Developing Community-Placed Resources to Engage Minority Participation in Research

Frederic De Pourcq, MS; Jacquelyn J. Gosse, MA; Jean Larson, MBA; Nancy S. Redeker, PhD, RN
Yale Center for Clinical Investigation, New Haven, CT; Mayo Clinic Center for Translational Science Activities, Rochester, MN

BACKGROUND

Minorities suffer disproportionately from numerous diseases, but they are underrepresented in clinical trials. The focus of the Yale Center for Clinical Investigation (YCCI) and Mayo Clinic Center for Translational Science Activities (CTSA) Community Engagement project was to identify opportunities to exchange best practices that fostered community-based research by developing and supporting services that enhance outreach, recruitment and retention of minority participants.

This collaboration was funded by the American Reinvestment and Recovery Act administrative supplement.

METHODS

The Mayo Clinic Office of Community Engaged Research (OCER) is a centralized resource that facilitates community-engaged research. OCER provides services that promote inclusion of racial and ethnic minorities in clinical research and ensures community participation in the design of research studies. In addition to a director, Mayo’s community engaged research staff includes:

- Coordinator of Multicultural Research
- Design of research studies.

YCCI is a centralized resource that facilitates community-engaged research.

Community Engaged Research Liaison
- Fosters sustainable relationships between community members and Mayo Clinic researchers.
- Assists in the planning and execution of community-engaged research.

Cultural Advisors
- Collaborate with institutional staff to create study participation plans.
- Assist in the planning and execution of community-engaged research.

Using the Mayo approach as a model, YCCI developed similar services by reaching out to two community organizations with strong cultural traditions as it builds bridges with other communities. 2

Cultural Advisors:
- Collaborate with institutional staff to create study participation plans.
- Provide translation and interpretative services for study participants.
- Collaborate with institutional staff to create study participation plans.
- Foster sustainable relationships between community members and Mayo Clinic researchers.

YCCI’s global and disease-specific recruitment campaigns. Cultural advisors are assisting in efforts to ensure that these campaigns are relevant to minority audiences. They are assisting with printed and web materials regarding clinical research and minority participation in clinical trials that the organizations can utilize to promote participation in clinical trials.

RESULTS

YCCI-supported Cultural Ambassadors participate in projects, community engagement activities and events designed to promote and increase participation in clinical trials. These include:

- Helping to develop printed and web materials regarding clinical research and minority participation.
- Assisting with the global recruitment campaigns to the needs of their communities.
- Assisting with the global recruitment campaigns to the needs of their communities.
- JUNTA representatives providing translation services for informed consent and other materials.
- YCCI has provided intensive training in all aspects of clinical research theory and practice to JUNTA and American Methodist Evangelical Zion Church representatives.
- Trained in introductory sessions on:
  - General research topics, including clinical research, academic medicine, cancer research, study design, human subjects protection, animal-based research, scientific misconduct, pediatric research, public health research, mental health research and community-based and participatory research.
- In-depth faculty presentations on relevant research at Community Grand Rounds that allows representatives to become research advocates in the community and educates members of their group about the research process.

YCCI’s global and disease-specific recruitment campaigns. Cultural advisors are assisting in efforts to ensure that these campaigns are relevant to minority audiences. They are assisting with printed and web materials regarding clinical research and minority participation in clinical trials that the organizations can utilize to promote participation in clinical trials.

LESSONS LEARNED

...about collaborative activities between two similar academic medical centers:
- Each institution is able to adopt a best practice and find its adaptation in the another (share-and-help) and collaborative partnership.
- Yale provided a fresh approach to expand and enhance an existing Mayo Clinic program.
- Even if entire projects can’t be replicated between institutions, major ideas can.

...about the Cultural Ambassador program:
- Mayo Clinic will evaluate and adapt training materials and the orientation program that Yale established.
- Peer-to-peer research communication and recruitment are embraced and welcomed.
- Community partner organizations are frustrated by multiple, individual PIs contacting them in an uncoordinated approach. Relationships, time and cost savings are enhanced by providing a central contact person and establishing mutually agreed-upon policies and procedures.
- As funding for non-profit community partner organizations decreases, providing mutually beneficial, creative strategies for new sources of revenue are critical and results in a win-win situation for each partner.

REFERENCES

2. www.juntainc.org/en/
3. Community partner organizations are frustrated by multiple, individual PIs contacting them in an uncoordinated approach. Relationships, time and cost savings are enhanced by providing a central contact person and establishing mutually agreed-upon policies and procedures.
4. As funding for non-profit community partner organizations decreases, providing mutually beneficial, creative strategies for new sources of revenue are critical and results in a win-win situation for each partner.

Figure 6: Mayo Clinic Office of Community Engaged Research Efforts to Engage Minority Participation

YCCIs Community Partnership Program to Increase Minority Participation in Clinical Research

- Community Engagement Partnerships
- Office of Research Services
- Recruitment Services
- Community Engagement Liaison