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Disclosure of individual research results at federally funded Alzheimer's Disease Research Centers

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Abstract (word count = 150/150 words)

INTRODUCTION: This study describes practices for disclosing individual research results to participants in Alzheimer's disease research.

METHODS: An online survey of Clinical Core directors at NIH-funded Alzheimer's Disease Research Centers in the US (response rate: 30/31, 97%) examined return of results practices across nine different types of research results.

RESULTS*:* Most Centers had returned consensus research diagnoses (83%) and neuropsychological test results (73%), with fewer having shared amyloid PET (43%), tau imaging (10%), or *APOE* genotype (7%) results. Centers reported having disclosed a mean of 3.1 types of results (SD = 2.1; range 0-8). The most commonly cited reason for disclosure was to inform participants' medical decision-making (88%). Disclosure involved multiple professionals and modalities, with neurologists (87%) and in-person visits (85%) most commonplace.

DISCUSSION: Centers varied widely as to whether and how they disclosed research results. Diagnostic and cognitive test results were more commonly returned than genetic or biomarker results.

Keywords: return of research results; genetic testing; biomarkers; risk communication; research ethics

1. INTRODUCTION

Return of individual research results to participants in health-related studies has become an increasingly debated topic in recent years. Decisions about whether, when, and how to share such results raise a host of ethical, legal, and practical questions regarding investigator and participant rights and responsibilities and the potential benefits and harms of disclosing research findings [1]. In addition, research participants themselves may vary widely in their preferences for receiving results and capacities for adequately comprehending the often complex and voluminous information generated by clinical research [2]. In 2018, the National Academies of Science, Engineering, and Medicine issued a report encouraging investigators to consider more frequent disclosure of research results to study participants, provided the results were reliable, valid, and of use and interest to participants [3]. Authors of the report contended that return of results was an important means of giving back to participants for their volunteer efforts and enhancing public trust and engagement in the research enterprise. Yet investigators are often reluctant to disclose research results to participants for a variety of reasons. For example, they may lack requisite financial and human resources for effectively conveying results to participants (e.g., health professionals with skills and expertise in disclosing sensitive results), they may fear potential legal liabilities brought on by disclosure, and they commonly collect data using procedures viewed as insufficiently reliable or valid for disclosure of clinically significant results [4].

This debate is particularly relevant in clinical research on Alzheimer's disease and related dementias, where individual-level data are routinely generated in areas of interest to patients and family members. For example, many clinical studies rigorously assess individuals' cognitive performance, produce consensus research diagnoses, and collect genetic and biomarker information. Oftentimes such information comes from cutting-edge

technologies (e.g., investigational neuroimaging, genome sequencing) that would not typically be available in general clinical practice. For individuals with cognitive impairment, such information might be used to inform medical decision-making. For asymptomatic individuals, dementia risk information via methods like *APOE* genotyping and amyloid neuroimaging is often of interest for a variety of reasons (eg, advance planning, informing health behaviors that might reduce dementia risk) [5–7], even if such testing is not recommended in clinical practice [8,9]. Studies of dementia research participants' preferences suggest high overall levels of interest in learning a range of individual research results, including genetic information and results from neuroimaging and cognitive testing [10].

Little is known about the extent to which dementia researchers disclose individual research results to study participants, or, where disclosure is taking place, how they share such results. Gauging researchers' current practices in this area would be an important step in understanding how best to address challenges posed by return of research results. A key stakeholder in this debate is the national network of Alzheimer's Disease Research Centers (ADRCs) in the United States, funded by the National Institute on Aging. Each of these Centers is charged with creating a longitudinal cohort study in which they follow a sample of older adults both with and without cognitive impairment. Standardized assessments across a wide range of domains are conducted annually, with data pooled across sites at the National Alzheimer's Coordinating Center (NACC). We conducted a survey study to examine how individual Centers within this national network are addressing a range of issues related to return of research results in their own longitudinal cohort studies. The goals of the study were to describe current practices regarding disclosure of individual research results (e.g., what types of results are being disclosed and under what conditions, how they are being

disclosed), reasons for returning or not returning results, and perceived barriers and facilitators.

2. METHODS

2.1 Survey development

The study survey was initiated under the auspices of the Advisory Group on Risk Evidence Education for Dementia (AGREED), a national working group of dementia research professionals and advocates convened to facilitate responsible and effective communication of dementia risk information [11]. We created a survey to assess disclosure practices at National Institutes of Health-funded ADRCs in the United States (note: AGREED is led by three ADRC-affiliated investigators, and all but one of this paper's authors are affiliated with ADRCs). The survey was reviewed in multiple iterations by various subcommittees of the AGREED working group, which included dementia researchers, clinicians, policy experts, individuals with early stage dementia, and research participants. The review process helped refine survey items (e.g., clarifying their wording and response choices, identifying additional survey topics), improve survey flow, and minimize respondent burden.

2.2 Survey administration

The survey was administered via Internet to all ADRCs that were actively funded at the time of data collection (N = 31). Invited respondents were Clinical Core directors across sites, given that those leaders were responsible for the main longitudinal cohort study of older adults required of each Center. Data collection took place from late September-early

November 2019. Out of 31 eligible Centers, 30 provided survey responses (response rate = 97%).

2.3 Survey measures

The primary focus of the survey was each Center's general practices of disclosure of individual research results to participants in their longitudinal cohort study. Specifically, questions were anchored to results generated in the site's Clinical Core for its participants in the Uniform Data Set (UDS), a national database to which all ADRCs contribute. Survey items asked about the following: 1) types of research results disclosed, the types of participants to whom results were disclosed, and the frequency with which disclosure typically occurred; 2) reasons for and against disclosing research results; and 3) the process of disclosure, including professionals involved, modalities used, and elements of the disclosure process. The survey itself is provided in a separate Appendix to this paper.

2.3.1 Disclosure of research results

The survey asked a series of questions regarding disclosure of research results within their Center's longitudinal cohort study. First, respondents were asked about the types of results that had been disclosed. Nine categories of results (e.g., consensus research diagnoses, genetic and neuroimaging results; Table 1) were presented, with response choices of yes, no, or not applicable (i.e., the site did not collect that information in the first place). A summed score was created for each Center to indicate how many of the nine types of results it had returned. On items where respondents indicated disclosure occurred, follow-up

questions asked about the types of individuals (i.e., research participants with dementia, MCI, subjective memory complaints, or normal cognition; participants' family members and/or health care providers) to whom results had been disclosed, and the frequency with which this occurred (routinely, sometimes, or rarely).

2.3.2 Reasons for and against disclosure

For each type of research result where disclosure had taken place, respondents were asked to indicate which of six potential reasons had prompted disclosure (e.g., result was potentially clinically useful, the participant had requested it; Table 2). For results where disclosure had not taken place, respondents were asked to indicate which of eight potential reasons had prompted lack of disclosure (e.g., result was not clinically useful, potential for unintended harms; Table 3). For both sets of questions, respondents could write in "other" reasons why disclosure had or had not been offered. Follow-up questions were asked regarding potential reasons for or against disclosure of results. At sites where genetic information had been collected from research participants, respondents were asked whether or not genetic testing had occurred in a CLIA-approved laboratory. All respondents were asked to indicate whether and how the longitudinal cohort study's informed consent form addressed return of results (e.g., it specified which results would be returned, it stated no results would be returned).

2.3.3 Disclosure process elements

For all types of research results where disclosure had occurred, respondents were asked to indicate which types of professionals had been involved in communicating results. Response choices included seven types of professionals (e.g., neurologist, psychologist, nurse; Table 4), along with an open-ended "other" item. For each type of result, respondents were also asked to indicate whether disclosure had taken place via an in-person visit, mailed letter, telephone or an "other" modality (Table 4). Finally, respondents were asked about various aspects of the disclosure process, indicating whether or not seven specific features had been included (e.g., recommendations for next steps, resources for more information; Table 5).

2.4 Data analyses

Given the small sample size of Centers surveyed, descriptive statistics were used to characterize survey responses. Chi-square analyses were used to assess whether disclosure of research results differed by participant type, collapsing responses into those with dementia or MCI vs. those with subjective memory complaints or normal cognition.

3. RESULTS

3.1 Disclosure of research results

Disclosure of research results was a frequent occurrence across ADRCs surveyed (Table 1), although practices varied by specific type of result (Figure 1). The mean number of types of results returned was 3.1 (SD = 2.1; range: 0-8) out of the nine types of results included in the survey with a mode of 2. A majority of Centers reported having returned

consensus research diagnoses (n=25, or 83%) and neuropsychological test results (n=22, 73%), with amyloid PET (n=13, 43%) and MRI results (n=12, 40%) the next most commonly endorsed items. Relatively few Centers reported having returned tau imaging (n=3, 10%) or *APOE* genotype (n=2, 6.7%) results. Even fewer Centers reported returning genetic or biomarker results on a routine basis. For example, only three Centers (10%) reported routinely returning amyloid PET results to participants; of these, only one routinely offered amyloid results to participants without cognitive impairment. Only two Centers (6.7%) reported routine disclosure of tau imaging results, with one of the two offering them routinely to participants without cognitive impairment. No Center offered routine disclosure of *APOE* genotype results. Across all categories of research results, whether or not disclosure had taken place did not differ significantly when comparing participants with dementia or MCI vs. those with no objective cognitive impairment.

3.2 Reasons for and against disclosure

Centers endorsed a range of reasons for disclosing research results to participants (Table 2). The most common was that results could potentially inform participants' health care decisions (88%). Other frequently endorsed reasons for returning results included participant and/or family requests for information (80%), thanking participants for their research volunteer efforts (73%), and enhancing retention in their longitudinal cohort studies (68%). Physician requests for information were less commonly endorsed but still notable as a reason for disclosure (45%).

Table 3 describes reasons cited by ADRCs for not returning individual research results. Overall, the most commonly endorsed reason for not returning results was that they

did not meet clinical standards (42%). Among the 27 Centers who reported collecting genetic data in their longitudinal cohort study, only 7 (26%) said that they used a CLIA-approved laboratory for analyzing results. Another relatively commonly endorsed reason for not returning results was that the study's consent form had explicitly noted that certain types of results would not be returned (35%). Other reasons cited for not returning genetic or biomarker results were their perceived lack of medical utility (31%) and potential for unintended harms (24%). Relatively infrequently endorsed as barriers to disclosure were time burdens involved for staff (13%), lack of expertise in disclosing results (10%), financial costs (2%), and concerns about legal liability (2%). "Other" reasons why results were not disclosed, indicated in open-ended responses, included that the research funder did not allow it and that the test had only recently become available.

Overall, while most Centers (18/30, 60%) reported that their study consent forms specified which results would or would not be returned, four Centers (13%) indicated their consent form stated that no results of any kind would be disclosed. Five Centers (17%) reported their consent form did not actually address return of results at all, while four (13%) elicited participant preferences for results disclosure as part of the consent process.

3.3 Disclosure process features

A wide range of health professionals were involved in disclosure of research results (Table 4). Neurologists were by far the most commonly reported type of professional (87%), taking part in disclosure of all categories of results. Psychologists were the next most commonly mentioned group, cited in 30% of all types of disclosures and a majority (64%) of those involving neuropsychological test results. Other professionals involved in disclosure

included geriatric psychiatrists (22%), nurses / nurse practitioners (17%), geriatricians (16%), and research coordinators (12%). In the rare instances where *APOE* genotype results were returned (n = 2 Centers), genetic counselors were not reported as being involved in disclosure, although they were for disclosure of other types of genetic results (e.g., high penetrance pathogenic variants for familial AD).

Research results were disclosed in a variety of formats, with in-person visits being the most commonly employed (85%). Telephone disclosure was reportedly used in half of all types of return of results (Table 4). Mailed letters were frequently used (38%), most commonly for neuropsychological test results but rarely for disclosure of genetic or biomarker results (e.g., only 1 of 13 Centers returning amyloid PET results).

There was considerable variation across Centers regarding elements of the disclosure process (Table 5). A majority of respondents indicated that return of research results at their site included recommendations for next steps (76%) and provision of resources for more information (55%). Fewer than half of types of results disclosure reportedly involved communication with participants' physicians (40%), provision of a take-home letter summarizing results (37%), and post-disclosure counseling (30%). Use of pre-disclosure education sessions (20%) and visual aids to assist communication of results (11%) were relatively infrequently employed.

4. DISCUSSION

This is the first study to systematically assess return of individual research results within the national US network of federally funded Alzheimer's Disease Research Centers. Study results indicate wide variety across Centers with regard to return of research results,

both in terms of what types of results are returned to participants and how the disclosure process is structured. Findings suggest that return of results is relatively common for certain types of results, such as consensus research diagnoses and neuropsychological test results, but relatively rare for others (e.g., *APOE* genotype results). Overall, return of results practices did not differ significantly by type of participant, with Centers reporting disclosure of results to participants with cognitive impairment (e.g., those with dementia or MCI) at roughly the same rate as disclosure to participants without significant cognitive impairment. Centers cited numerous reasons for returning individual research results, most commonly endorsing that such return could provide information that might inform participants' medical decision-making. This rationale is consistent with consensus recommendations [1] to most strongly consider return of results in cases where they are of potential clinical significance to participants and family members. Centers also commonly endorsed the idea that return of results could serve as a means of thanking participants for their research volunteer efforts and could potentially even enhance retention of participants in longitudinal cohort studies.

Most Centers did not disclose genetic and biomarker findings to participants. Prominent reasons cited for not returning these types of results included their lack of proven clinical utility, as well as the fact that some sites did not conduct such testing in CLIA-approved laboratories. Less frequently cited reasons were lack of appropriate human and financial resources for returning results, as well as concerns over legal liabilities and psychological harms to participants. Decisions not to share *APOE* genetic testing and amyloid neuroimaging results with asymptomatic populations are consistent with clinical guidelines recommending against such use, [8,9] and disclosure of the former raises ethical issues particular to neurogenetic testing [12]. However, disclosure of such information in controlled research settings has generally been shown to be safe and effective. For

example, *APOE* disclosure in at-risk older adults in the REVEAL studies has not typically resulted in significant psychological distress or misunderstanding of genetic risk information [13,14]. An emerging body of literature on disclosure of amyloid neuroimaging also provides guidance for responsible return of biomarker results in both asymptomatic and symptomatic populations [15–17].

A wide range of health professionals was involved in disclosure of results, including physicians, psychologists, nurses, genetic counselors, and research staff. Neurologists were the most commonly involved type of health professional, reflecting their expertise related to diagnostic and biomarker information pertinent to dementia, as well as their ADRC leadership roles and regular involvement in longitudinal cohort study visits. Disclosure sessions themselves also varied widely with regard to how they were carried out. In-person disclosure was most common, although some specific results were also commonly shared by telephone and mailed letter. That survey data were collected prior to the onset of the COVID-19 pandemic likely influenced the frequency with which the in-person approach occurred, as well as the fact that disclosure by videoconference (e.g., via Zoom session) was not commonly endorsed. The forced use of remote methods to communicate with research participants due to the pandemic may accelerate ongoing research to develop methods to streamline disclosure processes and address the dearth of expert clinicians skilled in education, counseling, and result delivery [18].

Centers varied widely with regard to how frequently they employed commonly recommended practices to support disclosure of health-related information. As part of results disclosure, participants were reportedly provided with recommendations for next steps by approximately three-quarters of Centers, with additional relevant resources provided by about half. A take-home summary letter of findings was reportedly provided by fewer than

half of Centers. Although use of these disclosure process elements may not have been called for in each case, study results suggest that there may be room for improvement in both how research results are disclosed and supplemented with supporting information. Use of pre-test education (19.6%) and post-test counseling sessions (30%) were reported in a minority of cases, while the use of visual aids in communication of results was infrequent (11%). Given the value of these processes and resources in enhancing health education and facilitating participant adjustment, more frequent use as part of results disclosure may be worth considering, particularly for results with complex or ambiguous implications and/or involving disclosure to individuals with cognitive impairment.

This study has several limitations that should be kept in mind when considering its findings. First, the exclusive focus on longitudinal cohort studies within the US network of federally funded AD research centers means that results may not generalize to dementia research in other contexts. Second, survey items may have been prone to various biases common to this type of work. For example, recall or other biases may have limited the accuracy of respondents' self-reported activities at their site. Finally, data collection took place prior to the onset of the COVID-19 pandemic, which has likely affected sites' ability and practices for disclosing research results.

There are several directions for future research on return of individual research in dementia-related studies. As noted above, an emerging body of literature has begun to assess the process and impact of disclosing genetic and biomarker risk information for Alzheimer's and related dementias. Such work could be expanded in several ways. First, most studies to date have focused on *APOE* genotyping and amyloid neuroimaging, but other types of genetic and biomarker information are of potential interest, including polygenic risk scores, tau imaging, and blood-based biomarkers such as p-tau-217 [19]. Within such

studies, it would be helpful to examine the utility of different methods for reducing barriers to the communication of research results (e.g., use of telehealth modalities for disclosure, creation of centralized education resources and protocols to support return of results at ADRCs). Second, studies of the impact of results disclosure could examine a broader range of outcomes, beyond psychological and behavioral effects. For example, such studies have not typically assessed the economic costs of disclosure (even though financial barriers to return of results are commonly cited), or how return of results might enhance retention of participants in longitudinal studies, even though this and other studies suggests Centers view this as an important potential benefit [20]. In addition, the potential for results disclosure to bias cognitive outcomes being collected in Center's longitudinal cohort studies could be further investigated, given preliminary findings that knowledge of *APOE* genotype could influence one's performance on objective and subjective measures of memory [21]. Finally, return of results studies could benefit from more diverse study samples, both in terms of race / ethnicity and socioeconomic status. Encouragingly, the National Institute on Aging has recently funded studies in this area that may help address some of these gaps in knowledge [22]. Such diversity would also be welcome more generally in AD research, given that the role of genetic factors and biomarkers in AD etiology may differ across populations.

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CONFLICTS OF INTEREST

The authors report no financial conflicts of interest.

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Table 1. Return of individual research results, by type (N = 30 centers)

	Type of participant		
Type of information	**Dementia or MCI***	**Normal cognition or SMC†**	**N/A‡**
Consensus research diagnosis	25 (83%)	23 (77%)	0
Neuropsychological test results	22 (73%)	21 (70%)	0
Amyloid PET results	13 (43%)	8 (27%)	6 (20%)
MRI results	12 (40%)	10 (33%)	3 (10%)
FDG PET results	8 (27%)	6 (20%)	10 (33%)
Genetic test results, not *APOE*	4 (13%)	3 (10%)	5 (17%)
Tau imaging results	3 (10%)	2 (7%)	13 (43%)
CSF biomarker results	3 (10%)	1 (3%)	8 (27%)
APOE genetic test results	2 (7%)	2 (7%)	0

*MCI = Mild cognitive impairment; †SMC = subjective memory complaints

‡N/A = Not applicable, information not collected as part of Center's longitudinal cohort study

Table 2. Reasons for disclosing individual research results

Reason for disclosure	*Type of test result*							
	Research diagnosis	**Neuro-psych**	**Amyloid**	**MRI**	**FDG PET**	**Other genetic test**	**Tau**	
Could inform participant's health care or medical decision-making	96.0% (24/25)	77.3% (17/22)	84.6% (11/13)	75.0% (9/12)	100.0% (8/8)	100.0% (4/4)	100.0% (3/3)	1
Participant or family requested it	72.0% (18/25)	90.9% (20/22)	84.6% (11/13)	83.3% (10/12)	75.0% (6/8)	75.0% (3/4)	100.0% (3/3)	
Sharing is a way of thanking participants	84.0% (21/25)	77.3% (17/22)	61.5% (8/13)	75.0% (9/12)	75.0% (6/8)	50.0% (2/4)	100.0% (3/3)	
Sharing could help retain participants	68.0% (17/25)	72.7% (16/22)	61.5% (8/13)	75.0% (9/12)	75.0% (6/8)	75.0% (3/4)	100.0% (3/3)	
Participants and/or their families find result valuable	84.0% (12/25)	77.3% (17/22)	61.5% (8/13)	66.7% (8/12)	87.5% (7/8)	75.0% (3/4)	100.0% (3/3)	
Participant's physician requested it	52.0% (13/25)	54.5% (12/22)	23.1% (3/13)	41.7% (5/12)	50.0% (4/8)	25.0% (1/4)	66.7% (2/3)	

Table 3. Reasons for not disclosing individual research results

Reason results are not returned	**Research diagnosis**	**Neuro-psych**	**Amyloid**	**MRI**	**FDG PET**	**Other genetic test**	**Tau**	**CSF bio**	**APOE**	**Total**
Results do not meet clinical standards (e.g., not from CLIA-approved laboratory, not FDA-approved test)	60.0% (3/5)	25.0% (2/8)	9.1% (1/11)	50.0% (7/14)	10.0% (1/10)	50.0% (10/20)	71.4% (10/14)	52.6% (10/19)	35.7% (10/28)	**41.9% (54/129)**
Study consent form explicitly notes results will not be returned	40.0% (2/5)	37.5% (3/8)	54.5% (6/11)	50.0% (7/14)	30.0% (3/10)	30.0% (6/20)	28.6% (4/14)	36.8% (7/19)	25.0% (7/28)	**34.9% (45/129)**
Results are not medically actionable	20.0% (1/5)	25.0% (2/8)	36.4% (4/11)	35.7% (5/14)	20.0% (2/10)	55.0% (11/20)	50.0% (7/14)	21.1% (4/19)	14.3% (4/28)	**31.0% (40/129)**
Information is not useful/action	40.0% (2/5)	37.5% (3/8)	18.2% (2/11)	42.9% (6/1	0.0% (0/1	45.0%	21.4% (3/14	26.3% (5/19	17.9% (5/28	**27.1% (35/12**

able for participants				4)	0)	(9/20)	)	)	)	**9)**
Potential for unintended harms (e.g., psychological distress)	40.0% (2/5)	50.0 % (4/8)	18.2% (2/11)	21.4 % (3/14)	10.0 % (1/10)	45.0 % (9/20)	28.6 % (4/14)	15.8 % (3/19)	10.7 % (3/28)	**24.0% (31/129)**
Time burdens involved for staff	40.0% (2/5)	25.0 % (2/8)	18.2% (2/11)	21.4 % (3/14)	10.0 % (1/10)	15.0 % (3/20)	13.3 % (2/14)	5.3% (1/19)	3.6% (1/28)	**13.2% (17/129)**
Lack of expertise in disclosing results	20.0% (1/5)	12.5 % (1/8)	9.1% (1/11)	7.1 % (1/14)	0.0 % (0/10)	20.0 % (4/20)	21.4 % (3/14)	5.3% (1/19)	3.6% (1/28)	**10.1% (13/129)**
Financial cost	0.0% (0/5)	0.0% (0/8)	0.0% (0/11)	7.1 % (1/14)	10.0 % (1/10)	5.0% (1/20)	0.0% (0/14)	0.0% (0/19)	0.0% (0/28)	**2.3% (3/129)**
Concerns about legal liability	0.0% (0/5)	0.0% (0/8)	9.1% (1/11)	0.0 % (0/14)	0.0 % (0/10)	5.0% (1/20)	0.0% (0/14)	0.0% (0/19)	0.0% (0/28)	**1.6% (2/129)**

Table 4. Types of professionals involved and modalities used in disclosure of research results

	Type of test result							
Type of professional*	**Research diagnosis**	**Neuro-psych**	**Amyloid**	**MRI**	**FDG PET**	**Other genetic test**	**Tau**	**C**
Neurologist	88.0% (22/25)	68.2% (15/22)	100.0% (13/13)	91.7% (11/12)	100.0% (8/8)	75.0% (3/4)	100.0% (3/3)	10 (
Neuropsychologist/ other psychologist	44.0% (11/25)	63.6% (14/22)	15.4% (2/13)	16.7% (2/12)	0.0% (0/8)	0.0% (0/4)	0.0% (0/3)	0 (
Geriatric psychiatrist	20.0% (5/25)	22.7% (5/22)	30.8% (4/13)	25.0% (3/12)	12.5% (1/8)	0.0% (0/4)	33.3% (1/3)	0 (
Nurse/nurse practitioner	40.0% (10/25)	22.7% (5/22)	0.0% (0/13)	8.3% (1/12)	0.0% (0/8)	0.0% (0/4)	0.0% (0/3)	0 (
Geriatrician	20.0% (5/25)	22.7% (5/22)	23.1% (3/13)	8.3% (1/12)	0.0% (0/8)	0.0% (0/4)	0.0% (0/3)	0 (
Research coordinator	20.0% (5/25)	22.7% (5/22)	7.7% (1/13)	0.0% (0/12)	0.0% (0/8)	0.0% (0/4)	0.0% (0/3)	0 (
Genetic counselor	0.0% (0/25)	0.0% (0/22)	0.0% (0/13)	0.0% (0/12)	0.0% (0/8)	75.0% (3/4)	0.0% (0/3)	0 (
Modality of results								

disclosure								
In-person visit	68.0% (17/25)	81.8% (18/22)	100.0% (13/13)	91.7% (11/12)	100% (8/8)	100% (4/4)	100% (3/3)	6 (
Telephone	60.0% (15/25)	59.1% (13/22)	23.1% (3/13)	58.3% (7/12)	37.5% (3/8)	25.0% (1/4)	66.7% (2/3)	6 (
Mailed letter	48.0% (12/25)	63.6% (14/22)	7.7% (1/13)	41.7% (5/12)	25% (2/8)	0.0% (0/5)	0.0% (0/3)	0 (

*Other professionals mentioned: neuropathologist (n=3), physician's assistant (n=3), and social worker (n=3)

†Other modalities mentioned: E-mail (n=3) and electronic health record (n=1)

Table 5. Features of disclosure process, by type of research result disclosed

Disclosure process feature	**Research diagnosis**	**Neuro-psych**	**Amyloid**	**MRI**	**FDG PET**	**Other genetic test**	**Tau**
Recommendations for next steps	84.0% (21/25)	72.7% (16/22)	76.9% (10/13)	75.0% (9/12)	75.0% (6/8)	75.0% (3/4)	33.3% (1/3)

Resources for more information	72.0% (18/25)	54.5% (12/22)	53.8% (7/13)	33.3% (4/12)	50.0% (4/8)	50.0% (2/4)	33.3% (1/3)
Communication with participant's doctor	52.0% (13/25)	45.5% (10/22)	23.1% (3/13)	33.3% (4/12)	50.0% (4/8)	0.0% (0/4)	66.7% (2/3)
Take-home letter	48.0% (12/25)	45.5% (10/22)	15.4% (2/13)	41.7% (5/12)	37.5% (3/8)	50.0% (2/4)	0.0% (0/3)
Post-disclosure counseling	32.0% (8/25)	22.7% (5/22)	38.5% (5/13)	33.3% (4/12)	37.5% (3/8)	50.0% (2/4)	33.3% (1/3)
Pre-disclosure education session	12.0% (3/25)	9.1% (2/22)	46.2% (6/13)	16.7% (2/12)	25.0% (2/8)	50.0% (2/4)	33.3% (1/3)
Visual aids	12.0% (3/25)	9.1% (2/22)	15.4% (2/13)	8.3% (1/12)	12.5% (1/8)	0.0% (0/4)	33.3% (1/3)

Figure 1. Number of Types of Results Disclosed by ADRCs (N=30)