Training and Support for Patients and Consumers Engaged in Research

Training and Support

- Training and continued learning opportunities are a key element for success
- Methods to support patient and consumer involvement are evolving
  - NBCC Project LEAD
  - FDA Patient Representative Program
  - Congressionally Directed Medical Research Program Consumer Representative Program
  - Consumers United for Evidence-Based Healthcare

Principles for Training Programs

- Set appropriate goals
- Target training for the specific project and roles
  - The FDA provides training on regulatory processes as it is specific to the activity
  - Cochrane Consumer Network provides training manuals for preparing plain language summaries
- Take into account level of knowledge & experience
- Understand motivations of learners
- Provide on-going and mixed training methods
  - Lectures, small group breakouts, problem solving, & case discussions

Employ established principles of adult learning
  - (e.g., repetition, use of plain language)
- Identify engaging and skilled faculty members for training courses
- Ensure that training is evaluated and continuously updated
- Advise on applied learning
- Provide information in small quantities in order to avoid overwhelming the individual.

Content for Training

- Content should be relevant to the project at hand
- Key content areas to consider include:
  - Basics of research
  - Context of research organization
  - Applied training in public speaking
  - Training in critical thinking
  - Training in how to negotiate
Additional Support Activities

- In addition to training opportunities, support offered includes:
  - Establish mentorship programs
  - Foster ongoing engagement (updates on research, newsletters, information on opportunities for involvement)
  - Provide networking opportunities
  - Reduce barriers to participation

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Advocacy Training: The NBCC Project LEAD® Story

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What is Project LEAD®?

Leadership Education Advocacy Development

- Science training for consumer advocates: learning concepts and language of science to influence research and public policy
- Students paired with mentors to help during the teaching as well as guide in their advocacy careers
- Collaborative: designed by NBCC with scientists, academics, and consumers
- Select participants: renowned faculty and committed students
- Adult learning: lectures, study group sessions, case studies, role play, homework, personal action plan, and continuing education
- Held several times a year in different locations; different levels and foci for variety of courses

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Why Project LEAD® is Important for Advocates

- Enables advocates to play integral role in breast cancer decision-making in research, policy, healthcare systems
- Gives advocates tools to critically appraise research proposals and scientific reporting
- Builds bridges between the consumer advocacy and scientific communities
- Builds credibility for the consumer advocacy community

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Center for NBCC Advocacy Training

- Created in 2008
- To consolidate, expand and enhance the range of NBCC research advocacy and public policy training
- Includes:
  - Full range of Project LEAD domestic and international science and quality care courses
  - Annual Advocacy Training Conference
  - Team Leader training
- Emerging Leaders
- Continuing Education – web community, advanced sessions
- Mentoring
- Over 2000 graduates, 74 courses – since 1995

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Types of Project LEAD Courses

- Project LEAD® Institute – an intensive science and research methodology course to prepare advocates to serve on breast cancer decision-making bodies and to critically analyze information (1995)
- Clinical Trials Project LEAD® – advanced course to improve design, implementation, outcomes of clinical trials (2001)
- Quality Care Project LEAD® – applies NBCC’s core values towards creating systems-wide improvements in quality breast cancer care. (2004)
- International Project LEAD® – bringing science and clinical trials training to international advocacy community to support advocate/researcher collaborations (2004)

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Types of Project LEAD® Courses

- Project LEAD® Workshop – introductory level course on basic scientific concepts and language; critical skill-building to understand scientific research reported in the media (2008)
- Over 2000 graduates, 74 courses – since 1995

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Identifying Need for Educated Consumers

- Dept. of Defense Breast Cancer Research Program
  - NBCC required that educated consumers work as peers with scientists from start of DOD BCRP – as co-chairs, reviewers, etc
  - Identified need to train advocates in concepts and language of science
- NBCC principles align with Project LEAD:
  - Evidence-based health care
  - Consumer perspective to shape research agenda
  - Keep efforts focused on mission to end breast cancer
- Health care reform legislation –
  - NBCC helped assure “educated consumer involvement on committees” language added to and remained in bill

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Educational Principles of Project LEAD®

- Set bar high – for student selection, curriculum
- Belief in adult ability to learn complex scientific concepts and critical appraisal skills
- Ground program in adult learning principles:
Repetition, small study groups, safe learning environment for weakest to learn most, risk zone theory, graduate action plan

- Offer continuing education, mentoring

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Faculty Criteria

- Faculty
  - Outstanding teaching skills – key requirement
  - Ability/willingness to commit significant time
- Commitment to Project LEAD’s goal of training educated consumers to sit at all breast cancer decision-making tables
- Continue to work with advocates and staff to update and refine curriculum

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Curriculum:

- Basic Science
- Epidemiology
- Clinical Medicine
- Advocacy Development

Slide 17
Curriculum: Advocacy Development

- Overview of research process
- Critical appraisal skills
  - Centrality of evidence-based healthcare
  - Grant review process
  - Influence strategies
  - Role playing in advocacy situations
  - Advocacy opportunities
- Graduate Action Plan with mentors

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Summary

- Research advocacy continues to grow and advance
- Training and support is a critical component for meaningful engagement
- Organizations with training programs in place are valuable resources for researchers
  - Project LEAD
  - Research Advocacy Network
  - CDMRP
  - Cochrane Consumers Network
  - FDA Patient Representative Program

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Resources

- Consumers United for Evidence-Based Healthcare (CUE)
- Online Course: Understanding Evidence-based Healthcare: A foundation for action
- Cochrane Consumer Network: http://consumers.cochrane.org/resources
  - Consumer guides to commenting on Systematic reviews
  - Consumer guides to writing Plain Language summaries
  - Glossary of terms
- Research Advocacy Network: www.researchadvocacy.org
  - Roadmap to Research Advocacy
  - Advocate Institute
- Food and Drug Administration Patient Advocacy Program
  - Role of Patient Advocates in FDA Advisory Committees
  - Overview of the FDA
  - Webinar training