

Title: Motivating Research Participation

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Description: A researcher struggles to recruit sufficient numbers of mental health consumers to participate in an evaluation study of county mental health services before and after a major reorganization of the delivery system.

Headings: Voluntariness and Undue Influence in Recruitment; Other voluntariness or recruitment issues; Survey and qualitative research (behavioral, social science); Mental health disorders, participants with (including addictive disorders and developmental disabilities)

Case Type: Decision making

Motivating Research Participation

A researcher at a major university received a contract from the County Mental Health Authority to rigorously evaluate the outcomes and satisfaction of consumers receiving mental health services before and after a major reorganization of the delivery system to make it more “consumer-directed” and focused on recovery. The researcher employed a pre/post design, randomized potential participants from the county information system (20% of total recipients), and developed a selection criteria to be applied to all those identified at recruitment.

The county stressed to the researcher that the study population should be large enough to assure sufficient power for analysis of the data to be able to identify significance where indicated. This was critical since the findings were to be used in making funding and treatment decisions that would affect the mental health of all the consumers receiving care within the public mental health system. Therefore, the researcher developed an aggressive recruitment strategy including the following steps:

1. Letters were sent to all county mental health consumers notifying them of the impending study signed by the county mental health director. Posters were also placed in county mental health facilities and an article published in a family advocate newsletter. The researcher attended consumer and family self-help group meetings to encourage participation and appeared on a local television talk show.
2. Case-managers were encouraged to discuss the importance of the study with their clients.
3. Postcards were sent to all those mental health services recipients selected in the randomization process explaining the importance of the study for the quality of their mental health services. The postcard also explained that they had been selected for interviewing and would be contacted soon.
4. Telephone calls were placed by recruiters to those selected for participation to schedule enrollment, including informed consent and baseline interviews. The recruiters tried to reach each potential participant at least three times by telephone to schedule an appointment, calling at different times during the day and evening. If these attempts were unsuccessful, the recruiter was to make at least two personal visits and leave a postcard if the person was not available.

5. If the initial attempts by recruiters were unsuccessful, the recruiter's supervisor would send an official letter to the potential participant asking them to call the research office and providing a toll-free number, contact the person's case manager and elicit support in making an appointment, and make a personal visit to schedule an appointment, or, if possible enroll the person at that contact.
6. Mental health consumers and family members were hired to be recruiters and surveyors on the study to help allay consumer reservations about participation.
7. Recruiters were trained using extensive role-playing methods in order to be able to present the study and answer all potential participant questions. Strategies were also developed to help the recruiter address any concerns about the study regarding support for transportation to interviews and babysitting needs, flexibility in scheduling of interviews, confidentiality, and reimbursement for incidental expenses. Recruiters had frequent refresher training sessions throughout the enrollment period to identify recruiting problems and to develop new approaches when participants refused to participate. Recruiter performance was closely monitored with rates for each recruiter shared at staff meetings.
8. If a person declined to participate, a letter was subsequently sent by the county mental health director encourage them to reconsider. In addition, the researcher paid a personal visit to those who declined participation, sometimes taking them to lunch or dinner, to convert them from a "refuser" to a "participant".
9. A coupon book with local services and goods was provided to participants (worth over \$50) for their cooperation. Money was not offered since many of the participants had substance abuse problems as well as a psychiatric diagnosis and it was feared that the money would be spent inappropriately.

Even though this recruitment protocol was well-implemented, it became apparent within a few months that at least half of the those selected for participation had declined participation or were avoiding making an appointment with a recruiter to discuss enrollment. In fact, some of the consumers who had been selected for participation had complained to the county mental health board, the county mental health director, and/or had called the number for research complaints and left message about their concerns regarding the recruitment process. One person indicated that she felt harassed by recruiters with requests to meet and participate. "They won't take no for an answer," she told a group of consumers who were meeting to discuss the problem. She was a shy person and found it difficult to tell people "no." She did not like interviews. She was too busy with her children and a full-time job to volunteer for the evaluation, and was not interested in the coupons that were being offered. At first she just through away the letters and postcards and erased the phone messages. But, when an official of the study dressed in a suit came to her door at dinnertime, she could not escape agreeing to a meeting with a recruiter to discuss the study. At that recruitment meeting, she was surprised to find that the recruiter was one of her peers from the local consumer drop-in center. "It seemed like everyone is pressuring me to participate," she said. She was a private person and did not want to talk about her treatment experiences with either strangers or peers. Because she refused yet another attempt to enroll her in the study by the researcher, she began to fear that she might be treated unfairly by her mental health provider. She also felt bad because they were making her feel like she was letting down her peers by hurting the findings of the study and jeopardizing money that could go to better services, including the drop-in center she attended.

Although the university IRB board had initially approved this study, because of consumer complaints, a meeting was planned with the researcher to discuss the study recruitment protocol. The researcher feels she must redouble her efforts to meet her recruitment goals or the study funding will be threatened. However, some members of the IRB board believe that potential participants are being pressured too much and undue influence applied to enroll them in the study.

What revisions to the recruitment protocol, if any, would you recommend?

Questions for Further Reflection

Can recruitment strategies cross an ethical line by making it too hard for a person to refuse participation--even if refusal is not related to issues of risk?

Could this recruitment protocol cause emotional distress among potential participants and be considered a study risk itself?

Does the researcher have any responsibility to empower potential participants to decline participation?