Past, Present and Future of an Obesity Practice-Based Research Network
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• William Stratbucker, MD, MS, Helen DeVos Children’s Hospital
• Ihuoma Eneli, MD, MS, Nationwide Children’s Hospital
• Shelley Kirk, PhD, RD, LD, Cincinnati Children’s Hospital Medical Center
• Bob Siegel, MD, Cincinnati Children’s Hospital Medical Center
Children’s Hospital Association

• 2011 National Association of Children’s Hospitals and Related Institutions (NACHRI) and the Child Health Corporation of America (CHCA) merged to form the Children’s Hospital Association

• Represents over 220 Children’s Hospitals
  – The Legislative Process
  – Defining Quality of Care
  – Improved Business Results for Members
FOCUS on a Fitter Future

• 2008 FFF Obesity FOCUS Group

• Goal is to articulate the role of children's hospitals in combating pediatric obesity while building consensus on performance measurement and quality improvement
COMPASS: Goals

- Promote multi-disciplinary collaboration between network centers
- Support studies that require multi-center methodology
- Develop and maintain a network infrastructure that is practical and sustainable
- Identify and seek funding sources for sustainability of the network and research activities
- Provide an evidence base to guide the prevention, evaluation and treatment of childhood obesity.
- Promote collaboration with other research networks and data registries
- Dissemination of evidence-based practices
  – “Because so few studies of this problem have been performed, the approaches to evaluation and therapy presented here rarely are evidence-based.” (p. 1)


  – “Because effective strategies remain poorly defined, the writing groups used both available evidence and expert opinion to develop the recommendations.” (abstract, p. S164)

The Evidence Base?

• PubMed April 21, 2013: search terms: overweight OR obesity AND prevention OR treatment (child: birth-18 yrs) = 1,314,370 publications

• Correlates and possible causes of obesity and many hypotheses about assessment and therapy.

• Lacking: solution-oriented research -- What to do, who to do it to (or with), how to do it, and when or where to do it.
Why a Children’s Hospital Obesity Research Network?

• Many children’s hospitals include expertise in research, patient care, and community programs.

• Single-site studies often lack sufficient power or population diversity.

• Children’s hospitals provide training and professional education, to facilitate diffusion of new innovations.
William Stratbucker, MD, MS
Helen DeVos Children’s Hospital
Multi-site Research Collaborations

• What?
• Who?
• Why?
• How?
Multi-site Research Collaborations

• What?
  – 2 or more clinical sites working together to accomplish a study
  – Local, state, region, national, international
  – Disease-specific networks
  – Specialty-specific networks
Multi-site Research Collaborations

- **Who?**
  - Many in primary care (PBRN)
  - AHRQ sponsors PBRNs and allows for registration
  - Several specialty PBRN (neonatology, etc.)
  - Several hospital-based (PRIS, BORN)
Multi-site Research Collaborations

• Why?
  – Higher quality study
  – More Power
  – Control group
  – Generalizability
  – Dissemination
Multi-site Research Collaborations

• How?
  – Similar interests and collaborative spirit
  – Clear operational plan and leadership
  – Drive, motivation and perseverance
  – Funding
Ihuoma Eneli, MD, MS
Nationwide Children’s Hospital
Network Tasks and Accomplishments

• Infrastructure
  • Membership database – characteristics of network

• Test the review and implementation process
  – Recruitment
  – IRB
  – Implementation and data analysis
  – Dissemination of scholarship

• Determine strengths and gaps
Membership

- Alfred I. duPont Hospital for Children
- American Family Children’s Hospital
- Arkansas Children’s Hospital
- Boston Children’s Hospital
- Children’s Hospital and Medical Center, Omaha
- Children’s Hospital & Research Center at Oakland
- Children’s Hospital Colorado
- Children’s Hospital of Illinois at OSF Saint Francis Medical Center
- Children’s Mercy Hospitals and Clinics
- Children’s National Medical Center
- Cincinnati Children’s Hospital Medical Center
- Connecticut Children’s Medical Center
- Dell Children’s Medical Center of Central Texas
- Doernbecher Children’s Hospital at OHSU
- Floating Children’s Hospital at Tufts Medical Center
- Helen DeVos Children’s Hospital
- Kosair Children’s Hospital
- Lucile Packard Children’s Hospital at Stanford
- Mt. Washington Pediatric Hospital, Inc
- Nationwide Children’s Hospital
- Seattle Children’s
- University of Michigan C.S. Mott Children’s Hospital
- Walt Disney Pavilion at Florida Hospital for Children
Geographic distribution of COMPASS sites

Participating Sites (N=23)
Infrastructure

Characteristics of program population

- Age:
  - 2-5%
  - 6-9%
  - 10-13%
  - 14-17%
  - 18%

- Race:
  - Caucasian
  - Latino
  - AA
  - Mixed Race

Champions for Children's Health
Infrastructure

COMPASS: Program characteristics

- Funding (out of 100+ IRB approved projects across sites)
  - Funded by grant
  - Funded by program

- Electronic Medical Records
  - Yes
  - No
Test the review and implementation process

• Current Projects
  – Text Messaging Intervention
  – Social Media Use of Teens that Attend Pediatric Weight Management Programs
  – Eating Behaviors, Self regulation and Childhood Obesity: Implications for Intervention
Text Messaging Intervention (TMI)
PI: Susan Woolford

- **Aim:** To address poor adherence to treatment plans and high attrition rates through frequent contact with patients between office visits using text messaging
- **Study design**
  - Randomized controlled trial
- **Inclusion criteria**
  - 12-18 years old
  - 3-month multidisciplinary program
- **Outcomes:** change in adherence, attrition, BMI, target behaviors
- Currently three sites are involved (20-60 subjects per site)
Social Media Use of Teens in Pediatric Weight Management Programs

PI: Bob Siegel

- **Aim:** To determine use of electronic/social media and preferred means of social media/technology communication with healthcare providers

- **Study design**
  - Cross-sectional survey
  - Use of “Survey Monkey”- home and clinic

- **Inclusion criteria**
  - 12-17 years old

- **Outcomes:** Description of ESM use and preferred means for communication

- Currently 8(?) sites are involved (all eligible subjects in a 3 month timeframe)
Self Regulation and Eating Behaviors Study
PI: Melissa Santos and Ihuoma Eneli

• **Aims**: To examine the eating behaviors of young children, parental eating and feeding behaviors and maternal perspective on focusing on feeding behaviors as an intervention for prevention or treatment of obesity

• **Study design**
  – Cross-sectional survey  
  - Use of structured interviews via phone

• **Inclusion criteria**
  – Mothers with children ages 2-5 years

• **Outcomes**: prevalence and predictors of controlling feeding behaviors, maternal eating behaviors and maternal perception of feeding behaviors as an intervention.

• Currently 6 sites are involved (all eligible subjects in a 6 week timeframe) N = 120 surveys, 20 structured interviews
Strengths and Gaps

• Wide range of interests and expertise
• Tested different study designs
• Assess IRB process across sites

Gaps

• Test our governance structure
• Helpful to have comprehensive data on our study sites and population to help researchers assess the appropriate fit for their studies
• Natural collaboration between two subcommittees of FFF III

COMPASS and POWER
FOCUS on a Fitter Future

POWER

Pediatric Obesity Weight Evaluation Registry

Shelley Kirk, PhD, RD, LD – Chair, Registry Subcommittee
Cincinnati Children’s Hospital
FOCUS on a Fitter Future II

FFF II: Selected Goals for 2010-2011

- Establish collaborative relationships with other pediatric hospitals (N=25) offering weight management programs for youth.

- Enlist other pediatric hospitals providing obesity care to help develop a multi-site clinical data registry

- Reach consensus on collection and evaluation of clinical, demographic, and process measures.
Building a Multi-Site Data Registry for Hospital-based Pediatric Weight Management Programs

**POWER:** Pediatric Obesity Weight Evaluation Registry

**Phase I:** Conduct a retrospective cohort study of youth presenting for weight management: 2009-2010

- **Objectives:**
  - Describe baseline characteristics of patients (age 2-18 years)
  - Investigate predictors of program response and retention
  - Determine feasibility of a national obesity registry

- **Participating sites:**
  - 13 pediatric institutions (8000+ patients)
Participating POWER Sites
Alphabetical by hospital name

• Alfred I duPont Hospital for Children, Wilmington, DE
• Arkansas Children's Hospital, Little Rock, AR
• Boston Children's Hospital, Boston, MA
• C.S. Mott Children’s Hospital, University of Michigan, Ann Arbor, MI
• Children’s National Medical Center, Washington, DC
• Children's Hospital and Research Center, Oakland, CA
• Cincinnati Children’s Hospital Medical Center, Cincinnati, OH
• Connecticut Children’s Medical Center, Hartford, CT
• Helen DeVos Children’s Hospital, Grand Rapids, MI
• Kosair Children’s Hospital, Louisville, Kentucky
• Nationwide Children’s Hospital, Columbus, OH
• Seattle Children’s, Seattle, WA
• Walt Disney Pavilion Florida Hospital for Children, Orlando, FL
Phase I: Retrospective Study

Participating Sites (N=13)
Phase I: Retrospective Study
Multi-site retrospective database of youth presenting for weight management in 2009 and 2010

Baseline BMI Percentile: Preliminary Outcomes*

<table>
<thead>
<tr>
<th>BMI Percentile</th>
<th>n</th>
<th>%</th>
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<tbody>
<tr>
<td>0-84</td>
<td>21</td>
<td>0.4%</td>
</tr>
<tr>
<td>85-94</td>
<td>169</td>
<td>3.5%</td>
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<tr>
<td>95-96</td>
<td>281</td>
<td>5.8%</td>
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<tr>
<td>97-98</td>
<td>1399</td>
<td>29.0%</td>
</tr>
<tr>
<td>99+</td>
<td>2952</td>
<td>61.2%</td>
</tr>
</tbody>
</table>

*Cleaned data only N = 4,822

Most patients at initial visit are severely obese (>99th percentile)
Phase I: Preliminary Outcomes

Sample Demographics and Baseline BMI Percentile by Race

- White: 98.5%
- African-American: 98.8%
- Hispanic: 98.6%
- Other/Mixed: 98.3%

BMI Percentile (%)
Phase I: Preliminary Outcomes

The youngest patients present at the highest BMI percentile.

<table>
<thead>
<tr>
<th>Sample Demographics and Baseline BMI Percentile by Age</th>
</tr>
</thead>
<tbody>
<tr>
<td>BMI Percentile (%)</td>
</tr>
<tr>
<td>-------------------</td>
</tr>
<tr>
<td>2-5</td>
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<tr>
<td>6-11</td>
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<tr>
<td>12-14</td>
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<tr>
<td>15-17</td>
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</tbody>
</table>

The youngest patients present at the highest BMI percentile.
Phase I: Preliminary Outcomes

Sample Demographics and Baseline BMI Percentile by Type of Health Insurance Coverage

![Bar chart showing BMI percentile by type of health insurance coverage. The chart compares Public, Private, and Self-Pay/Other categories.]

- Public: 98.8%
- Private: 98.4%
- Self-Pay/Other: 98.9%

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Phase II: Prospective Registry

Lessons learned from Phase I retrospective study to build more efficient process

• Standardize data collection items
• Standardize file structure for electronic “up-load”
• Develop data cleaning/query resolution processes
• Develop data use agreements
• Develop data extraction/archival process
POWER

Prospective Registry: Goals

• **Improve patient care**
  • Further establish evidence-based guidelines for the management of pediatric overweight and obesity
  • Help standardize and improve quality of care for overweight/obese youth and their families

• **Promote collaborative research**
  • Able to conduct comparative effectiveness research
POWER
Prospective Registry: Data Management

• Goals
  – Obtain high-quality, complete data across multiple sites
  – Ensure timely data collection using the most efficient processes
Data Workflow

Data Repository Build → Site Data Entry / Upload from electronic → Data Cleaning/Data Quality Monitoring

Core Data Management Process

Statistical Analysis ← Data Export Archive ← Data Export

Database Freeze

Champions for Children's Health
Phase II: Expectations

• 2-year pilot program
• 100 variables
• 15 sites (minimum)
• Full data management support
• Data analysis support available
POWER: Next Steps

- **Retrospective study**
  - Complete data analysis
  - Prepare manuscript

- **Prospective multi-site registry**
  - Shared Governance
    - Develop guidelines for structure, leadership and access
  - Expand Participation
    - Increase number of participating sites
POWER: Prospective Registry

Interested in receiving more information about POWER and/or want to explore becoming a participating site?

- Shelley.Kirk@cchmc.org

- Provide contact information
  - Name, institution and email address
COMPASS
+
POWER
=
SYNERGY
Bob Siegel, MD
Cincinnati Children’s Hospital
Proposed Governance Structure

Executive Committee

Regional Research Chairs
- Regions consistent with those of the Academic Pediatric Association

Regional Institution Coordinators

Steering Committee
- Network Director
- Communications Director
- Recruitment Director
- 2 Research Consultants

The Steering Committee will determine:
- Network infrastructure
- Overall policy and direction of network
- Selection and oversight of research studies
- Appropriate oversight of selected research studies
- Appropriate aid for PI's
- Practice participation in individual studies
- Oversight of study completion, dissemination of results, and publication

Ad hoc Research Advisory Committee
Proposed Interim Structure

- Network Director
- Steering Committee
  - Project Development/Evaluation
  - Recruitment
  - Evaluate Funding Opportunities
Next Steps

• Recruitment of additional programs
• Obtain Funding
• Determine structure and form post FFF sessions