

# Most support Alzheimer's research based on family consent

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By the time they have been diagnosed with Alzheimer's disease, many patients' decision-making ability is so impaired that they cannot give informed consent to participate in research studies.

Close family members are left with the decision, but there is no clear policy for this so-called "surrogate" consent. Because of that, research about the increasingly common disease is often stalled.

But a new study led by the University of Michigan Health System suggests that older Americans are very supportive of family surrogate-based research, and would support having their family members enroll them in research in case of future incapacity. The study appears in the new issue of the journal *Neurology*.

Because of uncertainties about federal policy, some institutions have gone so far as to not allow surrogate consent at all and research has been halted at other institutions, says lead author Scott Y. H. Kim, M.D., Ph.D., associate professor in the U-M Medical School's Department of Psychiatry; investigator in the U-M Center for Behavioral and Decision Sciences in Medicine; and core member of the U-M Bioethics Program.

The federal policy states that surrogate consent can be provided by legally authorized representatives of adult patients, but the federal government defers to states to define who these representatives are. The lack of a clear definition has caused widespread confusion and uncertainty for three decades, notes Kim.

If state policies are unclear, then it is the responsibility of hospitals and their Institutional Review Boards to determine the boundaries for surrogate-based research. Only three states—Virginia, New Jersey and California—have recently enacted research ethics laws that clearly address this issue.

Even though regulations remain unclear, however, the general public appears to accept the idea of family surrogate consent—both as a societal policy and for themselves, the new study found.

"We wring our hands about this issue in ethics circles," Kim says, "but people seem to understand that we need to do this kind of research to find ways of treating Alzheimer's." Kim also notes that the U.S. Department of Health and Human Services has formed an advisory committee that is looking at this issue.

**Methodology:** Survey data was based on the U-M Health and Retirement Study, a biennial survey of a nationally representative sample of Americans ages 51 and older funded by the National Institute on Aging.

The participants answered questions regarding one of four randomly assigned surrogate-based research scenarios: lumbar puncture study, a drug randomized control study, a vaccine study and a gene transfer study. Each participant answered three questions: whether our society should allow family surrogate consent, whether the individual would want to participate in the research, and whether the individual would allow a surrogate some or complete leeway to override stated personal preferences.

**Findings:** Most respondents in the survey stated that our society should allow family surrogate consent (68 percent to 83 percent, depending on the scenario) and would themselves want to participate in surrogate-based research (57 percent to 80 percent). Most also would grant some

or complete leeway to their surrogates (55 percent to 67 percent), though these numbers were higher among people who were also willing to participate.

Although ethnic and racial minority groups were slightly less willing to participate in surrogate-based research, there was overall broad support for surrogate-based research even in these groups.

**Significance:** Little research, and no national research, has been conducted about public opinion of surrogate-based research, Kim notes. The rates of Alzheimer's disease are rising rapidly; in 2000, there were 4.5 million Americans with the incurable disease, and by 2050, this number is projected to be 12.5 million if no effective treatments are found.

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