“Learning from Each Other: Building Academic-Provider-Community Partnerships for Research”

May 12, 2014

ACCELERATE HEALTH CARE

ACCEL Community Engagement and Outreach Component Community Partnership Conference
May 12, 2014

Learning from Each Other: Building Academic-Provider-Community Partnerships for Research
Welcome!

Omar Khan, MD MHS FAAFP
Associate Vice-Chair, Dept. of Family & Community Medicine, CCHS
Co-Director, Community Engagement & Outreach, ACCEL
Associate Director, Delaware Health Sciences Alliance
7:30-8:00AM  Breakfast & Registration

8:00-8:10AM  Introduction: Omar Khan MD

8:10-8:30AM  Kathy Matt PhD, University of Delaware; Jay Greenspan MD, Nemours

8:30-9:00AM  Overview: Michael Rosenthal MD

9:00-10:00AM  Keynote: Daniel E. Ford MD MPH

10:00-10:45AM  Invited Guests- Introduction: William Weintraub MD
U.S. Representative John Carney
Delaware Governor Jack Markell

10:45-11:00AM  Break

11:00-11:45AM  Panel Discussion #1: Provider Engagement in Research /Moderator: Heather Bittner Fagan MD

11:45- 12:30PM  Panel Discussion #2: Engaging Communities in Research/ Moderator: Carolyn Jenkins DrPH

12:30PM  Lunch

1:00-2:00PM  Keynote: From Research to Policy/Patrick Quinlan MD

2:00-3:30PM  Workshop Overview: Brian Rahmer PhD
Thematic Workshops: Obesity, Cardiovascular, Maternal & Child Health, Cancer, Social Media for Community Engagement

3:30-4:30PM  Closing Reception
WHO sounds alarm on spread of polio

By Ashley Hayes, CNN
updated 2:18 PM EDT, Mon May 5, 2014
“It is science alone that can solve the problems of hunger and poverty, of insanitation and illiteracy, of superstition and deadening custom and tradition, of vast resources running to waste, of a rich country inhabited by starving people.”

—Jawaharlal Nehru
Scientists are very much like people.

-Howard Gadlin PhD, NIH Ombudsman
Learning From Each Other: Building Academic-Provider-Community Partnerships for Research

Michael P. Rosenthal, MD
Chair, Department of Family & Community Medicine
Christiana Care Health System
Director, Community Engagement and Outreach, ACCEL
United Health Foundation “America’s Health Rankings, 2011,” of all 50 states:
Delaware is 31st in obesity, 40th in cancer deaths,
25th in cardiovascular deaths, 41st in infant mortality,
and 37th in premature deaths...

Information → systematic investigative approach (research)→ evidence →
knowledge → education → action → personal or system change→
improved health outcomes → new research and evidence......

Research for better health and well-being of people, families, and communities
Why We Are Here...

National Institutes of Health (NIH) Roadmap (2004)... *to transform the way biomedical research is conducted and accelerate medical research*

Clinical Translational Science Award (CTSA) and Clinical Translational Research (CTR) programs to create better research for extension, impact, and health

Take important research findings and evidence to effect...

Reach
Time
Inclusion
Opportunity
Overview

- Institutional Development Award (IDeA) Program
  - Infrastructure for Clinical and Translational Research
- Budget $20M for 5 years (NIH) + $5M State + $3M Institutions = $28M
- Reviewed February, 2013 – Score = 20 - Top of the outstanding range
  - “Overall, this is an outstanding application. The review panel agreed that this application has the potential to have a huge impact on translational research. “
- Council Met on May 16, 2013 – recommended funding
- NOA – September 25, 2013 - $19,865 (NIH) – DE-CTR (“ACCEL”)
ACCEL Components

• Administrative Core

• 5 Key Component Activities (KCA’s)
  o Clinical and Translational Pilot Grants Program
  o Clinical Research Mentoring, Education, and Career Development (MED) Core
  o Clinical Research Design, Epidemiology, and Biostatistics Core
  o Clinical Research Expansion and Support Program
  o Community Engagement and Outreach (CEO) Program

• Evaluation Core
ACCEL Leadership

Executive Committee

Stuart Binder-Macleod, PT, PhD (UD) – Principal Investigator (PI)

Tom Buchanan, PhD (UD): Program Coordinator

Steven Kautz, PhD (MUSC): Co-PI

William Weintraub, MD (CCHS): Co-PI

Julia Barthold, MD (Nemours): Co-PI

Internal and External Advisory Committees (on Program)
Community Engagement and Outreach (CEO) Component

**Christiana Care**
- Michael Rosenthal, MD
- Heather Bittner Fagan, MD MPH
- Deborah Ehrenthal, MD MPH
- Omar Khan, MD MHS
- Brian Rahmer, PhD MS CHES
- Liz O’Neill, BA
- Stephanie Rogers, RN
- Kathy Cannatelli, MS
- Katherine Kolb, RN BSN MHA MBA FABC
- Jennifer Passarella, BS
- Lee McCormick, BAAS
- Kristen Isaac, BS
- Dana Thompson, MPH
- Cynthia Callahan, BA

**Nemours**
- Sandy Hassink, MD
- Bob Colnes, PhD
- Mary Kate Mouser, M.Ed.

**University of Delaware**
- Mike Peterson, Ed.D.
- Mia Papas, PhD
- Barret Michalec, PhD

**Medical University of South Carolina**
- Carolyn Jenkins, Dr.PH RD CDE APRN

**Delaware Division of Public Health**
- Karyl Rattay, MD MS

**Consultants**
- Arch (Chip) Mainous, PhD
- Devona Williams, PhD
Community Advisory Committee (CAC)

Key contribution to translational research and ACCEL

Advisory to both the CEO Component and ACCEL Leadership Team

Community engagement & outreach considerations, across research spectrum

The Role of the CAC is to:
- Provide perspective for productive approaches to solving health problems
- Reach people across Delaware with research information
- Build connections for research in the broad community
Specific Aims, ACCEL

• Develop the **infrastructure** to facilitate the growth and development of clinical and translational research

• Facilitate the development of **outstanding clinical and translational research programs**; and

• Develop **model community engagement outreach programs** that promote health and wellness to a diverse population of Delawareans
• Establish a **new infrastructure that actively involves the community** in setting clinical and translational research priorities

• Develop **new community-institution partnerships** in clinical and translational science

• Identify, educate and **prepare community leaders, healthcare providers and institutional trainees, researchers and scholars** in the principles and practices of community-engaged and community-based participatory research
Clinical translational research aims to take findings from basic science and clinical investigation to useful practical applications that enhance human health and well-being.

The goal is to....
"translate" findings from research into practice and meaningful health outcomes.
Integrated Engagement Across the Spectrum of Clinical Translational Research (Hassink/Rosenthal)

ACCEL Program including CEO Component and Community Advisory Council

T0
- Basic Scientists
- Academic community
- Schools
- Industry
- Community participants in Needs Assessment

T1
- Basic Scientists
- Clinical Scientists
- Hospital patients
- Community volunteers
- Health Institutions
- Clinical scientists
- Hospital patients/practices
- Primary care practices
- Community Based Organizations
- Health Organizations

T2
- Clinical Scientists
- Population scientists
- Primary and specialty care
- Provider networks
- Community Health Centers
- Community Based Organizations

T3
- Population scientists
- Public Health
- Primary care
- Community Health Centers
- Community Based Organizations
- Community advisory councils
- Community institutions/industry
- Data systems
- Epidemiologists
- Policy councils
- Policy makers
- Community Based organizations
- Community participatory needs assessment

T4
- Health Outcomes

Community Engagement across the spectrum of research
“As modern research methods have become more specialized and the true complexity of today’s most pressing health issues and diseases is revealed, collaborations among.....different fields have become essential for exploring and tackling these problems.

This.....has made interdependence, joint ownership, and collective responsibility between and among scientists [and their collaborating community] near requirements.”
Seeking a Dynamic Balance to Solve Important Problems
(Smart-Kit)

Teeter-Totter Balance Puzzle
People and Partnerships

Appreciating broad spectrum of community (communities) for T3 research

- investigators/researchers

- providers of care (primary, specialty, health institutions, others)

- community members/neighborhoods

- community based organizations (“CBO’s”)

- multiple communities (multiple CBO’s, coalitions, etc.)

- state
Key Delaware Health Risks and Research Themes

- Cardiovascular Disease
- Cancer
- Obesity (Diabetes and other risks)
- Infant Mortality (Women, Children, Family Health)
- Disability, Degenerative Diseases, Rehabilitation
What’s Wrong With This Picture???
CARCINOMA OF THE LUNG

ALTON OCHSNER, M.D.
AND
MICHAEL DeBAKEY, M.D.
NEW ORLEANS

Until relatively recently the diagnosis of cancer of the lung inevitably signified a rapidly tragic outcome. Within the past six years, however, many patients with pulmonary malignant tumor have been spared this death sentence by the successful removal of the cancerous lung. Of even greater importance is the increasing incidence of such survivals. The successes in the earlier cases were few because of late diagnoses and also because preoperative preparation, anesthesia and operative technic were inadequately developed. Recently, because of early diagnoses as well as improvement in surgical management, the prognosis of pulmonary carcinoma has become relatively favorable.

INCIDENCE

Until relatively recently carcinoma of the lung was considered infrequent. Adler collected 374 cases of carcinoma of the lung in 1912 and stated: "On one point, however, there is nearly complete consensus of opinion and that is that primary malignant neoplasms of the lung are among the most forms of disease." Whether this opinion may have been...
Ochsner and DeBakey, 1939:

“A number of theories have been advanced to explain the increase in pulmonary carcinoma....

(age, gases, acute infection, chronic infection, occupational exposures, other)

.....It is our definite conviction that the increase in the incidence of pulmonary carcinoma is due largely to the increase in smoking, particularly cigarette smoking, which is universally associated with inhalation.”

Every one of our patients, with the exception of 2 women, was an excessive smoker.”
LUNG CANCER AND OTHER CAUSES OF DEATH IN RELATION TO SMOKING
A SECOND REPORT ON THE MORTALITY OF BRITISH DOCTORS

BY
RICHARD DOLL, M.D., M.R.C.P.
Member of the Statistical Research Unit of the Medical Research Council
AND
A. BRADFORD HILL, C.B.E., F.R.S.
Professor of Medical Statistics, London School of Hygiene and Tropical Medicine; Honorary Director of the Statistical Research Unit of the Medical Research Council

On October 31, 1951, we sent a simple questionary to all members of the medical profession in the United Kingdom. In addition to giving their name, address, and age, they were asked to classify themselves into one of three groups—namely, (a) whether they were, at that time, smokers of tobacco; (b) whether they had smoked but had given up; or (c) whether they had never smoked regularly (which we defined as having never smoked as much as one cigarette a day, or its equivalent in pipe tobacco or cigars, for as long as one year). All smokers and ex-smokers were asked additional questions. The previously have been a light smoker or may since then have given up smoking altogether; we shall have continued to count him, or her, as a heavy smoker. If there is a differential death rate with smoking, we must by such errors tend to inflate the mortality among the light smokers and to reduce the mortality among the heavy smokers. In other words, the gradients we present in this paper may be understatements but (apart from sampling errors due to the play of chance) cannot be overstatements.

In 1954 we published a preliminary report on the
T3, Community based research. Identify and Assess Community.

59,600 British physicians (over 40,000 responses)

“On October 31, 1951, we sent a simple questionary....”

Q1: Are you a smoker?
Q2: Have you ever smoked and given up?
Q3: Have you never smoked?

....all smokers and ex-smokers asked additional questions

Follow 53 months. Deaths/causes of death counted and analyzed.

Conclusion:

“...in this population there has been a marked and steady increase in the death rate from lung cancer as the amount smoked increases.”
Surgeon General, Luther Terry, 1964

"cigarette smoking is a health hazard of sufficient importance in the United States to warrant appropriate remedial action,"

Meeting at the National Library of Medicine on the campus of the National Institutes of Health in Bethesda, Maryland, from **November 1962 through January 1964**, the committee reviewed more than **7,000 scientific articles** **with the help of over 150 consultants**. Terry issued the commission's report on January 11, 1964,
Opioids induce while nicotine suppresses apoptosis in human lung cancer cells

Maneckjee, Minna; Cell Growth & Differentiation; 1994, 5(10):1033-1040

Previously...opioids...inhibit the growth of human lung cancer cells,
while nicotine....reverses this inhibition.

Therefore, we studied the role of apoptosis in these processes.

engagement of nicotine receptors suppresses apoptosis

These findings suggest new strategies for treatment and prevention of cancer using....
nicotine receptors antagonists and are consistent with the idea that nicotine functions as a tumor promoter.
Control of behavior by intravenous nicotine injections in human subjects

Henningfield, Goldberg; Pharmacology Biochemistry and Behavior; 19, 6; 1983

Human volunteers were tested using drug self-administration and avoidance procedures, whereby pressing a lever under a fixed-ratio schedule resulted either in the IV injection of nicotine or in the avoidance of programmed IV injections of nicotine, respectively.

Nicotine produced the same constellation of stimulus properties whether functioning as a positively or negatively reinforcing event. These functional properties of nicotine may be determined by schedule of access to nicotine, dose of nicotine, and past history of the subject.
Determinants of nicotine intake while chewing nicotine polacrilex gum

Benowitz, Jacob III, Savanapridi; Clinical Pharmacology and Therapeutics (1987) 41, 467–473

Nicotine polacrilex gum....

substitution therapy during cigarette smoking cessation.

We studied ...blood nicotine concentrations, daily intake of nicotine, and extraction of nicotine from gum in smokers switched experimentally to 2 or 4 mg nicotine gum, 12 pieces per day.

Nicotine levels and intake were much lower while chewing gum than during ad libitum smoking.
A Controlled Trial of Sustained-Release Bupropion, a Nicotine Patch, or Both for Smoking Cessation

Jorenby, Leischow, Nides, et.al. NEJM 1999; 340:685-691

Use of nicotine-replacement therapies and the antidepressant bupropion helps people stop smoking.

We conducted a double-blind, placebo-controlled comparison....

Treatment with sustained-release bupropion alone or in combination with a nicotine patch resulted in significantly higher long-term rates of smoking cessation than use of either the nicotine patch alone or placebo.
Increasing the efficacy of physician-delivered smoking interventions

(Ockene, Kristeller, Goldberg, et. al.; Journal of General Internal Medicine; 1991, 6; 1; pp 1-8)

To assess relative impacts of three physician-delivered smoking interventions....

Randomized controlled trial with pre-post measures of smoking rates.....reports six-month outcome data.

Participants were...patients seen by 196 medical and family practice residents in five primary care clinics.

Conclusion: Smoking intervention counseling provided by physicians is well received by patients and significantly increases the likelihood of cessation at six months...
Physician advice for smoking cessation
(Stead, Buitrago, Preciado, et al.; Editorial Group: Cochrane Tobacco Addiction Group; Published Online: 31 MAY 2013)

42 trials, between 1972 and 2012, including over 31,000 smokers.

Plain language summary:

Does advice from doctors encourage people who smoke to quit?

Advice from doctors helps people who smoke to quit. Even when doctors provide brief simple advice about quitting smoking this increases the likelihood that someone who smokes will successfully quit and remain a nonsmoker 12 months later.

*Cochrane Reviews are systematic reviews of primary research in human health care and health policy, and are internationally recognised as the highest standard in evidence-based health care.

The intervention consisted of: (a) nurse led behavioral/empowerment counseling; (b) nicotine replacement therapy; and, (c) community health workers to enhance smoking self-efficacy, social support, and spiritual well-being.

The results showed a 6-month continuous smoking abstinence of 27.5% and 5.7% in the intervention and comparison groups.

These findings support the use of a nurse/community health worker model to deliver culturally tailored behavioral interventions with marginalized communities.
A Social Ecological Based Smoking Cessation Intervention in Public Housing

The purpose of this study is to test a Community Based Participatory Research developed, multi-level smoking cessation intervention targeted at the neighborhood level, peer group, and individual level among African American Women in Public Housing.
Almost 21 million premature deaths attributed to smoking/second-hand smoke, 50 years
Steps Forward: Building Partnerships for Research

- Appreciate Clinical Translational Research, all levels
- Explore Opportunities
- ACCEL Pilot Grants Program
- “ACE” (ACCEL Community Engagement) Research Awards
- Develop Existing or New Research Efforts via Partnerships

......in order to create research to make a difference
ACCEL Pilot Grants Program

ACCEL Clinical and Translational Research Pilot Grants Program
  Dr. Tom Buchanan, Lead

All levels of Translational Research

Approximately $80,000 per award, 1 year period

Highly competitive awards designed to be a stepping stone towards federal-level research funding.

The goal of the pilot programs is to develop researchers to become independent principal investigators.

Proposals due July, 14, 2014; Application on ACCEL Website: http://de-ctr.org/
ACE Research Awards

ACCEL Community Engagement (ACE) Research Awards
Dr. Heather Bittner Fagan, Lead

Intended for T3 Levels of Translational Research

Collaborative investigators: Institutional PLUS Community Partnership (eg. provider, community member, community agency, etc.) required

Approximately $20,000 per award; 6 months education/project development and 6 months implementation of project;

Goal: to develop independent Community Engagement Scholars in Delaware, trained to conduct research that engages the community, and lead teams that will compete for external research funding.

Release by June 30, 2014; will post on ACCEL Website: http://de-ctr.org/
ACCEL Website
http://de-ctr.org/
A Research Hypothesis...

The ACCEL Program...

will have a great impact on clinical translational research development in Delaware and South Carolina;

will demonstrate significant improvement in health outcomes for people, families, and communities; and,

will be a highly successful model of innovative, creative, collaborative research involvement and team science across the spectrum of translational research.
Challenges and Opportunities in Community Engagement for CTR

Daniel E. Ford MD MPH
Director, Institute for Clinical & Translational Research, Johns Hopkins Medical Institutions
Vice Dean for Clinical Investigation, Johns Hopkins School of Medicine
Challenges and Opportunities in Community Engagement for Clinical and Translational Research

Daniel Ford, MD, MPH
Vice Dean for Clinical Investigation
Director, Institute for Clinical and Translational Research
Johns Hopkins School of Medicine
Outline

• What does the community expect of academic health centers in 2013? (for Research?)
• Are academic health centers meeting their expectations?
• Why do we need to create common expectations?
• What models of community engagement are likely to make a difference?
What is he thinking?

• I am a 25 yo African American man who went to the emergency room for my second episode of severe back pain. I graduated from community college and have a part-time job. Still waiting to get health insurance. My cell phone is my major computer but video games are my biggest hobby.

• I am not really political but my parents remind me about their past struggles. I have heard the stories about how black people were mistreated in research but I have no recent experience. My sister works for the local hospital. She likes it ok but wishes the pay was better.
Johns Hopkins Hospital
Johns Hopkins Health System
How has the environment changed?

- Academic health centers have generally prospered through the recent national recession
- Academic health centers have grown in size to become major health care providers
- Not-for-profit status of academic health centers is being challenged
- Scientists are not trusted
- Federal funding has decreased so partnering with for-profit organizations more common
How has environment changed?

- Disparities in health care outcomes recognized more broadly
- Expectations for research and health care are higher
- Patients are taking more control of their health care “Who is in charge of the cure of my disease?”
What does the community expect of academic health centers?
Community Expectations

• Communities do not differentiate the parts of large academic centers
• Equal regard for the health care experience of everyone
• Health care team that looks like them
• Participation in decisions about the academic health centers, particularly if the decisions impact them
Community Expectations

• Communicate the real story around decisions
• Recognition that communities include multiple voices
• Sustained focus on solving their problems
• New effective approaches to prevent and cure their problems that the community can access
Are AHCs meeting their expectations?

- Not easy to know if AHCs are meeting the community’s expectations
- Some AHCs taking on responsibility for health of populations either through managed medicaid or ACOs
- Limited objective measures to judge health care systems
Community Engagement

• The process of working collaboratively with and through groups of people affiliated by geographic proximity, special interest, or similar structures to address issues affecting the well-being of those people.
Five functions for community engagement in research

- Deciding on the research questions
- Developing the research protocol
- Conducting the research
- Analyzing the results
- Disseminating research findings and maximizing impact
Deciding on the Research Question

• Learning about and prioritizing the major health problems in the community
• Learning to use quantitative and qualitative data from community to get their input
• Examining the research portfolio of the academic health center
Developing the Research Protocol

• Consulting the community early in the process so we are evaluating interventions that make sense for the community
• Considering stakeholder input on sustainability at this early stage
• Incorporating community assets to the extent possible
• Identifying successful strategies for recruitment and follow up
• Making a determination about the ethical acceptability of the protocol
Conducting the Research

- Assisting with publicity and recruitment
- Identifying acceptable informed consent process
- Measure and evaluate research participant satisfaction
- Help research participants complete studies (transportation, babysitting, etc)
- Community input on data and safety monitoring boards
- Community input on how long observational studies should continue
Analyzing the Results

• How are results presented for subgroups
• How are results presented by sites
• How is non adherence described and accounted for
• Who owns the data for the analysis
Disseminating Research Findings

- Publication is just the beginning of maximizing impact
- Communicate findings to those who participated in the study
- Identify stakeholders needed to support sustainability including community organizations
- AHCs have to lead in changing practice based on results
<table>
<thead>
<tr>
<th>Increasing Level of Community Involvement, Impact, Trust, and Communication Flow</th>
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<tbody>
<tr>
<td><strong>Outreach</strong></td>
</tr>
<tr>
<td>Some Community Involvement</td>
</tr>
<tr>
<td>Communication flows from one to the other, to inform</td>
</tr>
<tr>
<td>Provides community with information.</td>
</tr>
<tr>
<td>Entities coexist.</td>
</tr>
<tr>
<td>Outcomes: Optimally, establishes communication channels and channels for outreach.</td>
</tr>
<tr>
<td><strong>Consult</strong></td>
</tr>
<tr>
<td>More Community Involvement</td>
</tr>
<tr>
<td>Communication flows to the community and then back, answer seeking</td>
</tr>
<tr>
<td>Gets information or feedback from the community.</td>
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<tr>
<td>Entities share information.</td>
</tr>
<tr>
<td>Outcomes: Develops connections.</td>
</tr>
<tr>
<td><strong>Involve</strong></td>
</tr>
<tr>
<td>Better Community Involvement</td>
</tr>
<tr>
<td>Communication flows both ways, participatory form of communication</td>
</tr>
<tr>
<td>Involves more participation with community on issues.</td>
</tr>
<tr>
<td>Entities cooperate with each other.</td>
</tr>
<tr>
<td>Outcomes: Visibility of partnership established with increased cooperation.</td>
</tr>
<tr>
<td><strong>Collaborate</strong></td>
</tr>
<tr>
<td>Community Involvement</td>
</tr>
<tr>
<td>Communication flow is bidirectional</td>
</tr>
<tr>
<td>Forms partnerships with community on each aspect of project from development to solution.</td>
</tr>
<tr>
<td>Entities form bidirectional communication channels.</td>
</tr>
<tr>
<td>Outcomes: Partnership building, trust building.</td>
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<tr>
<td><strong>Shared Leadership</strong></td>
</tr>
<tr>
<td>Strong Bidirectional Relationship</td>
</tr>
<tr>
<td>Final decision making is at community level.</td>
</tr>
<tr>
<td>Entities have formed strong partnership structures.</td>
</tr>
<tr>
<td>Outcomes: Broader health outcomes affecting broader community. Strong bidirectional trust built.</td>
</tr>
</tbody>
</table>

Reference: Modified by the authors from the International Association for Public Participation.
Biospecimens for Research

- Biospecimens increasing in value for biomedical research
- Concept of deidentification difficult to defend with new genetic knowledge
- Public education is essential – ex, living cell lines, stem cells, etc
- Potential for abuse of consent is high because future use is difficult to describe
- Scientific community needs to commit to universal IT solution that allows tracking of consents linked to biospecimens
- Consent depends on trust
Research and Justice

- US committed to development of drugs and diagnostic tests largely through private sector
- If donating specimens for research is for the social good, then universal health insurance to provide equal access to the intervention developed by the research is also necessary
What have we learned with our Johns Hopkins Community Engagement Program?

• Build capacity in the community to understand research principles
• Transparency in decisions
• Target long term relationships
• Ask for diverse opinions from community and not be rigid about representation
• Take advantage of high profile stories to engage community
The Immortal Life of Henrietta Lacks

Doctors took her cells without asking. Those cells never died. They launched a medical revolution and a multimillion-dollar industry. More than twenty years later, her children found out. Their lives would never be the same.

Rebecca Skloot
What is he thinking?

• I am a 25 yo African American man who went to the emergency room for my second episode of severe back pain. I graduated from community college and have a part-time job. Still waiting to get health insurance. My cell phone is my major computer but video games are my biggest hobby.

• I am not really political but my parents remind me about their past struggles. I have heard the stories about how black people were mistreated in research but I have no recent experience. My sister works for the local hospital. She likes it ok but wishes the pay was better.
What is he thinking?

- They told me I had severe hypertension and asked me to join a study, provide a blood sample, and receive care in one of the AHC’s outpatient center
Trust

- Built over years and may be lost in a single event
- Investigators, health care providers, AHCs, government and broad community of science all part of the relationship
- Need to focus on common goals, recognize each other’s strengths, and acknowledge our interdependency
Introduction of Guests

William Weintraub MD MACC FAHA FESC
John H. Ammon Chair, Chief of Cardiology
Director of Christiana Care Center for Outcomes Research, Christiana Care Health System

Invited Guests:  U.S. Representative, John Carney
                Delaware Governor, Jack Markell
Panel Discussion #1: Provider Engagement in Research

Moderator: Heather Bittner Fagan, MD MPH

Panelists: Arch Mainous, PhD; Thomas Bauer, MD; Gregory Hicks, PT PhD
ACCELERATE HEALTH CARE
The Delaware CTR ACCEL Program
Engaging physicians in research

Degree of Cf Involvement

More intensive
- Defining study questions and methods, writing the funding proposal, implementing the research project, analyzing the results, and disseminating

Medium
- Assisting with implementation, including participant recruitment, data collection, and/or providing feedback on aspects of study design or findings; act as a subcontractor with a defined set of responsibilities

Less Intensive
- Assisting in discrete steps of a researcher-designed study, such as participant recruitment

Arch G. Mainous III, PhD

Dr. Mainous is Chair and Florida Blue Endowed Professor in the Department of Health Services Research, Management and Policy at the University of Florida. He is also a Professor in the Department of Community Health and Family Medicine. He joined the University of Florida in September of 2013. Prior to joining UF he was a Professor and Research Director in the Department of Family Medicine and the Associate Dean for Assessment and Evaluation at the Medical University of South Carolina. He is an accomplished researcher having published more than 300 peer-reviewed articles and his work has been cited in more than 10,300 other scientific articles. He is also the Deputy Editor of the journal, *Family Medicine*. 
Dr. Bauer is the Chief of Thoracic Surgery at The Helen F. Graham Cancer and Research Center at Christiana Care Health System. He leads a multidisciplinary weekly Thoracic Oncology Conference and Clinic. Dr. Bauer leads and contributes to collaboration on numerous translational research projects as well as clinical thoracic trials. He led Christiana Care’s participation in the I-ELCAP lung cancer screening program and hosted the International Conference on the Christiana Campus previously. He current serves on Delaware’s Cancer Consortium to assist in developing a state-wide lung cancer screening program.

Dr. Bauer serves as the Christiana Care Principal Investigator for the Delaware INBRE program as well as a DE state supplemental DEDO grant. This program has supported independent research and mentoring on the Christiana Care campus. A student program has been developed on campus which links students with clinical mentors to encourage entry into future research programs for the students and increased clinical research for the mentors. The INBRE program has led to an increase in collaborations, extramural funding of that research and educational programs. Dr. Bauer has led over 1.5 million dollars in grant monies, authored 51 articles or book chapters, and led numerous clinical trials both nationally and locally.
Gregory E. Hicks, PT, PhD is an Associate Professor in the Department of Physical Therapy at the University of Delaware and the Director of the Delaware Spine Studies research program. Dr. Hicks is an academic physical therapist with doctoral training in Rehabilitation Science as well as post-doctoral training in Epidemiology of Aging from the National Institute on Aging. His research is focused on the development of novel intervention strategies to improve physical function for older persons with chronic musculoskeletal pain. This work has been consistently funded by the National Institutes of Health. Dr. Hicks is currently the principal investigator of an NIH-funded longitudinal study of older adults with LBP designed to identify modifiable rehabilitation impairments associated with the development and maintenance of activity limitations and participation restrictions in this vulnerable population. He has been invited to speak both at the national and international levels regarding his expertise on chronic pain in the geriatric population. Dr. Hicks currently serves as an editorial board member for the Journal of Gerontology: Medical Sciences and for Pain Medicine. He also serves regularly as an ad hoc reviewer for the National Institutes of Health, sits on Data Safety Monitoring Boards for two NIH funded trials, and is currently the Chair of the Scientific Review Committee for the Foundation for Physical Therapy.
“Don’t bring a solution in search of a problem”
“Doctors are not lazy, dumb or disingenuous”
Barriers to Community Physician Participation in Research

- Lack of time
- No inherent interest in research
- Perceived lack of benefit to them and their patients
- Concern that Researcher will steal their patients once they refer them to a study
Common Barriers to Patient Recruitment

- Financial and time constraints
- Child care issues
- Transportation issues
- Inclusion and exclusion criteria
- Mistrust of Researchers
Primary Limitation to Patient Recruitment is Trust

- A systematic review of barriers to minority participation showed that mistrust was the primary limitation.
- A patient’s personal physician’s recommendation to the patient to participate in a study is the strongest factor for likelihood of participation.
Trust in Medical Researchers Scale

- Self-report scale that assesses an individual’s trust in medical researchers
  - Minorities score lower than whites
  - Minority serving physicians tend to have lower trust in researchers than other physicians mirroring the attitudes of their patients
  - Lower scores on the scale are correlated with lower likelihood of future participation (patients) and referral of patients (physicians)
Strategies to Increase Trust and Participation

• Assure patients and physicians that you are looking out for their best interest
• Assure them that you are not using them for your own gain
• Assure them that you will not treat patients badly and with little respect
• Assure them of safeguards for their protection
• Emphasize altruism and academic stimulation
It’s not the People

» It’s the RIGHT people
» It’s the RIGHT program
» It’s the RIGHT support
» It’s the RIGHT community
» It’s The RIGHT “Marketing”

Thomas Bauer MD, CCHS INBRE PI
Collaboration at ALL Levels

» Leadership alignment and “buy in”
» Collaborator “buy in”
» Patient “buy in”
Encouragement "WIFM"

» "Compensation"
  > Money
  > Publications
  > Notoriety
  > Resources

» "Mandates"
  > Enrolment quotas
  > Accrual Listings
  > Competitions

Thomas Bauer MD, CCHS INBRE PI
How do we build **mutually beneficial, collaborative research partnerships** with community physicians?
Partnerships

• A relationship between individuals or groups that is characterized by mutual cooperation and responsibility, **as for the achievement of a specified goal**
Partnerships

• A relationship between individuals or groups that is characterized by mutual cooperation and responsibility, **as for the achievement of a specified goal**
Partnerships

How do we really do this?

• A process must be developed
  – Identify key leaders who can garner support
  – Determine and agree on common goals
  – Identify barriers
  – Develop strategies to achieve goals & overcome barriers
  – Regular check-ins to make sure that needs are being met by all partners
Partnerships

• **Buy-in is the key!**
  – Alignment of priorities/Identification of common goals
    • Value of research participation (publications and grants)
    • Altruism/Benefit to the patients
    • Improving process of care within the organization
    • Acquiring additional resources
  – Full recognition of the barriers to research
    • Clinician perspective
      – How will research interrupt the flow of care?
    • Trials/Study Coordinator perspective
      – What resources are needed to not interrupt the flow of care?
Panel Discussion #2: Engaging Communities in Research

Moderator: Carolyn Jenkins, DrPH RD CDE APRN

Panelists: Sandra Hassink, MD; Rosa Colon, PhD MBA; Tirzah Spencer, PhD MPH

Visit the ACCEL Website at: https://www.de-ctr.org/
Community Engagement and Community Engaged Research (CEnR)

Are We There Yet?
IOM Recommendation 6
for Clinical & Translational Research Awards (CTSAs)

Ensure community engagement in all phases of research.
Community Engaged Scholarship

Community-based participatory research
Practice-based research

Research
Teaching
Service

Community-engaged learning
Practice-based learning
Service Learning
Community service
Academic public health practice
Clinical service
Community-oriented primary care

Citation for figure: Commission on Community-Engaged Scholarship in the Health Professions. Linking Scholarship and Communities. Seattle, WA: Community-Campus Partnerships for Health, 2005.
Community Engagement

- Process of working collaboratively with and through groups of people affiliated by geographic proximity, special interest, or similar situations to address issues affecting the well-being of those people.

- A powerful vehicle for bringing about environmental and behavioral changes that will improve the health of the community and its members.

- Often involves partnerships and coalitions that help mobilize resources and influence systems, change relationships among partners, and serve as catalysts for changing policies, programs, and practices.

(CDC, 1997, p 9)
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
What is Participation in CEnR?

- **Minimum**—stakeholders involved at the beginning (formulating research questions) and end (interpreting and applying the findings).

- **Maximum**—stakeholders involved as active partners in all phases of the research

- **Right level** depends on type of research

ENGAGING COMMUNITIES IN RESEARCH

Tirzah R. Spencer
Nemours Health and Prevention Services
May 12, 2014
OVERVIEW

- Community Engagement: Two Phases of Research

- Research Design
  - HIV/AIDS prevention: Boston community
  - Smoking cessation: Vietnamese community

- Data collection and Methods
  - Obesity study: Trenton, NJ
  - Obesity study: Oakland, CA
Defining the problem:

- HIV/AIDS prevention: Boston community
- Smoking cessation: Vietnamese community
Community Engagement in Research

- **Research Design**
  - HIV/AIDS prevention: Boston community
  - Smoking cessation: Vietnamese community

- **Data collection and Methods**
  - Obesity study: Trenton, NJ
  - Obesity study: Oakland, CA
Philadelphia → Trenton

- Existing community engagement infrastructure
- Existing relationships with the community

Focus

- Theory:
  - interpret “meaning–making” processes of children, adolescents and families strategies to explore predictors of resiliency among urban low resourced youth
  - Normative responses to challenging environments

- Approach:
  - examine multiple cultural contexts: school, home, neighborhood, work
  - to assess the impact of incentives and to evaluate the effectiveness of a theoretically based, health–focused after–school intervention program
The purpose of this study was to examine factors associated with overweight and obese status among African American girls and Latinas.

- **Qualitative Approach**
  - Focused on parents perceptions of factors that lead to obesity among girls

- **Quantitative Approach**
  - Focused on girls’ perceptions of significant others’ influence on their weight concerns & physical activity involvement, eating practices & body esteem
Methodology

PARTICIPANTS (N = 1100)
- 4th – 8th grade students
- 164 African American females
- 158 Latin American females
- 34% reported having a paid job
- 63% of 6th – 8th graders: sibling who received free lunch
- 45% of African American females were overweight
- 62% of Latinas were overweight
Sample Items

Body Satisfaction – What My Body Looks Like

Response options range from A (obese) – H (thin)

1) Which shape looks the most like you?
2) Which shape would you most like to look like?
Community Engagement in Research

Research Design
- HIV/AIDS prevention: Boston community
- Smoking cessation: Vietnamese community

Data collection and Methods
- Obesity study: Trenton, NJ
- Obesity study: Oakland, CA
GEMS Study Overview

Aim: Test the efficacy of an after school dance program and a family-based intervention to reduce television, videotape and video game use to reduce weight gain

Design: 2-arm parallel group, randomized controlled trial

Subjects: 290 low SES Black pre-adolescent girls

Intervention Length: 2 years
## Background

### Parent education

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<td>Some high school</td>
<td>18 (6.9%)</td>
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<td>High school graduate or GED</td>
<td>53 (20.3%)</td>
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<td>Tech school/some college</td>
<td>122 (46.7%)</td>
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<td>College/post-graduate study</td>
<td>68 (26.1%)</td>
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### Household income

<table>
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<th>Income Level</th>
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<td>Refused to respond</td>
<td>4 (1.5%)</td>
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<tr>
<td>&lt;$20,000</td>
<td>107 (41.0%)</td>
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<tr>
<td>$20,000 to $40,000</td>
<td>73 (28.0%)</td>
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<tr>
<td>≥$40,000</td>
<td>77 (29.5%)</td>
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</table>
BMI & Depressive Symptoms

Aim: To explore the relationship between body mass index (BMI) and depressive symptoms among 261, 8–10 year old Black girls.

Measures: Stanford GEMS baseline data
Girls were measured for height and weight, depressive symptoms, overweight concerns, and self-esteem.

Ethnic identity was reported by parents.

Spencer, T., et al., Under Review
Depressive symptoms by strata of BMI and overweight concerns

- BMI <49th Percentile
- BMI 50th - 84th Percentile
- BMI 85th - 94th Percentile
- BMI ≥ 95th Percentile

Mean No. of Depressive Symptoms
- 0 Overweight Concerns (solid black)
- 10 - 20 Overweight Concerns (solid gray)
- 30 - 40 Overweight Concerns (open gray)
- ≥ 50 Overweight Concerns (open white)

Sample sizes:
- BMI <49th Percentile: n = 21
- BMI 50th - 84th Percentile: n = 27
- BMI 85th - 94th Percentile: n = 8
- BMI ≥ 95th Percentile: n = 6
Lessons Learned

- Time needed to understand the complexity of the problem
- Time to develop relationships and trust
- Infrastructure of support
- Measurement design
- Sharing results with all partners
- Publish or Perish
- Funding
Christiana Care Health System
Rosa M. Colon-Kolacko, Ph.D., MBA
Sr. VP System Learning, Exec. Director
Learning Institute and Chief Diversity Officer
Learning Institute

VISION

The Christiana Care Learning Institute foster collaboration, inclusion and innovative learning to build knowledge to serve and deliver equitable care that provides value.
Community Learning Projects

- **Participatory Action Research** is the process of systematic inquiry in which those experiencing a problem in their community or workplace participate with researchers in deciding the focus of knowledge generation, in collecting and analyzing data, and in taking action to manage, improve, or solve their problems. (Whyte)

- **Action Learning**: Is a developmental approach, used in a group setting but affecting the individual and organizational levels of experience, that seeks to apply and generate theory from **real not simulated work/life** situations. Participants learn as they work together to reflect with others who offer insights into their problems. (R. Revans)
Participatory Action Research and Action Learning Project Examples

• DE Hispanic Commission
  – Chair of Health and Social Services Committee.
    • http://bycell.co/bdlk
  – Community Conversations
  – 1st Latino Summit – November 13th

• Latin American Community Center, Vice Chair of the Board
  -Human Capital Strategies    -Leadership Behaviors

• Christiana Care Learning Institute
  – Language Services education experience and knowledge acquisition in healthcare providers
  – Impact of Language Services in patient experience and outcomes
The Challenge: Community-Based Healthy Weight Promotion
Six Strategies for Community Change

1. Commit to developing and implementing a community action plan
2. Develop and spread a consistent message about healthy weight based on current evidence and recommendations
3. Assess weight status both inside and outside of the healthcare setting
4. Develop a healthy weight plan
5. Build capacity to meet the needs of a community utilizing an integrated approach across sectors
6. Improve the environment to promote healthy weight
Why Community Action is Important

• Provides opportunity to move beyond individual solutions to create broader systemic change
• Healthcare and public health professionals can help change community norms and public policy to protect children’s health and well-being
• Works systemically to raise awareness, educate, and/or provide treatment solutions that can help keep children safe and healthy
• Collectively gains attention of decision-makers, the media, and the general public to create change on behalf of children’s health and well-being
Healthcare and Public Health Professionals as Change Agents
Healthcare and Public Health Professionals: Uniquely Qualified to Spread Change

- **Credibility** by position, reputation, experience
- **Strong relationships** with community members
- **Skill set**: The same skills you use every day to establish trust, develop relationships, and provide solutions to your patients and clients can be applied in your community action work.
- **Strength in numbers**: You are one of many, both within your profession and within your community, who cares about children’s health and well-being.
Fitting Community Change into your Professional Responsibilities

- **Doesn’t require a lot of time:** You can affect change in as little as an hour a month or less or as much as multiple hours a week.
- **Prioritize your interests:** you don’t have to work on every issue.
- **Partner with key stakeholders:** Other healthcare and public health professionals, school personnel, youth organizers, agricultural groups and others who, through their efforts and community partnerships, can help you focus and concentrate these goals.
Community Opportunities to Promote Healthy Weight

- Creating incentive programs to attract supermarkets and grocery stores to underserved neighborhoods
- Improving the nutritional quality of foods and beverages served and sold in schools and as part of school-related activities.
- Improving access to outdoor recreational facilities
- Increasing personal safety in areas children and their families could be physically active
- Collaborating with schools to implement a Safe Routes to School program to increase the number of children safely walking and bicycling to school
- Requiring physical education in schools and increase the amount of physical activity in physical education programs
- Encouraging employers to provide workplace wellness programs
How to Get More People in Your Community Involved

• Begin with a recognition that some people may be unfamiliar with community-level change and therefore, hesitant to get involved.
• Start with people you already know and who care about children’s health.
• Ask people (a natural and acceptable thing to do).
  • Connect your issue to others’ self-interests.
  • Convey why your issue is important and why their help is needed.
  • Have a concrete request and be clear about the time commitment.
Why Get More Organization in Your Community Involved?

- More resources (including person power) for your issue
- Diversity adds new perspective to your work
- Creates perception that the issue has visible and wide-ranging support
- Further captures attention of decision-makers
- Demonstrates collective power
Supporting Community Change (AAP Policy Opportunities Tool)

- Dynamic internet tool that delineates the various policy recommendations and opportunities into a matrix of 30 cells

- Each cell showcases:
  - Policy opportunities and possible action steps at various levels (community, school, etc)
  - Organizations recommending the policy strategies (IOM, CDC, etc)
  - Links to additional resources
  - Links to relevant data sources

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www.aap.org/obesity/matrix_1.html
Access to Health Beverages
Action steps to increase access to healthy beverages in local schools include:

A. Work with school wellness councils/school officials to require that all schools provide students with low-fat or non-fat milk.
B. Work with school wellness councils to ensure that schools have access to clean drinking water.

Limit Access to Unhealthy Beverages
Action steps to limit access to unhealthy beverages in local schools include:

A. Work with school wellness councils/school officials to eliminate the sale of soft drinks in schools during school and non-school hours.

Point of Purchase
Action steps for point of purchase in the local schools include:

A. Work with school wellness councils/school officials to promote
Access to Health Beverages
Action steps to increase access to healthy beverages in local schools include:

A. Work with school wellness councils/school officials to require that all schools provide students with low-fat or non-fat milk.
B. Work with school wellness councils to ensure that schools have access to clean drinking water.

Action steps to increase access to healthy beverages in local schools include:

A. Work with school wellness councils/school officials to require that all schools provide students with low-fat or non-fat milk.

The AAP-endorsed *Dietary Recommendations for Children and Adolescents: A Guide for Practitioners* recommends that school-aged children consume 2-3 servings of low-fat or non-fat milk. Schools should provide only low-fat and non-fat milk to students during school breakfast and lunch programs.

Recommended by:


For more information: [The National Dairy Council](https://www.dairy.org/)


B. **Work with school wellness councils to ensure that schools have access to clean drinking water.**

Schools in rural or unincorporated areas may not have access to municipal water sources and schools in impoverished districts may suffer from dilapidated plumbing causing water discoloration or contamination. These limitations discourage or in some cases prohibit students from accessing drinking water, instead encouraging the consumption of sugar-sweetened beverages or juices.

**Recommended by:**

- Institute of Medicine (IOM) Report: [Early Childhood Obesity Prevention Policies](https://www.iom.edu/Reports/2012/Early-Childhood-Obesity-Prevention-Policies)

**For more information:** [Environmental Protection Agency (EPA) Healthy School Environments Tool](https://www.epa.gov/energy/healthy-school-environments-tool)
Questions/Comments

How do we effectively expand Community Engaged Research within our Communities
CEnR: Are We There Yet?

- Yes, but who is at the table?
- No, but why?
Our Challenges

- Expand how we define community
- Partner with the community
- Define what is important to the community (and accept that)
“Could a greater miracle take place than for us to look through each other’s eyes for an instant?”

Henry David Thoreau
Visit the ACCEL Website at- https://www.de-ctr.org/

From Research to Advocacy and Policy Change

Patrick J. Quinlan MD
CEO, Ochsner Clinic Foundation & International Services
Executive Director, Ochsner Center for Community Wellness & Health Policy
Tobacco –
A Childhood Epidemic

Patrick Quinlan MD.
Ochsner Health System
Tobacco –
A Childhood Epidemic

• Context
• Targets
• Products to Entice Youth
• “Perfectly Safe”
• Tobacco: A Childhood Disease
• United States/Delaware Tobacco Tolls
• What Can Be Done?
Context

Part of a solution to a much larger problem
Our New Mental Model
75/25 Rule

The “75”
• 75% of diseases are caused by lifestyle (and are preventable)
• That is $1.5 Trillion annual savings for the nation

The “25”
• 5% of patients generate 50% of the healthcare costs
• 15% of patients generate 85% of the healthcare costs
• 30% reduction in cost by good medical management
Adult Average Annual Total Risk Cost

- **No Risks** $2,382
- **Obese** $3,679
- **Daily Cigarette Users** $3,081
- **Physically Inactive** $3,643
- **Obese** $3,441
- **Obese + Physically Inactive** $4,158
- **Daily Cigarette Users + Obese** $3,529
- **Daily Cigarette Users + Physically Inactive** $4,432
- **Daily Cigarette Users + Obese + Physically Inactive** $3,257
- **Cigarette Use** $2,690

O = Obese
P = Physically Inactive
C = Daily Cigarette Use

Combined Risk Factors
Reduce the Disease Load of the Population

- Focus on the Root cause
- Much of illness is a result of obesity or smoking - hypertension, heart failure, atherosclerosis, diabetes, cancer and joint disease
- Transform our region from one of the sickest populations to one of the healthiest.
- Eliminate obesity and smoking in the next generation by a series of interventions which will be primarily focused in the schools, the workplace and churches
- Focus on nutrition, physical activity, and education focus on fundamentals and commit for the long haul.
- Work by direct intervention and create a model which can be reproduced by others.
- Focus on the employer as a fulcrum for change
Our Focus

• To take on the **obvious issues**
  – Obesity
  – Smoking
  – Inactivity

• All:
  – Can be readily diagnosed
  – Are actionable
  – Are clearly beneficial to individuals
The cigarette is the only LEGAL substance, when used exactly as directed, will kill 480,000 Americans every year
Tobacco Industry Targets

• By 18 years old 90% of smokers are hooked
• The Target
  – Kids
  – Teens
  – Low Income
  – Minorities
The Business Model

- An Addiction Machine

- 1.5 million new children smokers per year

- 40 million adults smoker

- Marketing
  - Lobbying
  - Business Allies
  - Government Protection
  - Deception Distortion
  - Support for Smokers

- 480,000 deaths per year

- 260 million non-smokers are strangely silent and accepting
Here is What They Said

• **Philip Morris:** “Today’s teenager is tomorrow’s potential regular customer, and the overwhelming majority of smokers first begin to smoke while still in their teens... The smoking patterns of teenagers are particularly important to Philip Morris.”

• **RJ Reynolds:** “Evidence is now available to indicate that the 14-18 year old group is an increasing segment of the smoking population. RJR-T must soon establish a successful new brand in this market if our position in the industry is to be maintained in the long term.”

• **Brown & Williamson:** “Kool’s stake in the 16- to 25-year-old population segment is such that the value of this audience should be accurately weighted and reflected in current media programs... all magazines will be reviewed to see how efficiently they reach this group.”
Here is What They Said- continued

• **Lorillard Tobacco**: “[The base of our business is the high school student.]”

• **U.S. Tobacco**: “Cherry Skoal is for somebody who likes the taste of candy, if you know what I’m saying.”
Product to Entice Youth
Little Cigars and Cigarillos

- Cigars are defined by the US government as “any roll of tobacco wrapped in leaf tobacco or in any substance containing tobacco”.\(^1\)

- Size Comparison:
  - Cigarette < 3 lbs per 1000
  - Little Cigar < 3 lbs per 1000
  - Cigar > 3 lbs per 1000
  - (includes cigarillo)

1. USC 5702. Available at: http://frwebgate.access.gpo.gov/cgi-bin/getdoc.cgi?dbname=browse_usc&docid=Cite:+26USC5702
Snus

A spitless tobacco packaged in small teabag-like pouches. Modeled after a Swedish product

**Marlboro Snus**

Tested starting 2007 in plastic packs, now in smaller foil packs

**Camel Snus**

Ads now appear nationally in magazines
Dissolvable Tobacco

- Three new dissolvable tobacco products made of finely milled tobacco, dissolve in the mouth; do not require spitting. Orbs began test marketing in Jan, 2009
- Packaging appearance seems like it may appeal to youth

Camel Orbs - Looks like tic tac
  - Two Styles: Fresh and Mellow
  - 15 Orbs per package
  - Lasts 10-15 minutes
  - 1-3 milligrams of nicotine per Orb

Camel Strips - Like Breath Strips
  - One Style: Fresh
  - 20 strips per package
  - Lasts about 2-3 minutes
  - .6 milligrams of nicotine per strip

Camel Sticks - Looks like Toothpicks
  - One Style: Mellow
  - 20 Sticks per package
  - Lasts 20-30 minutes
  - 3.1 milligrams of nicotine per stick
Hookah

- Water pipe smoking that hails from Middle East
- Water does not "filter" all the toxic compounds and chemicals
Newer Products

• **Virginia Slims Superslims**
  – Introduced late 2008, early 2009, come in “purse packs”
  – Public health groups have called them out for marketing toward women and younger girls, with fashionable colors,
  – Ad sleek sparkling boxes.

• **Camel Crush**
  – Introduced fall 2008
  – Filter contains capsule to be crushed by squeezing, releasing menthol flavor

• **Marlboro Blend No. 54**
  – Introduced summer 2009
  – Mentholated and now the new Marlboro Black
Electronic Cigarette

Battery | Atomizer | Cartridge

- Screw atomizer to battery
- Push cartridge to atomizer

© 2009 K. Nacheff

www.ecig69.com
Electronic Cigarettes Continued
Dr. Alton Ochsner

- 75 years ago Dr. Ochsner wrote the landmark paper on cancer and smoking
- He was a life time advocate for non-smoking

Reprint from SURGERY, GYNECOLOGY AND OBSTETRICS, February IS, 1939, Vol. 68,435-451

PRIMARY PULMONARY MALIGNANCY
Treatment by Total Pneumonectomy; Analysis of 79 Collected Cases
and Presentation of 7 Personal Cases

ALTON OCHSNER, M.D., F.A.C.S.) and MICHAEL DeBAKEY, M.D.) New Orleans) Louisiana

UNTIL recently carcinoma of the lung whereas that in all carcinomas was 8.8 per cent Ims
been specialized methods of diagnosis, in the bronchus.'
Perfectly Safe?

• **The Filter**-In 1954, manufacturers introduced the filters more broadly, following a number of speculative announcements from doctors and researchers concerning a possible link between lung diseases and smoking. Since filtered cigarettes were considered "safer", by the 1960s, they dominated the market. Big Tobacco knew that the filter never made their cigarettes safe.

• **Light/ Low Tar Cigarettes**-In light cigarettes and some full flavor cigarettes, the filter is perforated with tiny holes that dilute the smoke with air. As such, the inhaled smoke contains less tar and nicotine. In theory, this should make the cigarette "safer" than full flavor ones. In practice, however, the average smoker compensates by inhaling more deeply or by covering parts of the holes with fingers or lips. Because of this, smokers of light cigarettes can be exposed to equal or greater doses of carcinogens and tar than they would be with medium tar cigarettes.
“Perfectly Safe” Continued

• **E-Cigarettes** is a battery-powered device which simulates tobacco smoking by producing a vapor that resembles smoke. It generally uses a heating element known as an atomizer, that vaporizes a liquid solution. Some solutions contain a mixture of nicotine and flavorings, while others release a flavored vapor without nicotine. The FDA and other agencies have found other toxins and inconsistent nicotine levels in e-cigs.
Why is it a Pediatric Disease?

- Exposing the developing brain to periodic surges of nicotine results in usually permanent alterations in brain structure and function
  - Increases brain receptor density, sensitivity, and permeability
  - Brain response to endogenous transmitters altered
  - Change in neuronal gene expression, second messenger functions, modulation mechanisms, and even arborization patterns
Why is it a Pediatric Disease?

- Tobacco use is a cycle of addiction and exposure that can begin at conception and persist throughout life.
- Second Hand Smoke (SHS) has also been associated with adverse behavioral outcomes, cognitive impairment, and poor school performance.
- The prenatal effects including miscarriage, premature delivery, low birth weight.
- On an annual basis, more than 200,000 episodes of childhood asthma have been directly attributed to parental smoking.

Denormalization of Tobacco Use and the Role of the Pediatric Health Care Provider, Calabro et al, Pediatric Allergy, Immunology, and Pulmonology, Vol 23, No. 4, 2010
Figure 1. The health consequences causally linked to smoking and exposure to secondhand smoke

<table>
<thead>
<tr>
<th>Smoking</th>
<th>Chronic Diseases</th>
<th>Secondhand Smoke Exposure</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cancers</td>
<td>Stroke</td>
<td>Children</td>
</tr>
<tr>
<td></td>
<td>Blindness, cataracts</td>
<td>Respiratory symptoms, impaired lung function</td>
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<tr>
<td></td>
<td>Periodontitis</td>
<td></td>
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<tr>
<td></td>
<td>Aortic aneurism</td>
<td></td>
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<tr>
<td></td>
<td>Coronary heart disease</td>
<td>Lower respiratory illness</td>
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<tr>
<td></td>
<td>Pneumonia</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Atherosclerotic peripheral vascular disease</td>
<td>Sudden infant death syndrome</td>
</tr>
<tr>
<td></td>
<td>Chronic obstructive pulmonary disease, asthma, and other respiratory effects</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Hip fractures</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Reproductive effects in women (including reduced fertility)</td>
<td>Nasal irritation</td>
</tr>
</tbody>
</table>

Children:
- Middle ear disease
- Respiratory symptoms, impaired lung function
- Lower respiratory illness
- Sudden infant death syndrome

Adults:
- Nasal irritation
- Lung cancer
- Coronary heart disease
- Reproductive effects in women: low birth weight

Nicotine and Childhood Obesity

- Exposure to prenatal smoking increases risk for overweight in childhood (OR 1.2 to 2.2)
- Mechanism probably multifactorial but directly related to effects of nicotine
  - Nicotine withdrawal results in hyperphagia and weight gain
  - Altering of metabolic programming
  - Relationship of nicotine and leptin concentrations
- Maternal SHSe may also contribute to higher childhood BMI
- Association does not persist if mother stops smoking

Prenatal environmental tobacco smoke exposure and early childhood body mass index, Braun et al, Paediatric and Perintal Epidemiology 2010;24:524-534
Why is it a Pediatric Disease?

• Kids under 18 alive today who will ultimately die from smoking (unless smoking rates decline): 6,000,000 Million

• Each year, more than 6,000 children die from tobacco exposure in the US

• 5.4 million childhood illnesses caused by smoking
Why is it a Pediatric Disease?

• Every year (in the US) approximately 1.4 million children younger than 18 yrs start smoking
• 23% of high school and 8% of middle school students are current smokers
• Each day in the United States, more than 3,200 people younger than 18 years of age smoke their first cigarette
• Each day an estimated 2,100 youth and young adults who have been occasional smokers become daily cigarette smokers

Tobacco is a global paediatric concern, Bull World Health Organ 2010:88
Why is it a Pediatric Disease?

![Bar Chart](image)

**FIGURE 1**
Prevalence of SHS exposure, indicated by a serum cotinine level of ≥0.05 ng/mL, United States, 2001–2002.¹

The Toll of Tobacco in America

DEATHS & DISEASE IN THE USA FROM TOBACCO USE

• People who die each year from their own cigarette smoking: 480,000

• Adult nonsmokers who die each year from exposure to secondhand smoke: 50,000

• People in the USA who currently suffer from smoking-caused illness: 16 million

• Smoking kills more people than alcohol, AIDS, car accidents, illegal drugs, murders, and suicides combined, with thousands more dying from spit tobacco use. Of all the kids who become new smokers each year, almost a third will ultimately die from it. In addition, smokers lose an average of 13 to 14 years of life because of their smoking.

• FOR EACH CIGARETTE SMOKED TAKES 7 MINTUES OF YOUR LIFE
Tobacco Tolls of America

Smoking-caused health costs and productivity losses per pack sold in USA (low estimate): $10.47 per pack

Average retail price per pack in the USA (including sales tax): $5.29
The Toll of Tobacco in America

- Total annual public and private health care expenditures caused by smoking: $96 billion
- Annual Federal and state government smoking-caused Medicaid payments: $30.9 billion
- Federal government smoking-caused Medicare expenditures each year: $27.4 billion
- Annual health care expenditures solely from secondhand smoke exposure: $4.98 billion
- Productivity losses caused by smoking each year: $97 billion
- Taxpayers yearly fed/state tax burden from smoking-caused government spending: $70.7 billion ($616 per household)
The Toll of Tobacco in Delaware

Adults who die each year from their own smoking: 1,300

Kids now under 18 and alive in Delaware who will ultimately die prematurely from smoking: 17,000

Smoking causes fatal lung cancer

www.tobaccofreekids.org
The Toll of Tobacco in Delaware

TOBACCO USE IN Delaware

- High school students who smoke: 18.3% (9,000)
- Kids (under 18) who become new daily smokers each year: 700
- Packs of cigarettes bought or smoked by kids each year: 2.3 million

www.tobaccofreekids.org
The Toll of Tobacco in Delaware

• Total annual health care expenditures in Delaware caused by smoking: $532 million

• Annual Portion by the state Medicaid payments: $79 million

• Annual health care expenditures solely from secondhand smoke exposure: $4.98 billion

• Productivity losses in Delaware caused by smoking each year: $323 million

• Taxpayers yearly fed/state tax burden from smoking-caused government spending: $636 per household
What Can Be Done?

• **Taxation**
  – Youth are particularly sensitive to prices
  – Sell Mini Cigars in Packs of 20
  – Tax loose tobacco the same as cigarettes

• **Create more obstacles to smoking**
  – Put cigarettes/tobacco products behind the counter
  – Plain Packaging
  – Only allow tobacco products to be sold at specific stores

• **Utilize Positive Behavior Models**
  – Incentivize High/Middle School Students to not smoke
    - Scholarship to College/Vocational School
    - Monetary Reward
    - Discount Car Insurance
  – Give incentives to employers who help people quit
What Can Be Done?

• Utilize Policy to Create Change
  – Eliminate exposure to second hand smoke by eliminating smoking in any public area parks, the street, etc... Toxic substances should be confined to a specific area
  – Resist efforts to make smokers a protected class.
What Should Be Done

• Create a grass roots movement to protect our children
• Change the language: “Cigarette smoke is poison”
  – Tobacco smoke contains a deadly mix of more than 7,000 chemicals. Hundreds are toxic. About 70 can cause cancer. Here are some of the chemicals.
    - Formaldehyde: Used to embalm dead bodies
    - Benzene: Found in gasoline
    - Polonium 210: Radioactive and very toxic
    - Chromium: Used to make steel
    - Arsenic: Used in pesticides
    - Lead: Once used in paint
    - Cadmium: Used to make batteries
Reframe The Issue

“LEAVE OUR KIDS ALONE“
Questions?

Patrick Quinlan, MD
Ochsner Health System
pquinlan@ochsner.org
Workshop Overview:
Brian Rahmer PhD MS

Thematic Workshop Locations

1. **Obesity**: Riverfront Ballroom South (near buffet);
   Sandra Hassink MD, Peggy Geisler MA

2. **Maternal and Child Health**: Riverfront Ballroom North (towards main stage)
   David Paul MD, Liz O’Neill, Stephanie Rogers RN

3. **Cardiovascular**: Harlan & Hollingsworth Room
   William Weintraub MD MACC FAHA FESC, Mary Kate Mouser MEd

4. **Cancer**: Harlan & Hollingsworth Room
   Heather Bittner Fagan MD MPH FAAFP, Devona Williams PhD

5. **Social Media for Community Engagement**: Lobdell Room
   (head towards main lobby and make a right, located on right hand side)
   Michael Peterson EdD