

Editorial

Big data, aging, and dementia: Pathways for international harmonization on data sharing

Among the impediments for the development of therapies to halt chronic diseases of aging and Alzheimer's disease, the need to integrate scientific, population-level, and clinical information is gaining distinction. In an era of declining biomedical research resources, international public health research funders are joining together in a growing chorus emphasizing the call for "translational knowledge" that spans from "bench to bedside". These governmental and non-governmental agencies are actively promoting and fostering international collaborations as a means to leverage resources to combat major public health problems.

This is sound public health policy. The strategy is derived from a well-established tradition of international cooperation in other areas of biomedical research, mostly in infectious and other acute diseases. Yet, the application of these methods for chronic diseases such as Alzheimer's disease requires a recalibration of tactics along three planes. The first is the recognition to build upon ongoing projects and integrate existing resources to establish an International Database for Longitudinal Studies on Aging and Dementia (IDAD) [1,2]. The second includes greater harmonization among the multitude of ongoing international collaborative research and data-sharing initiatives. The third is the formulation of standardized international data-sharing guidelines, including solutions to provide prospective and retrospective volunteer informed consent, to expand these endeavors. These shifts will enable better methods that may someday identify asymptomatic people at elevated risk for chronic brain disorders that effect cognition, motor functions, or mood [3].

There are many excellent ongoing efforts to organize multiple users, institutions and nations to support big data development, such as the National Alzheimer's Coordinating Center, Alzheimer's Disease Neuroimaging Initiative, European Medical Informatics Framework, Global Alzheimer Association Interactive Network, Dominantly Inherited Alzheimer Network, Alzheimer Prevention Initiative, and European Commission Joint Programming Initiative. However, the macro-level challenge of achieving seamless integration of data, information, and knowledge remains beyond the intended mission of these projects. In order to usher in the era of

big data for aging and dementia research, three key mission parameters need to be addressed:

1. Magnitude and multiple domains of data: With few exceptions, most ongoing efforts involve relatively small sample sizes designed to address highly focused areas of research questions. These datasets include specific, often nonoverlapping, domains of data that serve the special needs of particular data consumer clientele [e.g., genetic, imaging, epidemiology, etc.].
2. Harmonization: Linkage among ongoing efforts, networks, or databases has started, but issues of data sharing, data merging, and privacy concerns/volunteer informed consent need to be strengthened, expanded, and reviewed.
3. Funding: The most critical problem is lack of adequate and sustained funding to support the data management beyond the life cycle of a grant. The international big data initiative must identify new and/or hybrid financing mechanisms to support massive global enterprise.

The effort to launch a massive international enterprise, such as IDAD, will require the support and cooperation of not only the worldwide scientific community, but also an international body of policy makers. Without any doubt, this undertaking will be: a) extremely difficult (with a large array of scientific, technical, administrative, and financial barriers that have to be navigated), b) extremely costly (the project will need to explore novel models for financing), and c) extremely time-intensive.

The first step towards the creation of IDAD and the process of formulating international guidelines to harmonize data-sharing among collaborative research networks will require a thorough assessment of all existing databases, cohorts, ongoing longitudinal studies, and collaborative research networks. Thus, this call-to-action outlines an essential first step to assemble a comprehensive annotated inventory of all the relevant information on available resources or current efforts. The project of establishing a single location for citation and a process for documenting all databases-resources will be an interactive process between the worldwide scientific community and *Alzheimer's & Dementia*.

Global investigators are invited to participate in assembling and evaluating the proposed inventory of resources. Participation in this project entails providing input to the deliberations of virtual workgroups. Potential contributions may be considered towards the composition of an eventual

The authors have no conflict of interest to report.

big data special issue in *Alzheimer's & Dementia* and include topics related to computational and analytical approaches to knowledge extraction from large, complex datasets.

The special issue will aim to provide a set of seminal articles on the array of challenges confronted by various groups in their efforts to establish a multi-site collaborative research network, harmonize data sharing rules, and manage (governance/financing) of big databases as shared global resources. This pending special issue will contain not only a wide spectrum of thought-provoking perspectives on the rationale, utility and challenges of establishing a comprehensive multi-purpose database (as a shared international research and development resource), but also it will assemble a comprehensive inventory of all ongoing, cohorts, longitudinal studies/databases, and collaborative research networks. An initial listing of the pending comprehensive inventory can be found online in [Supplementary Table 1](#)

Alzheimer's & Dementia solicits suggestions from the wider scientific community of any additional databases, cohorts, or ongoing studies that should be included in the proposed comprehensive inventory. Readers are invited to suggest additional studies, cohorts, collaborative networks, public and private partnerships, or databases that should be considered for inclusion in the listing of the final version of this catalog. Once the initial survey is complete, periodic updates and amendments to the comprehensive catalog will be made with the addition of new studies or related efforts. Readers are also invited to share their thoughts about any aspect of this project, the special issue, and volunteers willing to support this venture.

The specific goals will be to survey and review all major data series that can be combined in standardized formats, codified and made accessible for truly international comparative purposes. There is also a need to assess the feasibility of integrating, harmonizing, and standardizing (whenever possible) all ongoing longitudinal databases comprising different domains of measurements (e.g., behavioral, biological, life-style, genetics, neuroimaging, biomarker, and other healthcare or services information). Subsequently, the volunteer workgroup will need to evaluate various models for the governance, financing and, harmonizing of IDAD.

The four questions requiring assistance during the initial phase of this endeavor are:

1. What are some of the key additional longitudinal studies, cohorts, databases, collaborative research networks, or other research consortia that should be included in the comprehensive inventory? ([Supplementary Table 1](#))
2. Who, what, and where are the additional key references, contacts, resources, and sources of information? ([Supplementary Table 2](#))
3. What are your suggestions for a categorization scheme for the items listed in the proposed comprehensive inventory? What types, major headings/categories, sub-headings, and other information should be used to cluster, characterize, or distinguish the items in the inventory? ([Supplementary Table 3](#).)
4. What types of the descriptors, data parameters or fields of information should be used to annotate each

entry or listing in the inventory? Are there additional items or information that should be included? ([Supplementary Table 4](#).)

Acknowledgment

We wish to express our gratitude to the following colleagues who provided invaluable information and suggestions in preparation for this project and their willingness to continue serving as *ad hoc* advisors and members of prospective workgroups described in the paper:

Dallas Anderson, Luigi Ferrucci, Richard Suzman, Molly Wagster, Carol Brayne, Mary Ganguli, Lew Kuller, Kristine Yaffe, Deborah Barnes, Martin Rossor, Francine Grodstein, David Bennett, Henry Brodaty, Hugh Hendrie, Giovanni Frisoni, Sandrine Andrieu, Howard Chertkow, Serge Gauthier, Lon Schneider, Kaj Blennow, Harald Hampel, Richard Frackowiak, Jim Mortimer, Amy Borenstein, and Rhoda Au.

Dr. Kukull's work is supported by grant number U01AG016976.

Ara S. Khachaturian
Executive Editor*

Alzheimer's & Dementia:
The Journal of the Alzheimer's Association
451 Hungerford Drive, Suite 119-355
Rockville, MD 20850, USA

*Corresponding author. Tel.: 301-309-6730.
E-mail address: adj_xed@kra.net

Dana H. Meranus
Research Assistant
National Alzheimer's Coordinating Center
Seattle, WA, USA

Walter A. Kukull
Director
National Alzheimer's Coordinating Center
Seattle, WA, USA

Zaven S. Khachaturian
Editor-in-Chief
Alzheimer's & Dementia:
The Journal of the Alzheimer's Association
Rockville, MD 20850, USA

References

- [1] OECD. Emerging Trends in Biomedicine and Health Technology Innovation: Addressing the Global Challenge of Alzheimer's." OECD Science, Technology and Industry Policy Papers. 2013. Available at: <http://dx.doi.org/10.1787/5k44zcpt65vc-en>. Accessed September 12, 2013.
- [2] Alzheimer's Association Expert Advisory Workgroup on NAPA. Workgroup on NAPA's scientific agenda for a national initiative on Alzheimer's disease. *Alzheimer Dement* 2012;8:357–361.
- [3] Khachaturian ZS, Petersen RC, Snyder PJ, Khachaturian AS, Aisen P, de Leon M, et al. Developing a global strategy to prevent Alzheimer's disease: Leon Thal Symposium 2010. *Alzheimer Dement* 2011;7:127–32.