

## Health services research / Policy and plans

# The formation of the advisory group on risk evaluation education for dementia

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#### Abstract

**Background:** When and how to communicate effectively the results of genetic and biomarker based prediction, detection, and quantification of the brain substrates of dementia involve important ethical and legal issues critical for precision medicine. The urgency of the issue has increased as People Living with Dementia (PLwD) and with Risk for Dementia (PwRD) can access direct to consumer genetic testing, amyloid targeting drugs, and clinical amyloid PET scans. To address the need for effective dissemination and consultation, an advisory group was convened that welcomes all interested members.

**Method:** Members attend two meetings monthly via phone/computer/WebEx. One meeting is a targeted working group that focuses on the following: 1. Symptomatic (PLwD), 2. Asymptomatic (PwRD), 3. Research, 4. Ethics/Healthcare Law, 5. Trainee/Mentorship. These discussion groups hear from and present to stakeholders (PLwD/PwRD/caregivers, professional organizations, companies) to solicit feedback on the efficacy of their efforts. Members also attend a monthly "all hands" meeting where they receive updates from other groups and hear presentations on emerging research and resources.

**Result:** The advisory group is composed of 104 members who represent advocacy/stakeholders (21%, e.g. professional organization representatives, (PLwD/PwRD/caregivers, FDA), academia (78%, e.g. university, funders, foundations), and healthcare law (1%). Professions include geneticists, genetic counsellors, researchers, clinicians, ethicists, and lawyers. Motivations for joining include improving communication in research and clinical contexts, mitigating potential negative impacts (e.g. emotional distress or discrimination), and protecting rights to know.

Topics have included DTC genomics, the impact of APOE disclosure, genetics and personalized medicine, ecological momentary assessment of response to disclosure, and ethical issues in national and international research registries (EPAD). Activities included a survey on disclosure practices in NIA funded ADCs and collaborations with ADEAR. Stakeholders varied in concerns ranging from a need to protect patients from disclosure to a need to protect the right of access.

**Conclusion:** Membership is increasing and is engaging diverse specialties and stakeholders who provide education and consultation around communication and use of genetic and biomarkers related to dementia. The group structure and inclusion of members from multiple organizations supports open and free collaboration. Future efforts will be developing structured education for stakeholders and publications.



FIGURE 1