



Participating in Research Studies: Behind the Scenes

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This article will explain how research funds are distributed to researchers so as to better inform potential participants, their families and those who donate funds for Alzheimer research. The more one understands the research process the more one can comprehend why research takes so long to plan and execute and what rigorous guidelines researchers must follow.

This article will not describe the process of drug development by pharmaceutical companies as it is regulated by Health Canada protocols. Visit the Alzheimer Society of Canada website www.alzheimer.ca under Treatments for a detailed explanation.

Funding for research into Alzheimer Disease can come from several sources: the local, provincial and national Alzheimer Societies and its partners; universities, colleges, hospitals and private foundations.

The primary federal agency is the Canadian Institutes of Health Research (CIHR). CIHR was founded in 2000 taking over the functions previously held by Medical Research Council. CIHR is organised around Institutes that reflect important research themes (see www.cihr-irsc.gc.ca). The Institute of Aging has been supportive of Alzheimer research but other Institutes support Alzheimer research as well (e.g., the Institute of Gender and Health and the Institute of Neurosciences and Mental Health).

Funds for the Alzheimer Society research program are raised by the provincial and local Alzheimer Societies as well as the Alzheimer Society of Canada. An attractive feature is the

Partnership Program. Funding for research projects and trainees (Young Investigators, post-doctoral fellows and doctoral students) is shared with Astra-Zeneca (Canada & US), CIHR, the Canadian Nurses Foundation, the Canadian Health Services Research Foundation, the Heart and Stroke Foundation, Pfizer, Fonds de la recherche en santé du Québec (FRSWQ) and the Alzheimer Society of Saskatchewan, the latter specifically for Young Investigators.

All of these organizations whether government or non-government have committees in place to oversee research competitions and the dissemination of funds for research. These agencies, in consultation with researchers, set guidelines for reviewing research proposals and granting funds. Guidelines usually outline how long the request for funds (research proposals) can be and when they have to be sent to the granting agency. Some organizations hold annual competitions while others only hold competitions on special occasions. Some grants are for a one-year period; others are for several years of support to allow time for more detailed research to be completed. The limiting factor is often the availability of funds.

Research proposals include a description of the relevant scientific literature, an outline of the rationale for the proposed research, hypotheses about the outcome of the research, a detailed description of how the research will be carried out, how the data collected will be analysed (statistical methods), the composition of the research team (their expertise and experience), the feasibility of carrying out the research, how ethical considerations will be dealt with and

a budget. Individual agencies often require a statement detailing the relevance of the research proposal to the objectives of that agency.

Budget items in a grant proposal may include monies for administrative assistance, trainee salaries, equipment and limited travel to conferences to present the results of the study. The budget does not include salary support for the principal investigator. The administrative costs are kept to a minimum to ensure that as much money as possible actually goes to the research projects.

Research proposals may be reviewed in depth by internal members of the agency research committee or may also be sent to external reviewers – experts in the area of the proposed research. This is called peer review. Reviewers have to complete an evaluation form and rate the proposals based on how convincing a case they feel was made that the proposed research is relevant, scientifically sound and feasible.

Once all these external and internal reports are gathered, there tends to be a common process among the agencies. The Alzheimer Society Research Program, for example, has two review panels: a biomedical and a social/psychological. Each panel discusses and scores the applications and the partners identify those relevant to their specific objectives. The committee uses the scores and the relevancy decisions to determine the applicants to be recommended for funding. Funds are allocated equally to biomedical and social/psychological research. Even proposals that are felt to be very deserving and scientifically sound may not be funded if there are insufficient funds to grant.

Once the monies have been distributed the researchers are notified of their success and can proceed with the project. They are asked to provide regular reports to the funding agency about the progress of the research and account for the research funds they have spent. Funding research is a complex process involving many individuals who prepare and submit proposals as well as those who review them and rate them. Some questions you may want to ask about research projects you are involved in include:

1. What agency funded the research?
2. What kind of review process does this agency undertake before granting funds?
3. What percentage of the research budget is spent on administrative costs?
4. Are there ways to get involved in setting Alzheimer research policy or priorities?
5. Has an ethics committee approved the study protocols?

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