominees must adhere to the Alzheimer's Association established conflict of interest disclosure process; there are established evaluations for reviewing these forms and finalizing selection of panel members, as well as the process for managing conflicts during and after guideline development. Ultimately, all financial and intellectual disclosure and our methods for managing them will be publicly reported in our published guideline manuscripts.
- Alzheimer's Association convened workgroups and panels require completion of ICJEM forms and updates of these forms in a regular cadence; when draft documents are being shared, author disclosures are included and updated with each iteration.
- For Association-funded researchers, the Alzheimer's Association requires awardees to disclose any significant financial interest that may affect their work and it is their institution and/or organization's responsibility to ensure appropriate monitoring and management of investigator-related financial conflict of interests.
- Reviewers are asked to confirm their conflicts for each grant application or conference abstract they agree to review.
- Grant reviewers are asked to further verify whether they trained with, were trained by or trained the applicant; whether they have any financial benefit to the application; whether they have a philosophical bias to reviewing the application; as well as institutional overlap. In addition, they are asked to abstain if they have a personal relationship with the applicant(s) that will prevent them providing an unbiased review.
- Abstract reviewers are asked to abstain if they have a conflict of interest.

#### Utilization of scientific discourse to establish direction

The state of Alzheimer's and dementia research is larger than any one specialty, one individual, one paper or one study. Through the use of activities such as peer review processes, summits and council discussions, the Alzheimer's and dementia field at large defines direction by listening and engaging with a broad field of experts. As such, the field builds off of years of direction, advances, failures and redirection.

Scientific discourse is a key element to strong science, supporting ideation among diverse perspectives and disciplines, evaluating data and observations. In addition,

discourse opens research to the scrutiny necessary to expose substandard work or fraudulent behavior(s).<sup>4</sup>

Through the Alzheimer's Association's vehicles of convening and communication (i.e., conferences and journals), there is a core foundation to facilitate opportunities that support communication, transparency and sharing of information that are critical to maximizing scientific discovery, while also working to overcome scientific mistrust.<sup>5</sup>

**Commitment to communication and disclosure to participants in research studies** Commitment to and carrying out the necessary communication of the evolving scientific understandings and related information is critical to address mistrust in science.<sup>6</sup> This is inclusive of sharing balanced communications and interpretations of studies, results and their potential implications for the individuals that may be affected. This also means that participants in research studies should be at the forefront of any communications related to said study. Research participants should expect to receive communication about the study design, sponsor information, and outcomes of the research; these should be shared with study participants in a timely and considerate manner that centers the participant in those communications.<sup>7</sup> In addition, participants should expect the research team to share with them information about research outcomes that are similar in approach and substance to the study in which they are engaged.

### Our Commitment to Research Integrity for All We Serve

As a funder, convenor, and thought leader in the field of Alzheimer's and dementia research, the Alzheimer's Association is dedicated to working with our volunteers, employees and the larger scientific community to support the mission of the Association and align our behaviors and expectations with these principles. To that end, we are committing to conducting all of the Alzheimer's Association's affairs and activities with the highest standards of ethical conduct, in line with these principles.

- Proactively incorporate and promote the principles of research integrity in the work and activities of the Alzheimer's Association, including our scientific convenings, communications and research funding opportunities.
- We disclose all conflicts of interest when publishing, speaking at Alzheimer's Association research meetings and conferences, and through the Alzheimer's

https://www.crick.ac.uk/about-us/our-approach-to-science/scientific-discourse#:~:text=Scientific%20discourse%20 is%20core%20to.substandard%20work%20or%20fraudulent%20behaviour

<sup>&</sup>lt;sup>5</sup> https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8215623/

<sup>&</sup>lt;sup>6</sup> https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8215623/

<sup>&</sup>lt;sup>7</sup> https://pubmed.ncbi.nlm.nih.gov/35917209/

Association vehicles of disclosure when serving on committees or panels. We adhere to clear standards regarding peer-review of all journal articles, conference sessions, and research funding.

- We expect our staff and research volunteers to provide constituents and the broader community with information that is accurate and objective.
- The Alzheimer's Association does not allow staff to personally benefit financially from participation on an advisory council or other opportunity received as a result of work with the Alzheimer's Association.
- We require recipients of our funded research to adhere to our standards regarding scientific misconduct, including fabrication, falsification and plagiarism. We investigate any allegation of misconduct with the award institution and work with the institution on appropriate actions if any misconduct is identified. We require that authors of articles staff and research volunteers in Alzheimer's Association owned publications, including the *Alzheimer's & Dementia* journal family, disclose any real or perceived affiliations and interests, financial or otherwise using ICJME standards. We expect our staff and volunteers to follow this same standard when publishing in other journals, regardless of their policies.
- We expect staff and research volunteers to accept responsibility to prevent, detect and report all manner of fraud or other illegal activities through the organizational defined processes.
- We require all staff and expect all research volunteers to be honest and ethical in their conduct, including the reporting and handling of real or perceived conflict of interest between personal and professional relationships and in the conduct of all research activities. The Association has established rules for collecting intellectual and financial conflict of interest disclosures from guideline panel nominees, our criteria for evaluating these forms and selecting panel members, and our process for managing conflicts during and after the guideline development process.

As staff and research volunteers of the Alzheimer's Association, the Association believes that our individual and collective responsibility is to ensure the collective success of our community by practicing and promoting these principles that reflect a shared view of how we want to operate and be seen by others. Violations of these principles will result in adverse consequences, including employee termination or removal of a volunteer from their position, journal paper retraction, withdrawal of funding or other appropriate action.

As noted above, we require recipients of our funded research to adhere to our standards regarding scientific misconduct, including fabrication, falsification and plagiarism. We investigate any allegation of misconduct with the award institution and

work with the institution on appropriate actions if any misconduct is identified. For researchers funded by the Alzheimer's Association, suspected violations will be shared with the researcher(s) institutions; any investigation regarding research misconduct will be led by the researcher(s) institution and a report and/or summary of their report will be shared with the Alzheimer's Association. Based on these findings, the Alzheimer's Association will either take no action, withdraw funding, require return of funds or another appropriate action based on the investigation's findings.

The Association leads numerous scientific workgroups and panels, including guidelines panels. All disclosures, both financial and intellectual, are publicly reported in our published guideline manuscripts, and must be reported. Failure to do so will result in removal of the individual(s) from the guideline panel and disclosure of this change in living manuscripts and relevant public facing websites. They will not be eligible for future guideline panels.

In addition, we require that authors of articles — staff and research volunteers — in Alzheimer's Association owned publications, including the *Alzheimer's & Dementia* journal family, disclose any real or perceived affiliations and interests, financial or otherwise using ICJME standards. For researchers who have published a paper in an Alzheimer's Association owned journal with alleged research misconduct, the *Alzheimer's & Dementia* journals will take action based on COPE guidelines.