



Carolinus HealthCare System

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Engaging Patients, Stakeholders, and Community as Partners in Patient-Centered Care and Outcomes Research



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Why do we need patient or stakeholder voices in patient care or outcomes research?

- As providers and researchers we've been trained for many years in disease knowledge, research methods, and patient management.
- Aren't we all patients anyway?
- Is there really a problem?



*"When we want your opinion,
we'll give it to you"*



Principles for Engaging Patients in Research

- Engage patients and surrogates in all research phases
- Engage patients based on the research questions being asked and the overall aims of the research
- Initiate patient engagement as early and frequently as possible
- Select representatives similar to the community or population studied



Trust

- Key element for patient-centered research
- By establishing and maintaining trust between researchers and patients, patients are motivated and empowered to actively participate in a learning environment
- Trust is achieved through a process of continuous partnering with the patient, family, and community



Evaluation Methods

- Mapping of Patient Population with Disease or Condition to Census Tracts
- EMR Disease Outcome Data
- Reduction in ED and Inpatient Visits
- Focus Groups – access to care; disease management
- Surveys (patient satisfaction; quality of life; disease specific)
- Key Informant interviews
- Ethnography



Engaging Patients in Patient Centered Care

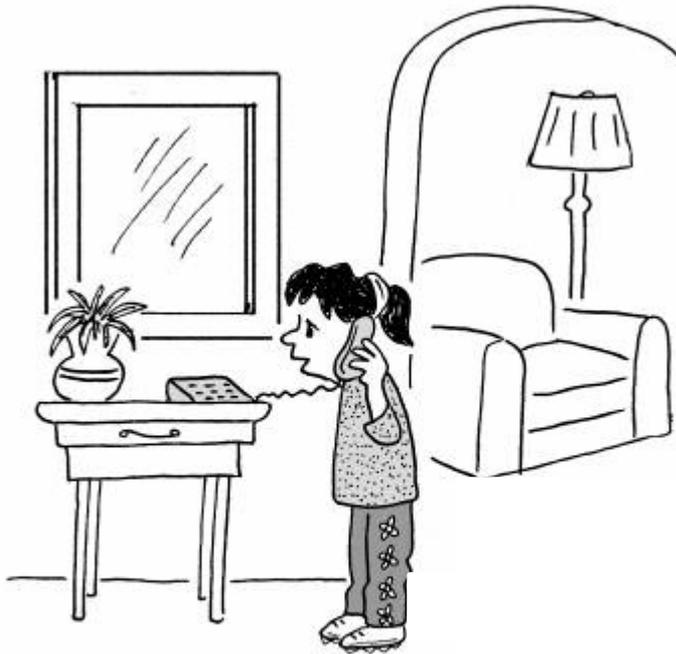
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Shared Decision Making



**"You want to speak to the head of the household?
There is no head of the household. My parents are
into shared decision making."**

- Patient provides information to the physician on values and preferences
- Provider gives treatment options and the benefits and risks of each

Cartoon by Aaron Bacall

2/6/2015

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A Meeting of Two Experts

Patient gives information on: values, preferences, lifestyle, beliefs, and current knowledge about the illness and its treatment

Provider gives all relevant disease information: benefits and risks of various treatments and potential effects on the patient's psychological and social well being



Engaging Patients in Research

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Patient and Stakeholder Roles in ADAPT-NC

- Individual Patients
 - Study design discussions
 - Planning meetings and materials assistance (eAAP)
 - Participate in meetings with practices to discuss how the implementation of the intervention is going.
- Community Care of North Carolina Asthma Workgroup
 - Assist with recruitment and gave input into the toolkit
- Members of Mecklenburg County Asthma Coalition
 - Dissemination
- Patient Advisory Board
 - Feedback and updates



Community Advisory Boards (CAB)

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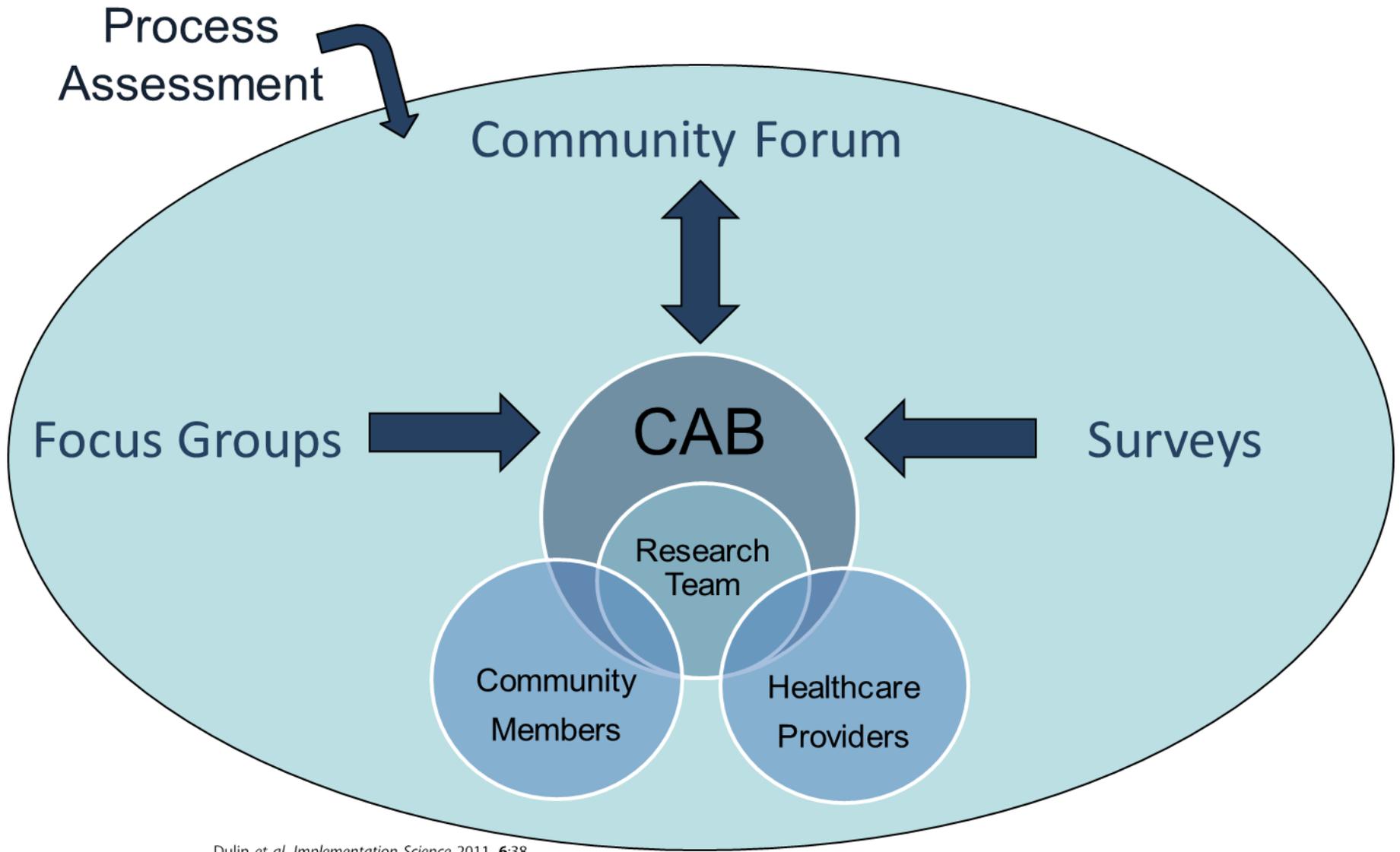
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Community Based Participatory Research (CBPR)

- “Is the collaborative approach to research that involves all partners in the research process and recognizes the unique strengths that each brings.
- CBPR begins with a research topic of community importance, and has the aim of combining knowledge with action to achieve social change that improve health outcomes.”







Dulin et al. *Implementation Science* 2011, 6:38
<http://www.implementationscience.com/content/6/1/38>

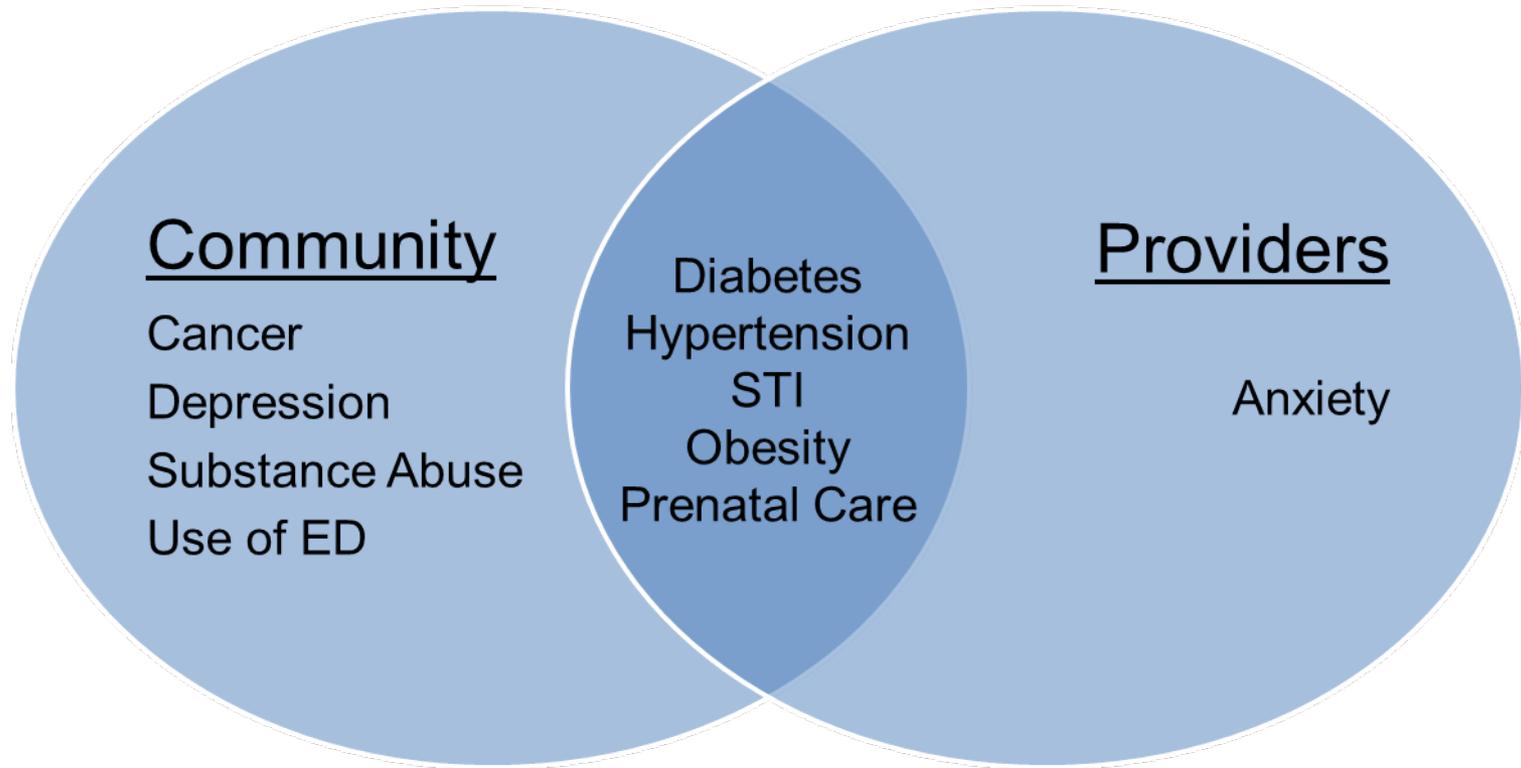


Community Advisory Board

- Reach out to key community stakeholders and engage in the development of the research proposals
- Establish a set time and day that meetings will take place
- Provide meals
- Encourage members to take part in the research process
 - Assist in data collection
 - Participant recruitment
 - Direct contact with community members
- Ask for constant feedback about the process and their participation



Needs Assessment



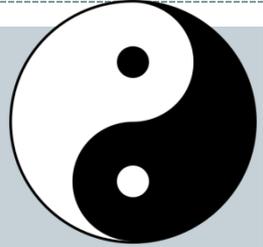
Designing, Conducting and Disseminating Results of Pragmatic Research:



A Few Considerations for Patient Engagement

Milton “Mickey” Eder
PBRN Pragmatic Research And Translation
Learning Group
January 5, 2015

Ethical Issues for Patient Engagement?



Do Pragmatic Clinical trials blur distinctions between
Treatment and Research?

Doctor/patient and investigator/subject-participant
relationship?

e.g., therapeutic misconception; current standard of
care questions (SUPPORT study)

Who Engages Patients?

Research Staff?
and/or
Practice Staff?



How is recruitment organized?

Who obtains informed consent?

Who responds to questions about a research project within the office?

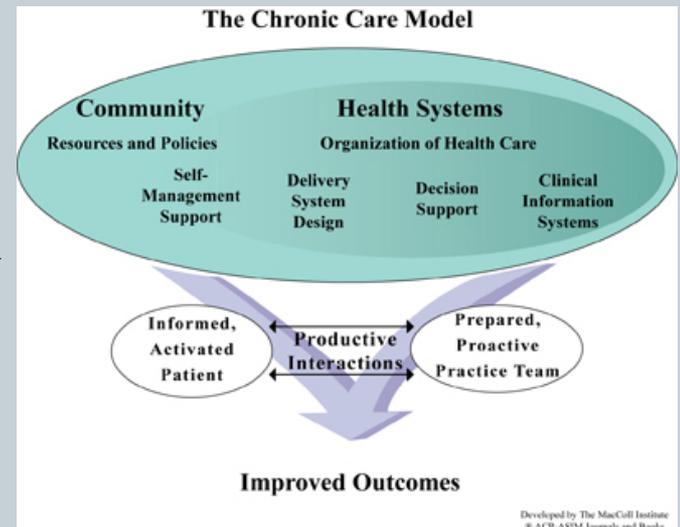
Engaging Patients and Practices



? Who trains/educates patients?

? Can Pragmatic Trials successfully compare treatment options and involve patients in asking health services and office/practice questions?

? How to include physician and staff practice issues (e.g., practicality of treatment, cost/reimbursement) in projects?



Results: Timeliness Challenges



- ? Will researchers share preliminary results with patients? Communities? How to present preliminary results?
- ? Will publication delay release of results?
- ? Are researchers prepared to translate results for non-specialists and develop multiple reports



Dr. Susie Nanney, University of Minnesota
Community Presentation, November 13, 2014