Translation Research: Where are our Communities?

Carolyn M. Jenkins

Medical University of South Carolina
Keynote

“Translation Research: Where are our Communities?
Carolyn Jenkins, DrPH, SPRN, BC-ADM, FAAN
Professor, College of Nursing
Medical University of South Carolina
Translation Research
Where are our Communities?

Carolyn Jenkins, DrPH, MSN, MS, FAAN
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Director, Center for Community Health Partnerships
and
Co-Director, SCTR Community Engagement

http://academicdepartments.musc.edu/sctr/programs/community_engagement/index.html
Objectives

• Review principles of CEnR with focus on CBPR
• Describe community engagement in the context of research frameworks
• Explore methods for training academic and community members for CEnR
• Review Community Engaged Scholars Program and examples of CEnR and action
Clinical and Translational Research Awards (CTSA)

• Designed to develop innovative solutions that will improve efficiency, quality and impact of the process for turning observations in the laboratory, clinic and community into interventions that improve health of individuals and the public.

• n = >50

Reference: http://www.ncats.nih.gov/ctsa
Translation is the process of turning observations in the laboratory, clinic and community into interventions that improve the health of individuals and the public.

Translational science is the field of investigation focused on understanding the scientific and operational principles underlying each step of the translational process.

“If you have built castles in the air, your work need not be lost; that is where they should be. Now put foundations under them.”

Henry David Thoreau
Translational Spectrum

T0: Basic and applied science research
  Preclinical and animal studies
  Defining mechanisms, targets and lead molecules

T1: Translation to humans
  Proof of concept
  Phase 1 clinical trials
  New methods of diagnosis, treatment and prevention

T2: Translation to patients
  Phase 2 clinical trials
  Phase 3 clinical trials
  Controlled studies leading to effective care

T3: Translation to practice
  Phase 4 clinical trials and clinical outcomes research
  Delivery of recommended and timely care to the right patient

T4: Translation to community
  Population level outcome research
  True benefit to society

T0: Translation from basic science to human studies
T1: Translation of new data into the clinic and health decision making
Evaluating Translational Research: A Process Marker Model


Working Passionately Separately

Community

Academic Research
Do our communities view our academic institutions as “Ivory Towers?”
Our Role in CBPA and Research: Connect the Silos in Communities, Own the Issues, Address the Issues, Communicate Findings

Connect the Silos

- Health Systems
- Justice and Homeless
- Social Services
- Younger and Older Community Members
- Basic Needs
- Academic Institution
IOM Recommendation 6 (out of 7) for Clinical & Translational Research Awards (CTSAs)

Ensure community engagement in all phases of research.

NCATS and CTSA Program should:

• **define community engagement broadly** and use definition consistently in requests for applications and communications about the CTSA Program.

• **ensure active and substantive community stakeholder participation** in priority setting and decision making across all phases of clinical and translational research **and in the leadership and governance** of the CTSA Program.

• **define and clearly communicate goals and expectations for community engagement** at individual CTSA level and across program and ensure broad dissemination of best practices in community engagement.

• **explore opportunities and incentives to engage a more diverse community.**
NIH Definition of Community Engagement

“Scientific inquiry conducted in communities and in partnership with researchers. The process of scientific inquiry is such that community members, persons affected by the health condition, disability or issue under study, or other key stakeholders in the community's health have the opportunity to be full participants in each phase of the work (from conception - design - conduct - analysis - interpretation - conclusions - communication of results).”

Models or Frameworks commonly used in Community Engagement
Community Engaged Research

Community Engagement Continuum

Increasing Level of Community Involvement, Impact, Trust, and Communication

**Outreach**
- Some Community Involvement
- Communication flow is from one to the other, to inform
- Provides community with information
- Entities co-exist
- Outcomes: Optimally, establishes communication channels and channels for outreach

**Consult**
- More Community Involvement
- Communication flows to the community and then back, answer seeking
- To get information or feedback from the community
- Entities share information
- Outcomes: Develops connections

**Involve**
- Better Community Involvement
- Communication flows both ways, participatory form of communication
- Involve more participation with community on issues
- Entities are cooperating with each other
- Outcomes: Visibility of partnership established

**Collaborate**
- Community Involvement
- Communication flow is bi-directional
- Form partnerships with community on each aspect of project from development to solution
- Entities form bi-directional communication channels
- Outcomes: partnership building, trust building

**Shared Leadership**
- Strong Bi-directional Relationship
- Final decision making is at community level
- Entities have formed strong partnership structures
- Outcomes: Broader health outcomes affecting broader community. Strong bi-directional trust built.

Reference: Modified by DJ McCloskey and from the International Association of Public Participation
Community Engaged Research Continuum

Increasing Level of Community Involvement, Impact, Trust, and Communication

Community Engaged Research

Reference: Modified by DJ McCloskey and from the International Association of Public Participation
Ladder of Participation
Community Engaged Research

From: Jurkowski JM, CBPR Workshop, 2016
CBPR Key Words and Benefits

- Equal
- Empower
- Cultural Specificity
- Accepted
- Systems Development
- Trust
- Mutual Benefit
- Capacity Building
- Sustain
- Decision-Making
- Shared
- Problem-Solving
- Shared Priority
- Ownership
Determinants of Health and Their Contribution to Premature Death

Proportional Contribution to Premature Death

- Genetic predisposition: 30%
- Behavioral patterns: 40%
- Health care: 10%
- Environmental exposure: 5%
- Social circumstances: 15%

Adapted from: McGinnis JM, Williams-Russo P, Knickman JR. The case for more active policy attention to health promotion. Health Aff (Millwood) 2002;21(2):78-93.
Socio-Ecological Model

- Social & Economic Policies
- Institutions
- Neighborhoods/Communities
- Living Conditions
- Social Relationships
- Individual Risk Factors
- Genetic/Constitutional Factors
- Pathophysiologic Pathways
- Individual and Population Health

Life Course → Environment
Health Impact Pyramid

Increasing Population Impact

- Counseling and Education
- Clinical Interventions
- Long-Lasting Protection Interventions
- Changing the Context to Make Individuals’ Default Decisions Healthy
- Socioeconomic Factors

Increasing Individual Effort Needed

Frieden T. American Journal of Public Health | April 2010, Vol 100, No. 4
Ideal CBPR

Ideal is Achieved when Community and Academic Perspectives are Balanced at Each Research Stage

Community Reality
Gives faith that findings will translate into real world outcomes

Academic Rigor
Gives faith that findings are real
Benefits of Community Engagement

- Community participation increases:
  - Identification of a shared priority
  - Local knowledge
  - Buy-in
  - Commitment
  - Practical and effective solutions
  - Empowerment
  - Problem-solving skills
  - Acceptance of projects and solutions
  - Sustainability

(Penn State Engagement Toolbox, [Website](https://psu.edu/))
Community Involvement in CBPR

Viswanathan, Ammerman, Gartlehner, et al.
Community Based Participatory Research

QUESTIONS

• What organizations can join the network?
• What do they bring and how is it financed?
• How and what needs to be sustained?
Community Engagement Complexities

• Community engaged participatory research has many benefits, but it also adds layers of complexity at many stages:
  – Training for Regulatory and Study Requirements
  – Contracts and Professional Service Agreements
  – Regulatory Approvals
  – Budgets
Common Data Collection Methods

• Qualitative: Often seeks to explore phenomena
  – Focus Groups
  – Informational Interviews (Photo Voice)
  – Key Informant Interviews
  – Cognitive Interviews
  – Observations/Interviews (Walking Interviews)

• Quantitative: Often seeks to confirm hypotheses about phenomena
  – Surveys
  – Biological and Clinical Data
Who best represents the organization or the community?

- Persons with time, energy, and motivation to participate in research may not represent or understand the issues in the community.
- Explore diverse participants of those most affected by issue.
- What is the participants' agenda?
- Who is missing?
Coalition vs. CAB vs. BOD

Coalition¹
- An alliance for combined action
- Agreed upon purpose with shared decision-making
- Each member maintains own autonomy

Comm. Advisory Board²
- Does not have formal authority to govern the organization
- Makes recommendations
- Provides information and materials
- Provides linkages

Board of Directors
- Formal authority to govern and manage
- Provide strategic direction
- Hire leader

¹ Mizrahi & Rosenthal (2001)
² Newman, Andrews, Magwood, Jenkins (2011)
Stakeholder feedback on the draft Framework and Toolkit
(focus groups, webinars, interviews)
Evaluation of Academic Infrastructure

- What’s in place?
- Impact on addressing health concerns
- Evidence of progress in conducting clinical and translational research enabled by infrastructure
- Promotion and tenure criteria
- Challenges encountered and solutions
- Evidence of overall research productivity
- Partnerships with others
- Professional development

http://academicdepartments.musc.edu/sctr/843-792-8300
Evaluation of Community Infrastructure

• What’s in place?
• How do we identify health concerns?
• What processes are used to identify and address health concerns?
• Evidence of progress in addressing health concerns enabled by infrastructure
• Challenges encountered and solutions
• Evidence of overall productivity in addressing community concerns
• Partnerships with others
• Professional development

http://academicdepartments.musc.edu/sctr/ 843-792-8300
“Are We Ready?” The Partnership Readiness for Community-Based Research (CBPR) Toolkit was developed by MUSC academic and community co-investigators in response to an investigation of partnership readiness to conduct CBPR.

The goal of the toolkit is to foster a firm foundation for the partnership to conduct CBPR and to achieve desirable health outcomes.

Free English and Spanish version
https://sctr.musc.edu/index.php/dissemination/products
Overview

- Toolkit Overview
- Basic Tenets of the Partnership
- Goodness of Fit
- Capacity of Partnership/Project
- Partnership Operations
- Summary and Implications

https://sctr.musc.edu/index.php/community
(843) 792-4647
Partnership Readiness Model

ANTECEDENTS
- Catalysis
- Mutual Interest

GOODNESS OF FIT
- Shared Values
- Compatible Climate
- Mutually Beneficial
- Commitment

CAPACITY
- Effective Leadership
- Inclusive Membership
- Complementary Competencies
- Adequate Resources

OPERATIONS
- Congruent Goals
- Transparent Communication
- Conflict Resolution
- Equal Power

OUTCOMES/EFFECTIVENESS
Intermediate
- Sustainable Partnership and Product
- Mutual Growth
- Policy

Long-term:
- Social and Health Impact on Community

https://sctr.musc.edu/index.php/community
(843) 792-4647
Formalizing Commitment

- A memorandum of understanding (MOU) or contract to have written documentation:
  - commitment for the research
  - principles of the partnership
  - responsibilities of community and academic partners
  - methods for decision-making and communications
  - resources and ownership of the resources
  - methods of reporting
  - expectations for sustainability and ongoing relationship

https://sctr.musc.edu/index.php/community
(843) 792-4647
Communication plans

- Decisions regarding what/how/when communication with all partners and the wider community is an important step in establishing operations.
<table>
<thead>
<tr>
<th>Framing Element</th>
<th>Traditional Approach</th>
<th>Racial Justice Approach</th>
</tr>
</thead>
<tbody>
<tr>
<td>1) What's the Problem?</td>
<td>High rates of Type 2 Diabetes</td>
<td>Persistent inequities in Type 2 diabetes rates</td>
</tr>
<tr>
<td>2) What's the Cause?</td>
<td>Poor nutrition, lack of exercise, overweight/obese</td>
<td>Food deserts, racism, stress, transportation, lack of access to healthy, affordable food, structural barriers for communities of color, disinvestment in communities of color, government, policy, institutions, businesses</td>
</tr>
<tr>
<td>3) Who/What is responsible?</td>
<td>Individuals</td>
<td>Educating policy makers, investing in communities of color, increasing access</td>
</tr>
<tr>
<td>4) What action is needed</td>
<td>Nutrition education, exercise classes, medication, weight loss monitoring</td>
<td>Partnerships across sectors, community organizing, engagement</td>
</tr>
<tr>
<td>5) What values are highlighted?</td>
<td>Individualism, personal responsibility</td>
<td>Trust, honesty, relationship, respect, equity, shared responsibility, sustainability, shared power, decision making</td>
</tr>
</tbody>
</table>
Successful Community Engaged Research and Care involves:

- Commitment to long-term community investment
- Openness to organizational and cultural change
- Willingness to share power, as appropriate, between academic, practitioner, and community organizations
- Development of trust and respect among all those involved

Adapted from: National Institute for Health and Clinical Excellence (UK)
The goal of CES-P is to increase the capacity of community-academic partnerships to conduct research with mutual ownership of processes and products, and ultimately, improve the health of our communities in South Carolina and beyond.
Innovation: One of first initiatives in US to provide simultaneous community-engaged research training to teams of community and academic partners through interactive group sessions, apprenticeship opportunities and pilot project funding across multiple therapeutic domains.

Findings: CES Program research training and pilot funding support of community and academic partner teams can be an effective method for addressing community priorities, training research teams and contributing to health improvements among diverse populations.
**CES-P Goals**

- Incentivize and foster translational team science through community and academic partnerships
- Encourage shared identification of community health priorities
- Advance a community-based participatory research (CBPR) co-learning curriculum for academic and community partners
- Promote equitable and lasting partnerships
- Stimulate subsequent research funding, projects and peer-reviewed publications

http://academicdepartments.musc.edu/sctr/843-792-8300
CES-P Competencies

- Articulate concepts and components of CBPR and other methods for community engaged research
- Apply CBPR principles in conduct of research
- Communicate with audiences in both community and academic settings about CBPR principles and components
- Implement a pilot CBPR initiative to address a shared community health priority
- Incorporate CBPR principles and approaches in funding applications
- Develop a 3-4 year plan for subsequent CBPR research

http://academicdepartments.musc.edu/sctr/843-792-8300
CES-P: Application

- Requests for applications
- Informational call
- Application components
  - Academic and Community co-PIs
  - Description of partners and partnership capacity
  - Research proposal addressing shared community health goal
  - Supervisor Consent Forms
  - Signed Memorandum of Understanding

http://academicdepartments.musc.edu/sctr/
843-792-8300
Successful Research Proposals

• Specific Aims: include partners
• Significance: address relevance to community
• Research strategies: how is community involved
• Investigators: include partner as Co-PI
• Evaluation: include community
• Timeline: account for participation of community
• Budget: shows community involvement
• Letters of support: describe role of community
• Human subjects: CAB or workgroup—participants in research; monitor CBPR process

http://academicdepartments.musc.edu/sctr/
843-792-8300
CES-P: Grant Review & Selection

• Academic and Community Reviewers
• Scored based on:
  • Partnership
  • Environment for community-engaged research
  • Significance of health issue
  • Project approach
  • Innovation
  • Potential for future research

http://academicdepartments.musc.edu/sctr/
843-792-8300
CES-P Goals

- **Formal Training**: 10-15 weekly 90-minute sessions
- **Mentorship**: Each team meets with a community and/or academic mentor at least monthly throughout project development and implementation.
- **Pilot Grant Proposal Development**:
  - Application → Revision based on session information, mentors, IRB, and consultation feedback → final IRB approval
- **Funding Project**
- **Future Funding and Contribution to Research**

http://academicdepartments.musc.edu/sctr/
843-792-8300
CES-P Methods

Academic and Community Partner Co-Ownership

Didactic Training

Pilot Grants

- $5,000 - $10,000
- 1-year projects
- Mechanism to inform future grants

Community-based Participatory Research and Sustainable Partnerships

Co-ownership

Didactic Training

Pilot funding

http://academicdepartments.musc.edu/sctr/
843-792-8300
# Formal Training Curriculum

## Curriculum Topic Examples

<table>
<thead>
<tr>
<th>Partnership readiness</th>
<th>Feasibility and pilot testing</th>
</tr>
</thead>
<tbody>
<tr>
<td>Research frameworks and theory</td>
<td>Intervention development</td>
</tr>
<tr>
<td>Community problem identification</td>
<td>Data collection</td>
</tr>
<tr>
<td>Ethics</td>
<td>Data analysis</td>
</tr>
<tr>
<td>Institutional Review Board</td>
<td>Evaluation</td>
</tr>
<tr>
<td>Grant Writing</td>
<td>Translation, Dissemination, and Implementation</td>
</tr>
</tbody>
</table>

Speakers and instructors include a multidisciplinary team of academics, community members, and CES-P alumni who are involved with community-engaged research.

http://academicdepartments.musc.edu/sctr/

843-792-8300
## Informal Training Curriculum

### Examples

<table>
<thead>
<tr>
<th>Teamwork</th>
<th>Discussion: What else is needed?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Active listening</td>
<td></td>
</tr>
<tr>
<td>Building respect</td>
<td></td>
</tr>
<tr>
<td>Communications</td>
<td></td>
</tr>
<tr>
<td>Co-learning</td>
<td></td>
</tr>
</tbody>
</table>

[Source](http://academicdepartments.musc.edu/sctr/843-792-8300)
Are We Ready? Toolkit

Are We Ready?” The Partnership Readiness for Community-Based Research (CBPR) Toolkit was developed by MUSC academic and community co-investigators in response to an investigation of partnership readiness to conduct CBPR.

The goal of the toolkit is to foster a firm foundation for the partnership to conduct CBPR and to achieve desirable health outcomes.

Free English and Spanish version http://academicdepartments.musc.edu/sctr/programs/community_engagement/tools_links_glossary.htm
Evaluation

• Are the right people at the table?
• Does the process and structure allow for all voices to be heard and equally valued?
• How are community members involved in:
  – developing the program or intervention?
  – implementing the program or intervention?
  – program evaluation or data analysis?
• What kind of learning has occurred, for both the community and the academics? Have community members learned about evaluation or research methods? Have academics learned about the community health issues? Are there examples of co-learning?

From: Principles of Community Engagement 2nd ed. (2011)
Partnerships for Environmental Public Health Evaluation Metrics Manual

Available for download from:
http://www.niehs.nih.gov/research/supported/assets/docs/a_c/complete_peph_evaluation_metrics_manual_508.pdf
Themes Addressed in the Manual

- Partnerships
- Leveraging
- Products and Dissemination
- Education and Training
- Capacity Building

How do you measure progress or achievement in these areas?

The approach: **Goal-based Logic Models**
Logic Models

Logic Model – organized, project-specific, informs metrics

• **Inputs** – resources available

• **Activities** – actions that use available resources

• **Outputs** – direct products of activities

• **Impacts** – benefits or changes resulting from activities, outputs

Since 2009, CES-P has trained:

- 5 Cohorts
- 21 Teams
- 65 team members
- 3 to 6 teams per year

50% of participants were community members

Academic Partners

- MUSC, Clemson University, VA
- Medicine (27%), Nursing (24%), Psychology and Behavioral Sciences (18%), Food and Nutrition (12%), Pediatrics (9%), VA (6%), Health Professions (3%), and Dental Medicine (3%).

http://academicdepartments.musc.edu/sctr/
843-792-8300
Since 2009, CES-P has trained:

- 5 Cohorts
- 21 Teams
- 65 team members
- 3 to 6 teams per year

50% of participants were community members

9 follow-on grants amounting to:

$6,344,358

$46:$1

Return on Investment

17 podium presentations and posters

8 peer-reviewed publications

http://academicdepartments.musc.edu/sctr/
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CES-P Cohorts

Cohort 1

Cohort 2

Cohort 3

Cohort 4

Cohort 5

http://academicdepartments.musc.edu/sctr/
843-792-8300

South Carolina Clinical & Translational Research Institute

CTSA Clinical & Translational Science Awards
SCTR Resources

• SPARC Request
  – https://sparc.musc.edu

• SCTR Community Engagement Program
Community Based Participatory Research & Action: Are We There Yet?

- Yes, but who is at the table?
- No, but why not?
EXAMPLES FROM THE FIELD
Community-Driven Participatory Action Research:

REACH
Charleston And Georgetown Diabetes Coalition

Carolyn Jenkins, Dr.P.H., M.S.N., F.A.A.N.
Principal Investigator and Associate Professor of Nursing

Arlene Case-The Lesson
Disparities for African Americans with Diabetes in Charleston and Georgetown

All disparities were first identified through focus groups and validated with epidemiological or quantitative data except those with asterisk *. For those with asterisk, quantitative data showed difference in outcome.

- **Lower levels of:**
  - Per capita income and education
  - Access to health care
  - Funding and insurance
  - Care and education
  - Satisfaction with care *
  - Medications and continuing care
  - Treatment
  - Trust in health systems *

- **Higher levels of:**
  - Poverty
  - Prevalence of diabetes
  - Complications including:
    - Amputations
    - Renal failure (dialysis)
    - CVD
  - EMS and ED use
  - Hospitalizations
  - Costs of care paid by client *
  - Deaths, especially CVD
Our Coalition Goals

• Improve diabetes care and education in 5 health systems for >13,000 African Americans with diabetes.

• Improve community access to diabetes care and self-management education, diabetes supplies and social services for people with diagnosed diabetes.

• Increase community ownership sustainability of program.
Methods for Collaboration

- The health professionals/scientists determine “science” or “evidence-base” for diabetes care.

- Community leaders/members/CHA/health organizations determine “what, when, where, and how” to apply “science” or “evidence” in their community while generating “evidence” and “science” for community empowerment.

- Together we translate into skills for individual, organizational, and community behavior change, advocacy, and policy change across systems, and we evaluate/report our results.
Community Actions

- Community-driven activities and creating healthy learning environments where people live, worship, work, play, and seek health care.

- Evidence-based health systems change using continuous quality improvement teams (CQI).

- Coalition power built through collaboration, trust, and sound business planning with a focus on systems, community, and policy change and sustainability.
Interventions

• Community skill-building & neighborhood clinics
  – 175 lay educators trained
  – Diabetes Self Management & Foot Care education
  – Wise Women & Wise Men, Wise Communities helping each other—SDOH

• Community health professional training
  – > 90% of health professionals in 5 systems attended update on diabetes care
  – 500 RNs completed advanced foot/wound education and care
  – 27 physicians completed foot care education and return demonstrations

• Outreach by professional & lay educators/navigators (CHAs)
  – 8 different 30 minute TV programs aired 34 times on cable
  – Library program/Internet use focused on diabetes resources
  – Weekly diabetes management groups in 10 sites
  – Navigation for diabetes care, supplies & social services

• Health systems change
  – Registry & reminder system and now EHRs
  – CQI teams with chart audit & feedback to providers and systems

• Coalition building, sustainability (501c3), & policy change
Working effectively with communities moves the science from Bench to Bedside to Countryside more rapidly—but plan and champions are needed.

Available from: musc.edu/reach
Community Activities reached >125,000 African Americans

Skill-Building for CHAs and Volunteers

Community Screening and Education

Individual/Group Education

≥ 3 sessions = 3.2% drop in A1c

Neighborhood Walk and Talk Groups

Photos used with permission of participants and partners
Womanless Wedding

Men’s Talk

Talk about Diabetes & Foot Care

Recognition and Rewards
Georgetown County Diabetes Core Activities

Physical Activity

Health Screenings

Walk-A-Thon

Educational Classes
Media

- Printed Material
- Garage Banner
- Flyers
- Bus Placards
REACH at the Library

Cybermobile
Equipped with 6 Internet laptop computers
Results
The Community Chronic Care Conceptual Model
REACH Charleston and Georgetown Diabetes Coalition

External Environment, Resources, and Dissemination influences:

Prepared, Proactive, Community Systems
Community Members and Systems
- Community Information System
- Community & Service Delivery System Design
- Community Decision Support
- Self-Management Support
Influences

Informed, Activated Persons
- Prepared, Proactive Health Systems
- Policies & Actions Social, Health, & Economic

Improved Community-Wide Health Outcomes and Elimination of Health Disparities

Health Care Provider Systems
- Clinical Information System
- Delivery System Design
- Clinical Decision Support
- Patient Self-Management Support
Influences

(Jenkins, Pope, Magwood et al., PCHP 4 (1): 73)
7 P’s
- Policy Makers
- Patients & Public
- Principal Investigators
- Providers
- Purchasers
- Payers
- Product Makers

<table>
<thead>
<tr>
<th></th>
<th>2000</th>
<th>2007</th>
<th>2011</th>
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<tbody>
<tr>
<td>A1C Testing</td>
<td>76.8</td>
<td>97.1</td>
<td>97.2</td>
</tr>
<tr>
<td>Blood Pressure &lt;130-80</td>
<td>24</td>
<td>38</td>
<td>46.3</td>
</tr>
<tr>
<td>Lipid Testing</td>
<td>47.3</td>
<td>87.2</td>
<td>92.0</td>
</tr>
<tr>
<td>Eye Exam</td>
<td>34</td>
<td>76</td>
<td>81</td>
</tr>
<tr>
<td>Feet Exam</td>
<td>64</td>
<td>97.3</td>
<td>97.5</td>
</tr>
<tr>
<td>Kidney Tests</td>
<td>13.4</td>
<td>56</td>
<td>67.4</td>
</tr>
<tr>
<td>Depression Screening</td>
<td>0</td>
<td>0</td>
<td>5.4</td>
</tr>
</tbody>
</table>
Lower Extremity Amputation Rates by Race/1000 Hospital and ED Visits for Diabetes

Charleston and Georgetown County, SC

Data Source: SC Hospital Discharge Data, SC ORS
DHEC Office of Chronic Disease Epidemiology and Evaluation        In Press: MMWR
Inflation-Adjusted Lower Extremity Amputation
Total Charges for Charleston & Georgetown compared to SC, 1992-2011

Data Source: SC Hospital Discharge Data, SC ORS
DHEC Office of Chronic Disease Epidemiology and Evaluation 08/12
Outcomes for Reduction in Diabetes LEAs for African Americans in 2 Counties

- **Cost savings:**
  - Costs per amputation in Georgetown County = $54,736 in 2008
  - Costs per amputation in Charleston County = $42,783 in 2008
  - Reduction in amputations compared to 1999 = 44% in African Americans
  - Cost savings of $1.6 million/year in 2011.
CASE STUDY:
BAMBERG DIABETES TRANSITIONAL CARE FEASIBILITY STUDY
Diabetes in Bamberg County

Diabetes Prevalence

- An estimated 1791 adults (14.7% of adults) in Bamberg County suffer annually from diabetes (Fig 2).

![Diabetes Prevalence Chart]

**Fig. 2 Prevalence of Self-Reported Diabetes among Adults, 2012**

Reference: South Carolina Department of Health
Bamberg Diabetes Transitional Care Feasibility Study

Closed in 2012
This graphic reflects the views of the authors of the Discussion Paper “Ten Attributes of Health Literate Health Care Organizations” and not necessarily of the authors’ organizations or of the IOM. The paper has not been subjected to the review procedures of the IOM and is not a report of the IOM or of the National Research Council.
3 Arm Feasibility RCT for Patients with Uncontrolled Diabetes

- Usual Care (n = 15)
- Nurse Telephone Care Coordination (n = 25)
- CHW In-Home Care Coordination (n = 25)

Nurse and CHW Intervention Groups received medication reconciliation within 72 hours, and 8 visits/calls over 3 months
Study Challenges and Successes

• Study Challenges:
  – Administrative components, staff and participant competing demands, technology
  – Mental health and literacy limitations

• Participant Successes:
  – Prioritizing and managing own health
  – Decrease in A1C, depression, weight

• Community Successes:
  – Working together to create ongoing support group
  – Diabetes screening and prevention program
Good Intentions ≠ Good Results

"I think it's important to note that we really did try hard."

-Adapted from PEX Network Cartoons
• Metrics and Measures (CTSA Priority)
• Community Engaged Research
• Publishing Community Based Participatory Research
• EQUATOR Network: Enhancing the QUALity and Transparency Of health Research
  http://www.equator-network.org/reporting-guidelines/
Thank You and Questions

http://academicdepartments.musc.edu/sctr/
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