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# The state of clinical research in neurology 

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#### Abstract

\section*{Objective}

To study and provide an update on the state of clinical research in neurology in the United States.

\section*{Methods}

US American Academy of Neurology members and chairs of departments of neurology were surveyed regarding clinical research in 2016. NIH data on the neuroscience pipeline and extramural grant funding were also collected.

\section*{Results}

The response rate was $32 \%(\mathrm{n}=254)$ for nonchair researchers and $58 \%(\mathrm{n}=67)$ for department chairs. Researcher respondents were on average 50 years old, $66 \%$ were men, and $81 \%$ were actively conducting clinical research, with phase II/III clinical trials and outcome measure studies being the most common type of research conducted. Time to conduct research, recruitment, and administrative burden were the major barriers reported. According to department chairs, funding and training opportunities in patient-oriented research have increased over the last 10 years. Overall, applicants to neuroscience-specific NIH institutes for extramural funding have decreased over the same time period.

\section*{Conclusions}

The state of clinical research in neurology has remained relatively stable over the last 10 years, but neurologists still have barriers in conducting clinical research. There has been an interval decrease in neuroscience applicants for NIH funding, which raises concerns about the pipeline and future of clinical research in neurology. These results will serve as a reference for the development of solutions to these issues.


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## Glossary

AAN = American Academy of Neurology; NIA = National Institute on Aging; NIMH = National Institute of Mental Health; NINDS $=$ National Institute of Neurological Disorders and Stroke.

Over the last few decades, there has been a perceived crisis in clinical research attributed to reduced federal funding rates for clinical research, decreased recruitment of clinicians into research, and excessive clinical responsibilities. ${ }^{1,2}$ On the forefront of assessing clinical research in neurology, the American Academy of Neurology (AAN) published the first "Status of Clinical Research in Neurology" report in 1995, which described the results of a survey conducted through chairs of neurology. ${ }^{2}$ At the time, clinical researchers thought that they were poorly regarded as researchers and a substantially lower number of clinical researchers (20\%) had more than half of their time protected for research compared to their basic science colleagues (70\%). Reported reasons for this lack of necessary research time among clinicians included reduced reimbursement for clinical care necessitating more time spent in clinical duties, insufficient time to seek research funding, and grant applications that were not competitive with their basic researcher competitors. The survey was repeated in 2004 and $50 \%$ of chairs of neurology agreed that patient-oriented researchers had more difficulty getting research support and being adequately supported by grants. Furthermore, they reported that managed care had a negative effect on patient-oriented research. No institutional startup funds or training opportunities were available for patient-oriented researchers in $40 \%$ of the departments.

Many of these same concerns are present for clinical researchers in the current climate, as well as potentially new or growing barriers. Dramatic shifts in the clinical environment over the last 10 years, including the introduction of the electronic medical record, resident work hour restrictions, and higher demands for monitoring of clinical productivity that have increased the clinical burden on neurologists also threaten clinical research in neurology. Government shutdowns, budget stagnation, and decreasing funds for clinical research are potential factors in a worsening situation for the clinical research neurologist.

Herein, we report the results of the 2017 Clinical Research Survey, a survey of AAN members who were conducting research to (1) determine the current state of clinical research in neurology in the view of members of the AAN, (2) survey neurology chairs for their perception of the current state of clinical research and for comparison to survey responses in prior years, (3) identify perceived barriers for clinical research in neurology, and (4) explore NIH funding from institutes supporting neuroscience and neurology research for R01 and mentored awards over the same time period. ${ }^{2,3} \mathrm{NIH}$ data were used to show award data regarding the funding climate for clinical research.

## Methods

## Clinical research survey

For this study, AAN definitions of patient-oriented or clinical research were used. ${ }^{3}$ The nonchair researcher population included neurologists and researchers who were current members of the AAN with a primary US address at the time of the sample pull on May 4, 2016 ( $\mathrm{n}=14,973$ ). Of these, 9,710 were excluded because they were 65 years of age or older, were serving on an AAN committee, a neurology department chair, or did not self-report spending at least $1 \%$ of their professional time conducting research as determined by their AAN member record. It is standard practice for the AAN to remove those who are 65 and older, those on an AAN committee, and any member who has received a survey in the past 6 months to prevent survey fatigue and reduce burden on these groups of members. Of those 5,263 members remaining, 2,315 were excluded because they had received an AAN survey within the last 6 months, leaving 2,948 eligible members, of whom 800 were randomly sampled. Twelve of the 800 members from the researcher sample had invalid contact information, leaving a final sample of 788 researchers. The surveys were primarily conducted online but were supplemented with paper and fax distribution. Respondents answered between 10 and 41 questions depending on their roles (nonacademician researcher, academician, or chair). The authors designed 10 new questions but kept the remainder the same as in prior versions to allow for comparison. The instrument was vetted by the AAN Member Research Subcommittee and piloted by 2 AAN committee members.

The clinical research survey (appendix e-1, links.lww.com/ WNL/A336) included questions to define the type of research conducted, aspects of the research environment, and funding by individuals who identified themselves as participating in clinical research. Survey respondents were asked whether they were conducting clinical research currently and, if not, what barriers had prevented them from doing so. Those conducting clinical research were asked to detail the specific types of clinical research they had conducted in the last year, the types of clinical research training they had received, and obstacles they had encountered. The amount of time spent in various research and clinical activities, percentage of funding for salary from various specified sources, and types of funding received were asked. Respondents from academic institutions were asked to agree or disagree with several statements addressing institutional support and publications, and whether they had participated in training fellows or other trainees in clinical research.

## Neurology department chair survey

The chair population included the entire population of 116 US neurology department chairs listed in the AAN member
database. The survey of department chairs included a series of questions about the size, environment of the department, as well as effect on clinical and basic research from both funding and payer perspectives (appendix e-1, links.lww.com/WNL/A336). Chairs were asked about departmental resources for training programs and promotional tracks, were provided questions regarding managed care, and were asked to make comparisons between clinical and basic researchers at the institution. These questions and the questions asked of academic researchers were kept the same as the questions asked on the 1995 and 2004 surveys to allow for a comparison of change in attitudes about clinical research over time. To improve response rates, members of the Clinical Research Subcommittee of the AAN also personally reached out to individual chairs by e-mail, phone calls, or in person to encourage survey completion.

## NIH data

NIH data were collected through publicly available tools on NIH.gov and NIH RePORTER with additional help from the office of the director of the National Institute of Neurological Disorders and Stroke (NINDS).

## Statistical analysis

Standard descriptive statistics were used to characterize survey responders. Associations between researcher respondents and nonrespondents were evaluated using $\chi^{2}$
tests for categorical variables (sex, member type, and practice setting) and independent $t$ tests for continuous variables (age). No sampling margin of error or significance testing was calculated for the chair responses because of the use of the entire population. Descriptive statistics (mean, median, range for continuous variables; percentages for categorical) were calculated for the individual survey questions. Longitudinal differences to Likert scale questions for chair responses in 2004 and 2016 were compared using $\chi^{2}$ tests, with the significance level set to $p=0.05$. All analyses were performed using IBM SPSS Statistics version 23 (IBM Corp., Armonk, NY). Descriptive statistics were used to summarize NIH data.

## Results

## Clinical research survey

The AAN initially contacted 788 randomly sampled nonchair members who spent $\geq 1 \%$ of their time in research activities between May and August of 2016. The response rate for the nonchair researcher survey was $31.8 \%$ (254/788). Demographic (age and sex) characteristics (table 1) were comparable between the nonchair responders and the nonresponders, with the exception that nonneurologist research scientists accounted for a higher proportion of responders ( $19.7 \%$ vs $13.9 \%$ ). The

Table 1 Demographics of researcher sample respondents and nonrespondents

|  | Respondents ( $\mathrm{n}=254$ ) | Nonrespondents ( $\mathrm{n}=534$ ) | $p$ Value |
| :---: | :---: | :---: | :---: |
| Age, ${ }^{\text {a }} \mathrm{y}$, mean (SD) | $49.7{ }^{\text {b }}$ (10.3) | 47.4 (9.5) | $0.002^{\text {c }}$ |
| Sex, ${ }^{\text {d }}$ \% |  |  |  |
| Men | 66.3 | 64.1 | $0.548^{\text {e }}$ |
| Women | 33.7 | 35.9 |  |
| AAN membership type (\%) |  |  |  |
| Neurologist | $80.3^{\text {b }}$ | 86.1 | $0.036{ }^{\text {e }}$ |
| Nonneurologist research scientist | $19.7{ }^{\text {b }}$ | 13.9 |  |
| Practice setting, ${ }^{\text {f }}$ \% |  |  |  |
| Academic/university | 51.7 | 46.9 | $0.575^{\text {e }}$ |
| Government | 5.4 | 4.4 |  |
| Hospital | 7.1 | 7.4 |  |
| Multispecialty group | 6.7 | 9.7 |  |
| Neurology group | 17.1 | 15.6 |  |
| Solo | 4.6 | 5.5 |  |
| Other | 7.5 | 10.5 |  |

[^1]majority of researcher nonchair respondents ( $62.7 \%$ ) were from an academic medical center-based group and reflect the overall sample in terms of practice setting.

With 254 of 788 researchers responding, percentage estimates for researchers were accurate to $\pm 5.9 \%$ with $95 \%$ confidence. Among the 254 nonchair respondents, $19 \%$ of the respondents had not conducted clinical research in the past 12 months. Among those who had not conducted clinical research within 12 months, time, upfront costs, and formal training were the most likely barriers (table 2). The respondent characteristics are described in table 3 . On average, $75 \%$ of the nonchair respondents were involved in clinical research, $9 \%$ were involved in basic science research, and $13 \%$ in translational research. Forty-five percent of the nonchair respondents mentored trainees in clinical research. Of their trainees, an average of $33 \%$ had applied and received a research grant. For those that conduct clinical research, the survey identified several barriers to research (table 3).

## Neurology department chair survey

The AAN contacted all 116 chairs of US neurology departments. A total of 67 ( $57.7 \%$ response rate) of 116 US neurology department chairs responded to the survey

Table 2 Barriers to conducting research

| Barrier | $\%^{\mathbf{a}}$ |
| :--- | :--- |
| Respondents not conducting clinical research ( $\mathbf{n}=\mathbf{5 8}$ ) |  |
| Time | 55 |
| Upfront costs | 21 |
| Formal training in research methodology | 17 |
| Access to personnel | 15 |
| Access to sponsors | 15 |
| Interest | 15 |
| Respondents conducting clinical research ( $\mathbf{n}=\mathbf{2 4 7 )}$ |  |
| Time | 74 |
| Recruitment | 58 |
| Regulatory environment | 45 |
| Finding/keeping research staff | 44 |
| Funding | 44 |
| Administrative tasks | 40 |
| Lack of departmental support | 31 |

${ }^{\text {a }}$ Percentage of respondents who endorsed barrier; may answer more than one.

Table 4 Chair responses in 2004 vs 2016

| Please indicate your level of agreement | $\begin{aligned} & 2004^{\mathrm{a}, \mathrm{~b}} \\ & \text { Agree } \end{aligned}$ | $\begin{aligned} & 2016^{\text {c }} \\ & \text { Agree } \end{aligned}$ | $p$ Value ${ }^{\text {d }}$ |
| :---: | :---: | :---: | :---: |
| Patient-oriented researchers have more difficulty than basic researchers getting research support at my institution. | 50.0 (53) | 47.4 (27) | 0.748 |
| Basic researchers have more difficulty than patient-oriented researchers getting research support at my institution. | 10.7 (11) | 15.8 (9) | 0.349 |
| Patient-oriented researchers are adequately supported by grants at my institution. | 27.4 (29) | 39.3 (22) | 0.120 |
| Basic researchers are adequately supported by grants at my institution. | 59.4 (63) | 47.4 (27) | 0.140 |
| Managed care in my institution has a negative effect on patient-oriented researchers. | 74.5 (79) | 44.6 (25) | $<0.001{ }^{\text {e }}$ |
| Managed care in my institution has a negative effect on basic researchers. | 31.4 (33) | 14.5 (8) | $0.020^{\text {e }}$ |
| Institutional startup funds are available for patient-oriented researchers. | 61.0 (64) | 59.6 (34) | 0.872 |
| Training opportunities are available for patient-oriented researchers. | 60.4 (64) | 87.7 (50) | $<0.001{ }^{\text {e }}$ |
| Data are \% (n). <br> ${ }^{\text {a }}$ Total chair responses from 2004 survey: $\mathrm{n}=107$. <br> ${ }^{\text {b }}$ Because of a large difference in response rates from 2004 and 2016 ( $84 \%$ vs 58\%, respectively), <br> ${ }^{\text {c }}$ Total chair responses from 2016 survey: $\mathrm{n}=57$. <br> ${ }^{\text {a }}$ Pearson $\chi^{2}$. <br> ${ }^{\text {e }}$ Significant at the $p<0.05$ level. Analysis conducted using $\chi^{2}$ tool from quantpsy.org/chisq/chisq. | used | rpreting | results. |

researchers are less adequately supported by grants (47\% in 2016 vs $59 \%$ in 2004 [ $p=0.14$ ]). Only $45 \%$ of chairs thought that managed care was having a negative effect on clinical research (compared to $75 \%$ in 2004 [ $p<0.001]$ ), and only $15 \%$ thought basic research was negatively affected by managed care (compared to $31 \%$ in 2005 [ $p=0.02]$ ). Institutional startup funds for patient-oriented researchers were available according to $60 \%$ of chairs, similar to 2004. Perceived availability of training opportunities for clinical research had
improved, with $88 \%$ of chairs affirming these opportunities at their institution, compared with $60.4 \%$ in 2004 ( $p<0.001$ ).

## NIH data

Overall NIH success rates for grant applications had remained stable over the last 10 years (2006-2015) at $16 \%$ for all types of applications (table 5). From 2006 to 2011 (the only years for which there were data available), there was an increase in MD, $\mathrm{MD}-\mathrm{PhD}$, and PhD applicants and awardees across the entire

Table 5 Comparison of R01 (investigator-initiated award), K23 (mentored patient-oriented research career development award), and K08 (mentored clinician scientist development award)

| Institute | Type of grant |  |  |  |  |  |  |  |  |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
|  | R01 |  |  | K23 |  |  | K08 |  |  |
|  | No. applied | No. awarded | Success rate, \% | No. applied | No. awarded | Success rate, \% | No. applied | No. awarded | Success rate, \% |
| 2006 |  |  |  |  |  |  |  |  |  |
| NIH | 22,148 | 3,610 | 16.3 | 666 | 180 | 27 | 635 | 215 | 34 |
| NINDS | 2,401 | 456 | 19 | 45 | 14 | 31 | 69 | 24 | 39 |
| NIA | 1,344 | 228 | 17 | 72 | 16 | 22 | 28 | 6 | 21 |
| NIMH | 1,661 | 325 | 19.6 | 94 | 20 | 21 | 28 | 11 | 39 |
| 2015 |  |  |  |  |  |  |  |  |  |
| NIH | 24,587 | 3,934 | 16 | 589 | 206 | 35 | 79 | 35 | 44.3 |
| NINDS | 1,886 | 362 | 19.2 | 45 | 10 | 22 | 43 | 14 | 32.6 |
| NIA | 1,279 | 184 | 14.4 | 45 | 17 | 37.8 | 16 | 7 | 43.8 |
| NIMH | 1,322 | 284 | 21.5 | 70 | 27 | 38.6 | 13 | 4 | 30.8 |

[^2]Table 6 Applicants and awards by degree across $\mathrm{NIH}^{a}$

| Fiscal year | Degree | No. of applicants | No. of awardees | Funding rate, \% |
| :--- | :--- | :--- | :--- | :--- |
| $\mathbf{2 0 0 6}$ | MD | 5,446 | 1,484 | 27.2 |
| $\mathbf{2 0 0 6}$ | MD-PhD | 3,472 | 911 |  |
| $\mathbf{2 0 0 6}$ | PhD | 23,763 | 5,940 | 26.2 |
| $\mathbf{2 0 0 6}$ | Total | 33,119 | 8,406 | 25.4 |
| $\mathbf{2 0 1 1}$ | MD | 5,687 | 1,493 | 26.3 |
| $\mathbf{2 0 1 1}$ | MD-PhD | 3,761 | 6,481 | 27.1 |
| $\mathbf{2 0 1 1}$ | PhD | 27,104 | 9,270 | 23.9 |

${ }^{\text {a }}$ Research project grants include the following activity codes: R00, R01, R03, R15, R21, R22, R23, R29, R33, R34, R35, R36, R37, R55, R56, RC1, RC2, RC3, RC4, RL1, RL2, RL5, RL9, P01, P42, PN1, UA5, UC1, UC2, UC3, UC4, UH2, UH3, UH5, UM1, UC7, U01, U19, U34, DP1, DP2, DP3, DP4, and DP5.

NIH , including all funding mechanisms (table 6). Growth was largest in the PhD applicant pool compared to MD or $\mathrm{MD}-\mathrm{PhD}$ applicants.

For NIH institutes with a specific focus on neurology and neuroscience (NINDS, National Institute on Aging [NIA], National Institute of Mental Health [NIMH]) over the last 10 years, however, there has been a $17 \%$ decrease in applicants overall for Research Project (R01) grants comparing between 2006 and 2015 (table 5). Mentored awards saw larger decreases in applicant number, with a $24 \%$ decrease in Patient-Oriented Research Career Development Award applicants and a $42 \%$ decrease in Clinical Scientist Research Career Development Award applicants. While success rates for neurology-specific NIH institutes remained largely stable or increased over the 10-year period, the success rate for K23 awards and K08 awards at NINDS dropped from 33\% and $39 \%$ in 2006 to $22 \%$ and $32.6 \%$ in 2015, respectively.

For midcareer investigator awards in Patient-Oriented Research (K24), there were 12 applicants total in 2015, with $75 \%$ funded, compared to 33 applicants in 2005, with $36 \%$ funded. From 2008 to 2015, the total number of NIH-defined clinical research grants awarded has decreased from 6,065 to 5,472. Funding for NIH-defined clinical research grants has remained relatively stable for NINDS and NIA, but decreased for NIMH. NIH-defined, high-risk, high-reward clinical research programs have risen, including Pioneer Awards (1/10 awarded in 2008 to 3/23 in 2015), New Innovator Awards (2/36 in 2008 to 7/42 in 2015), and Early Independence Awards (1/9 in 2010 to 7/ 16 in 2015). Transformative Research Awards, established in 2009, have decreased from $8 / 43$ in 2009 to $2 / 8$ in 2015.

## Discussion

The results of this clinical research in neurology survey suggest that both the environment and funding for clinical research have remained relatively stable over the last 10 years. Unexpectedly,
department chairs reported a reduced negative effect of managed care on academic research compared to 2004 and an increase in training opportunities in patient-oriented research.

Time to conduct research, recruitment challenges, and administrative burden remain major obstacles for clinical researchers. The mean time spent on research (30\%) as compared to other professional activities, is likely inadequate for the performance of more complex or larger-scale research, which ultimately affects the type of clinical research that is being done in our community at large. Within the qualitative comments at the end of the survey, researchers in academic practices identified high clinical demands as a barrier to research; in direct contrast, private practice respondents reported that clinical research (industry) was critical for financial solvency. This has allowed those in private practice to participate in clinical research, when they otherwise might not have. However, it may be noted that the type of clinical research conducted in academic vs private practices may contribute to responses, with private practices more likely to conduct clinical trials and less likely to conduct investigatorinitiated research. Other concurrent time-consuming clinical activities that reduce the ability to conduct clinical research were not specifically queried (e.g., time spent on electronic medical record activities). Potential solutions to increase and provide clinical researchers with protected time include using indirect funding related to grants to buy clinical research faculty time ${ }^{4}$ and/or research "performance-based" programs ${ }^{5}$ that provide in-kind time for successful achievement of specified research milestones (e.g., submitted grant applications, completing projects, and/or publishing results). The latter could also be used for incentive-based payments, similar to those used for clinical-focused faculty, which would incentivize clinical research faculty productivity and provide payment models that are on par with seeing clinic patients.

Difficulty with patient recruitment was cited as a major barrier to clinical research. The NIH has established clinicaltrials.gov, which allows patients to directly search for appropriate studies
and ResearchMatch, an online national clinical research registry that matches patients with studies at institutions in order to facilitate research recruitment. The AAN and other neurologic organizations may need to work with the NIH to provide other solutions. Regulatory burden may be eased with the new federal policies for the protection of humans subjects research (the "Common Rule"), which are anticipated to change in 2018, including expansion of the definition of exempt research and elimination of some continuing reviews that need to be submitted to institutional review boards. Other resources for clinical researchers that could resolve barriers could include centralizing services, such as biostatistics, research personnel, and regulatory experts, at institutions that do not have established clinical research centers. ${ }^{6}$

The number of applicants for neurology institute-specific NIH R01 awards has dropped between 2006 and 2015, as have applications for K23 and K08 awards from $42 \%$ to $24 \%$ during that same time period. These reductions do not appear to be secondary to a substantial decrease in success rates because most NINDS, NIA, and NIMH success rates have remained stable or improved. In addition, these decreases in applicant numbers do not appear to reflect NIH-wide trends, since the overall number of MD, MD-PhD, and PhD applicants for grants NIH-wide increased comparing 2006 to 2011. Instead, it appears that the decrease in R01 applicants was associated with an increase in R21 and U01 application rates across these institutes. Although beyond the scope of this project, determining whether R21 applicants are more junior researchers and have a lower conversion to a subsequent R01, contributing to the overall decrease in R01 awards, would be important.

The decrease in application rates for mentored awards to neurology-specific institutes suggests that within the neurosciences, there are factors unrelated to funding rates or available training in clinical research that are driving a decision not to pursue research (and research funding). If the trend continues, there will be fewer and fewer individuals pursuing NIH-funded neuroscience-oriented research in the future. Because of low application rates, the K24 program was not renewed at NINDS, which will have the anticipated effect of providing fewer NIH-funded mentors for K awardees. A novel attempt to increase research by the NINDS is the R25 program, which sponsors educational activities that complement other formal training programs including activities during the summer academic break for students, and may help the pipeline. An important potential factor in reduced funding applications not studied in this survey includes neurologist burnout. ${ }^{7}$ In fact, increased research time, which often provided increased autonomy and decreased time spent in direct patient care, might be expected to protect academic researchers from physician burnout.

Limitations to the current study should be acknowledged. First, response rates for both AAN nonchair members and US
neurology department chairs were substantially lower compared to previous surveys. Repeated efforts to increase response rates, including individualized contact to all neurology department chairs by the authors, were not successful in increasing response rates up to that seen in prior years. This low response rate may reflect the general lack of time cited by AAN survey respondents as a barrier to research in the current climate rates and could have biased findings reported in the current survey as respondents may differ from nonrespondents in terms of time, research interests, or other factors. The low response rate could also reflect systematic biases in those who completed the surveys. Second, there is a caveat to looking at the NIH data at 2 time points in that it may not best represent linear trends over the 10 years. Finally, this survey and past surveys have not distinguished between investigator-initiated research as opposed to neurologist participation in clinical trials. Both of these research pursuits are important, and future surveys may benefit from adding more questions relevant to each of these types of studies.

The state of clinical research in neurology has remained stable in many areas over the last 10 years. However, fewer neurology researchers are applying for NIH funding, with the greatest decrease found in the number of early career award applicants, a mechanism to support mentored research. While the reasons for this decrease in applicant rates remain unclear, our survey suggests that limited time, challenges of subject recruitment, and administrative burden are the largest barriers for neurologic clinical researchers. These barriers, and others, must be identified and addressed to avoid an efflux of talent from bringing new cures to neurologic patients.

## Author contributions

D.H.: design/conceptualization of the study, analysis and interpretation of the data, drafting and revising the manuscript for intellectual content. A.R.R.: design/conceptualization of the study, analysis and interpretation of the survey data, revising the manuscript for intellectual content. J.M.G.: design/ conceptualization of the study, analysis and interpretation of the survey data, revising the manuscript for intellectual content. A.V.: design/conceptualization of the study, analysis and interpretation of the survey data, revising the manuscript for intellectual content. M.B.: design/conceptualization of the study, interpretation of the data, critically revising the manuscript for intellectual content. B.M.K.: design/ conceptualization of the study, analysis and interpretation of the survey data, revising the manuscript for intellectual content. C.C.: design/conceptualization of the study, analysis and interpretation of the survey data, revising the manuscript for intellectual content. M.G.: design/conceptualization of the study, analysis and interpretation of the survey data, revising the manuscript for intellectual content.

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## References

1. Wyngaarden JB. Irvine H. Page lecture 1983. The future of clinical investigation. Cleve Clin Q 1984;51:567-574.
2. Status of clinical research in neurology. Report of the Clinical Research Subcommittee of the Scientific Issues Committee of the American Academy of Neurology. Neurology 1995;45:839-845.
3. Sacco RL, Malow BA, Williams LS; Clinical Research Subcommittee of the Science Committee of the American Academy of Neurology. The state of patient-oriented research in neurology. Neurology 2004;62:1051-1055.
4. Meador KJ. Decline of clinical research in academic medical centers. Neurology 2015; 85:1171-1176.
5. Sakai T, Hudson M, Davis P, Williams J. Integration of academic and clinical performance-based faculty compensation plans: a system and its impact on an anaesthesiology department. Br J Anaesth 2013;111:636-650.
6. Croghan IT, Viker SD, Limper AH, et al. Developing a clinical trial unit to advance research in an academic institution. Contemp Clin Trials 2015;45:270-276.
7. Busis NA, Shanafelt TD, Keran CM, et al. Burnout, career satisfaction, and well-being among US neurologists in 2016. Neurology 2017;88:797-808.

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## Study question

How do members of the American Academy of Neurology (AAN) view the state of clinical neurology research in the US?

## Summary answer

Survey responses from AAN members suggest that barriers to research exist but have not worsened over the past decade.

## What is known and what this paper adds

Past reports have highlighted various difficulties for US clinical neurology researchers, such as increasingly burdensome clinical responsibilities and reduced federal funding. This study uses data from the AAN's 2017 Clinical Research Survey to provide an updated overview of how AAN members view the state of US clinical neurology research. NIH data on extramural grant funding was also collected.

## Participants and setting

In 2016, this study surveyed all 116 US neurology department chairpersons registered with the AAN. It also surveyed 788 randomly selected non-chairperson AAN members who were $<65$ years old, were not serving on AAN committees, and selfreported spending $\geq 1 \%$ of their time conducting clinical research.

## Design, size, and duration

The surveys were conducted primarily online with supplementary fax and paper distribution. The non-chairperson AAN members were chosen from among those who had not been surveyed in the past 6 months. Depending on the individual's institutional role, the survey asked 10-41 questions about research participation, aspects of the research environment, and various factors potentially hindering research. Chairpersons were additionally asked about the departmental environment.

## Main results and the role of chance

Responses were received from 254 (32\%) non-chairperson researchers and 67 (58\%) chairpersons. Altogether, 247 respondents reported clinical research participation in the

| Potential barrier | Percentage of research <br> participants endorsing barrier |
| :--- | :--- |
| Time | $74 \%$ |
| Recruitment | $58 \%$ |
| Regulatory environment | $45 \%$ |
| Finding/keeping research staff | $44 \%$ |
| Funding | $44 \%$ |

past year. The major reported research barriers included time, participant recruitment difficulties, the regulatory environment, staffing difficulties, and inadequate funding. Among department chairs, $47 \%$ believed that clinical researchers at their institution faced more difficulties in securing funding than basic researchers did, which is comparable to the $50 \%$ figure recorded in a 2004 survey ( $p=0.748$ ). Applicants to neuroscience-specific NIH institutes for extramural funding have decreased over the same time period.

## Bias, confounding, and other reasons for caution

Survey response rates were lower than in previous years. The surveys did not distinguish between initiating research and participating in research initiated by others.

## Generalizability to other populations

This study's findings may not be generalizable to countries other than the US.

## Study funding/potential competing interests

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[^1]:    Abbreviation: AAN = American Academy of Neurology.
    ${ }^{\text {a }}$ Missing data for $0 \%$ of respondents and nonrespondents.
    ${ }^{\mathrm{b}}$ Significance at the $p<0.05$ level.
    ${ }^{c} t$ test.
    ${ }^{\mathrm{d}}$ Missing data for $2 \%$ of respondents and nonrespondents.
    ${ }^{e}$ Chi-square test.
    ${ }^{\mathrm{f}}$ Missing data for $6 \%$ of the respondents and $11 \%$ of the nonrespondents.

[^2]:    Abbreviations: NIA = National Institute on Aging; NIMH = National Institute of Mental Health; NINDS = National Institute of Neurological Disorders and Stroke.

[^3]:    A draft of the short-form article was written by M. Dalefield, a writer with Editage, a division of Cactus Communications. The authors of the full-length article and the journal editors edited and approved the final version.

