

# VAMHCS RESEARCH SERVICE HOT TOPIC

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## The Public's Perception of Our Research Program

- Anyone who's tried to recruit participants for research studies knows that it's frequently a difficult task. When designing and refining recruitment strategies, study staff make assumptions about their target populations, yet even then recruitment can be a slow challenging process. Then, once an individual has enrolled in a study, the challenges continue with participant retention and compliance.
- Do you know what our veterans and the public at large think about us and our research program? Do you think that negative media coverage about research in the last few years has had an impact? What do you think are the reasons that people say "No" to research participation? Do you think your research participants are satisfied with their experiences in your studies? Would their families agree?
- During several sessions since 2006, the Research Service conducted surveys of our VAMHCS community in an effort to gauge the public's perceptions about our research program. We set up displays in the second floor lobby of the BVAMC and in the outpatient lobby of Perry Point and asked

passers-by to complete an anonymous pen & paper survey.

- ▣ There were 120 respondents ranging from 18-75+, most in the 45-65 year old range.
- ▣ Most of the participants were veterans and male.
- ▣ The sample was relatively evenly divided between patients, visitors, and employees.
- ▣ Some had participated in research studies, some had declined when asked to participate in research studies, many had never been asked.
- ▣ Of the persons who had participated in research, studies were at the VAMHCS, UMMS and elsewhere.

Here's what we found out:

- ▣ Of the folks who said they had participated in research in the past (n=50):
  - ▣ They appeared to have had generally positive experiences.
  - ▣ They felt well-informed about the study (effective informed consent process!) and in the hands of competent, prepared staff.
  - ▣ Most had agreed to participate because they or a family member had the medical or psychiatric condition that was the focus of the study, or because they had an interest in science or the advancement of knowledge. The least important reason was financial compensation.
  - ▣ Several participated in order to help friends or employers reach their recruitment goals(!).
  - ▣ They would be willing to participate in future studies.

- ▣ Negative experiences tended to be expected (needle sticks and other study-related procedures, including disclosure of personal information or feelings). However, there were some negatives that were in the control of study staff: staff who didn't say thank you, impolite or disrespectful staff, delays and inconveniences, minor expenses.
- ▣ Of the folks who said that they had never participated in research (n=70):
  - ▣ Almost 2/3 of the respondents stated they were aware that the VAMHCS conducted research studies and 80% said they would consider volunteering for a study.
  - ▣ The major reasons that they would say “no” to a research study were fears of rude or impersonal treatment by staff and fear of not being informed truthfully.
  - ▣ Additional considerations are: the risks of the research, convenience, the scientific importance, and the particulars of study procedures.
  - ▣ The least important considerations were: privacy issues, pain, “nice” staff, and pain.
- ▣ “Take home messages”:
  - ▣ There is a disconnect between the fears of non-participants and the actual experiences of participants: the major fears of nonparticipants (rude staff and unexpected study requirements) did not seem to be factors in actuality (the most positive experiences of participants were polite &

- competent staff and the feeling of being well-informed about the study).
- ▣ Therefore, if your educational and outreach programs are designed to enhance the community's understanding of research studies, you may improve your recruitment efforts.
  - ▣ The “face” of your research study is very important when you recruit and interact with participants. A courteous, approachable, forthright person could enhance recruitment and retention. From the comments we received, simple things like a smile, a “Thank You”, and making the participant feel valued can make a world of difference.
  - ▣ Remember that your participant today could be your recruiter tomorrow. Your participant's word of mouth to others could prompt some to walk through your door (or keep some out!).
  - ▣ Note that scientific interest and advancement of knowledge was a motivating factor for many people. When recruiting or interacting with your participants, keep that in mind: an interesting project could be a draw for some people. Telling participants the results of a study and the scientific questions that were answered by the study could be a nice way to say thanks to them.
  - ▣ Take note that some individuals agreed to participate in research in order to help a friend or employer reach a recruitment goal. Be very careful of power relationships when recruiting for studies. Protections must be in place when there

is potential for the enrollment of employees, house staff, students, etc. over which you have a supervisory role! This is actually a required element in BRAAN (when applicable) when you submit protocols for IRB review.

VAMHCS researchers Leslie Katzel, MD, PhD and Marianne Shaughnessy, PhD assisted with this project. There are plans to continue with further community outreach.

**For questions concerning this or other Research Service Hot Topics OR for adding staff or colleagues to the Hot Topics mailing list, contact:**

Jessica Mendoza, RN, BSN, CCRC  
Research Compliance Specialist  
Rm 3-A-125  
(410) 605-7000 x5591  
[jmend001@umaryland.edu](mailto:jmend001@umaryland.edu)

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**For comments, complaints or suggestions regarding the Research Service or Office of Research Compliance, contact:**

Melody Higgins, RN, MSN, CCRC  
Research Compliance Officer  
Rm 3-A-125  
(410) 605-7000 x6512  
[melody.higgins2@va.gov](mailto:melody.higgins2@va.gov)