

MEW Network Annual Evaluation
September 30, 2015-September 29, 2016 (FY16)
Grant Year 2

EXECUTIVE SUMMARY

The Managing Epilepsy Well (MEW) Network was established in 2007 with support from the CDC Epilepsy Program and Prevention Research Centers Program (PRC). The mission of the MEW Network is to advance the science related to epilepsy self-management by facilitating and implementing research, conducting research in collaboration with network and community stakeholders, and broadly disseminating the research findings. The MEW Network includes eight collaborating centers (Case Western Reserve University, Dartmouth College, Morehouse School of Medicine, New York University, University of Arizona, University of Illinois-Chicago, University of Minnesota, and University of Washington). Two previously funded (FY07-14) collaborating sites remain active through sub-contracts: University of Texas Health Science Center at Houston and Emory University. Since FY15 Dartmouth College has been the Coordinating Center of the Network.

FY16 projects include: continued development of new programs from the previous year, pragmatic trials of evidence-based programs, and replication studies that expand the scope of epilepsy self-management research to include high priority vulnerable populations (e.g., African Americans, Hispanics, Teens and Young Adults with epilepsy). Significant milestones were reached for each of the individual programs, including publications on the efficacy of two programs (HOBSCOTCH, TIME). The year was also marked by a strong collaborative effort which advanced the development, research, and dissemination of the programs. Sites shared knowledge and experiences ranging from the implementation of instruments and procedures to research the cost-effectiveness of programs, to a completed program dissemination toolkit accompanied with presentations on lessons learned.

One significant focus of FY16 has been the sharing of information regarding technology and how to successfully incorporate it into program design and study procedure. The implementation of online data collection through the program Redcap was discussed throughout the year and data dictionaries for validated instruments were re-created and shared with members. The incorporation of mobile broadband enabled tablets was discussed throughout the year as several programs are now using this technology. The experiences of sites have been shared during monthly conference calls, and has sparked multiple in depth conversations with others who are currently using or looking to use this technology.

MEW network members continue to be active in promoting the network as a whole and their individual programs through attendance and presentations at local academic and community organizations, however this year included several collaborative activities. For the first time, the MEW Network participated in the American Epilepsy Society Annual Meeting as an exhibitor. Members worked together to staff an exhibit booth and reached a wide audience of healthcare providers and discussed the network as a whole and individual self-management programs. This effort was duplicated at the American Academy of Neurology Conference later in the year, and

both exhibitor efforts resulted in the formation of new relationships, most notably, an official partnership with the American Epilepsy Society and a reoccurring publication initiative with the journal Epilepsy & Behavior. Other activities included three presentations by network members as part of a webinar hosted by the Epilepsy Foundation. The network jointly submitted and received acceptance for an article in the AJPM special issue on PRC programs.

Select FY16 highlights

- 10 active research projects were supported
 - Programs in development: YESS!
 - Programs under evaluation: SMART, PAUSE
 - Adaptations of programs for special populations: Project UPLIFT for Hispanics
 - Program adaptations under evaluation: Project UPLIFT for African Americans, MINDSET for Hispanic-Americans
 - Evidence-based programs under further evaluation: HOBSCOTCH, PACES
 - Dissemination of evidence-based programs: HOBSCOTCH, Project UPLIFT Training, WebEase 2.0, TIME

 - 2 programs (SMART, PAUSE) concluded development and randomized controlled trials were commenced.
 - Evidence about effectiveness was published for two programs (HOBSCOTCH, TIME)

- In FY16, the following products were generated:
 - 11 articles in peer-reviewed journals
 - 6 published
 - 4 in press
 - 1 in review
 - 3 chapters in edited books
 - 2 published
 - 1 in press
 - 8 presentations at regional, national, and international professional meetings
 - 3 grand rounds presentations at local clinical sites
 - 2 local presentations and lectures
 - 2 student research presentations
 - 1 national webinar
 - 7 scientific abstracts/posters presented at regional, national and international professional meetings
 - 4 updated/translated versions of program material (2 software/applications, 2 manuals)
 - 3 new manuals/instructions
 - 1 new study protocol
 - 5 other documents (1 script, 1 enrollment packet, 1 newsletter, 1 community forum summary, 1 advisory committee description)

- The MEW Network formalized a partnership with the American Epilepsy Society (AES).

- The collaborating sites coordinated multiple public and Continuing Medical Education (CME) training activities:

- Seizure first aid training
- Youth with Epilepsy training
- HOBSCOTCH BTACTm (cognitive assessment training): 2 trainees
- Project UPLIFT Training for Mental Health Professionals: 12 trainees
- 2 CME presentations at national professional conferences (APA and AES)
- Public health workforce development support to 25 academic mentees (3 Bachelor-level, 15 Master-level, 4 Doctoral-level, 3 Medical School)
- The MEW Network supported three workgroups: (1) Article Workgroup (2) Pediatric Epilepsy Self-Management (3) Dissemination Workgroup. Outcomes include 2 publications (1 in press).
- The MEW Network continues to support the MEW-Database Steering Committee. Multiple sites contributed individual study data and obtained and revised data use agreements.
- Two evidence-based programs have been adopted and/or adapted outside of the original study design and population:
 - MINDSET is being used by Community Health Workers in the University of Texas Health Neurology Clinic.
 - Project UPLIFT was implemented in Chicago, Colorado, Connecticut, and Delaware.
 - A pilot study of UPLIFT was conducted in collaboration with the Epilepsy Foundation of Metropolitan New York that involved delivering Project UPLIFT to caregivers of people with epilepsy.
- Technical Assistance Calls Series was continued for all collaborating sites. Two presentations occurred in FY16.
- All sites participated in monthly MEW conference calls and in the annual business meeting, during which they provided regular updates on their progress.
- The coordinating center has been an active participant in the CDC PRC Thematic Network Steering Committee.
- The MEW Network maintains on-line and social network presences through its website and Twitter account (@MEWNetwork).
 - 171 Tweets sent, resulting in 74.8k impressions
- The MEW Network website transitioned to a new domain: managingepilepsywell.org.
- MEW Network sites collaborated throughout FY16, select topics include:
 - Tablets and Data plans- Several programs are utilizing tablets with mobile broadband technology in order to reach participants without access to the internet. Many discussions (individual and on monthly conference calls) were held regarding data plans, Wi-Fi/tablet security, and recovering tablets.
 - MEW Database – The collaborative database effort lead by Case Western Reserve University engaged all sites. Discussions were held regarding epilepsy appropriate measures, common data elements, data sharing, and proposed projects through the Steering Committee
 - Discussions regarding a new initiative were begun at the end of FY16. In FY17 the MEW Network will be pursuing a Recurrent Feature in *Epilepsy & Behavior*.