The Community as a Learning System for Health: 

*Using Local Data to Improve Local Health*

**PRESENTED BY:**
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- Linda L. Kloss M.A., Kloss Strategic Advisors, Ltd.
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- Susan Baird Kanaan, MSW, Consultant Writer, National Committee on Vital and Health Statistics (NCVHS)
- Marjorie S. Greenberg, Executive Secretary, National Committee on Vital and Health Statistics (NCVHS)

**MODERATED BY:** Kate Berry, CEO - National eHealth Collaborative

May 23, 2012
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- **Timothy A. Swope** – Personalized Medicine Coalition
- **Steven Waldren, MD, MS** – American Academy of Family Physicians
- **Chantal Worzala, PhD** – American Hospital Association
NeHC University provides unique opportunities for interested stakeholders to learn about multiple health IT initiatives, programs, and trends all in one place.

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<th>HIT Orientation</th>
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Spotlight Learning Series: Beacon Communities

This series will provide in-depth case studies of the Beacon Community grantees’ projects as they work to further build and strengthen their health IT infrastructure and exchange capabilities.

Mark Your Calendar!

- **Spotlight on San Diego and Utah**
  - *Date*: Thursday, May 24 1:00PM-2:30PM ET
  - *Faculty*:
    - Christie North, Vice President of Utah Programs – HealthInsight
    - Anupam Goel, Co-Principal Investigator – San Diego Beacon Collaborative
    - Janhavi Kirtane, Director of Clinical Transformation, Beacon Community Program, ONC
Executives give valuable insight into the successes and challenges of maintaining HIE sustainability.

Mark Your Calendar

- Spotlight Learning Series on Payer Engagement: Case Study on Cigna’s HIT Strategy
- Tuesday, June 5, 2012
  12:00PM-1:30PM ET
- Faculty:
  - Gary Austin, Founder, TranzformHealth
  - Dr. Richard Salmon, National Medical Executive for Performance Measurement and Improvement, Cigna Healthcare
Upcoming NeHC University Programs

Mark Your Calendar

June 7: Behavioral Health Landscape
1:00PM ET-2:30PM ET

June 12: Spotlight Learning Series on Consumer Engagement: Aetna and iTriage
1:00PM ET-2:30PM ET

June 18: “How To Achieve Stage 1 Meaningful Use”
1:00PM ET-2:30PM ET
Presentation slides are available now!  
http://www.nationalehealth.org/LocalDatatoImproveHealth

Recorded webinar will be available in 24 to 48 hours  
Full transcript will be available in approximately 7 to 10 days

Want more?

Check out the supplemental materials available on the NeHC website!

You can also continue today’s discussion by joining the Consumer Consortium on eHealth group in NeHC’s online community:  
http://www.nationalehealth.org/collaborate/groups/consumer-consortium-ehealth
Please enter your questions or comments in the Q&A window at the bottom right of your screen.

You can also send us an email at university@nationalehealth.org, tweet a question using hashtag #NeHC, or comment on our Facebook page at www.facebook.com/nationalehealth
The National Committee on Vital and Health Statistics
The Public Advisory Body to the Secretary of Health and Human Services

The Community as a Learning System:
Using Local Data to Improve Local Health
May 23, 2012

Justine Carr, MD, Chair, NCVHS,
Larry Green, MD, Co-Chair, Population Health Subcommittee
Linda Kloss, RHIA, Co-Chair, Privacy, Confidentiality and Security Subcommittee
Today’s Goals

1. To engage you in improving community health through the use of local data.
2. Update you on the work of the NCVHS
3. Solicit your involvement in the Committee’s deliberations.
Published, November 2011
Joint Project of the
Population Health and
Privacy, Confidentiality and
Security Subcommittees
The National Committee on Vital and Health Statistics - Mission

• The statutory public advisory body to the Secretary of Health and Human Services in the areas of health data, statistics and health information policy

• Provides advice and assistance to the Department

• Serves as a forum for interaction with interested private and public sector groups on a variety of key health data issues.
<table>
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<th>Year</th>
<th>Event</th>
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<tr>
<td>1949</td>
<td>Established as federal advisory committee</td>
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<tr>
<td>1974</td>
<td>Public Health Services Act gave NCVHS official status as a statutory public advisory committee to the Secretary of HEW (now HHS)</td>
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<tr>
<td>1996</td>
<td>HIPAA charged NCVHS with advising Secretary on health data standards and privacy policy</td>
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<td>2003</td>
<td>Medicare Modernization Act charged NCVHS with recommending standards for electronic prescribing</td>
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<tr>
<td>2010</td>
<td>Affordable Care Act charged NCVHS with advising the Secretary on Operating Rules for HIPAA Administrative Simplification</td>
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NCVHS Configuration

• 18 members appointed for four year terms
• Drawn from fields including medicine, law, public health, economics, privacy, security, informatics, health plans, consumers
• Through hearings and open deliberation, develop practical, timely, thoughtful recommendations to the Secretary of HHS
## NCVHS Subcommittees

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<td><strong>Standards</strong></td>
<td>Health data standards as required under HIPAA, MMA, and ACA</td>
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<td><strong>Quality</strong></td>
<td>Health data for clinical uses, quality improvement, and informed consumers</td>
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<tr>
<td><strong>Population Health</strong></td>
<td>Population-based data and data about specific vulnerable groups</td>
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<tr>
<td><strong>Privacy, Confidentiality and Security</strong></td>
<td>Emerging issues in information privacy, confidentiality and security and data stewardship</td>
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NCVHS Notable Contributions

• Visioning Documents (2002)
  – 21st Century Vision for Health Statistics report
    • Emphasized role of all factors influencing health
  – National Health Information Infrastructure:
    • Led to creation of Office of the National Coordinator for Health Information Technology

• Administrative Simplification
  – Decade of oversight of adoption and implementation of standards for HIPAA and ACA administrative simplification provisions
A Learning Health System

Governance
Engagement
Trust
Analysis
Dissemination

State Public Health
Pharmaceutical Firm
Community Practice
Federal Agencies
Health Information Organization
Integrated Delivery System
Beacon Community
Health Center Network
Impetus for Focus on Community Health Data

Upsurge in community health Initiatives

Learning Health System project

How communities can become learning systems for health and what resources exist and are needed to help them?
Health is a Community Affair

“Getting data into the hands of communities and ensuring they have tools and capacities to use them could move the nation toward realizing the public benefits of the informatics revolution.”

The Community as a Learning System for Health,
NCVHS, December 2011, p. 7
14 Leading edge Learning Communities

1. Boone County, MO – Public Health
2. Bronx, NY – Care transitions
3. Denver, CO – cardiovascular health, childhood obesity
4. Grand Junction, CO – population health
5. Indiana and HIE – population health
6. King county, WA – data democratization
7. Mahoning Valley, OH – children’s health insurance coverage
8. New York City – BMI screening for children
9. Olmsted County, MN – childhood asthma
10. Sonoma County, CA – health information for citizens
11. Columbia, SC – data to improve childcare
12. South Los Angeles, CA – land use policies and health disparities
13. State of Arkansas – childhood obesity
14. Utah – consumer education about health data use
Age-Adjusted Death Rate due to Breast Cancer

Value: 26.2 deaths/100,000 females
Location: County: Sonoma
Comparison: CA Counties
Categories: Health / Cancer, Health / Mortality Data, Health / Women's Health

What is this indicator? This indicator shows the age-adjusted death rate per 100,000 females due to breast cancer.

Why this is important: Breast cancer is the most common type of cancer among women in the U.S. other than skin cancer. Breast cancer forms in tissues of the breast, usually the ducts (tubes that carry milk to the nipple) and lobules (glands that make milk). In the United States in 2009, it is estimated that there will be 192,370 new cases and 40,170 deaths from breast cancer.

The Healthy People 2020 national health target is to reduce the breast cancer death rate to 20.6 deaths per 100,000 females.

Technical Note: The distribution is based on data from 57 California counties. The value represents the average annualized rate.
I'm not going under there. It's your ball, you go get it.
Identifying priorities and building partnerships and collaboration

- Involving citizens and community groups; generating new partnerships
- The role of local data

“Consensus about local priorities emerges when quantitative data are combined with community members’ insights and preferences.”

The Community as a Learning System for Health, NCVHS, December 2011, p. 12
Developing data around a broad definition of health

- Leveraging and linking multiple data sources on health and determinants
- Linking clinical and population health data
- Generating local data
- Innovatively displaying and disseminating data: dashboards and more
- Mobilizing for information-driven action and evaluation
- Town-gown partnerships to improve local health
Building Trust

- Educating community members and leaders about data use and benefits
- Involving community members in decisions about data use and more
- Trust-building among organizations and agencies that are data sources
- Governance fosters a sense of ownership and control

“…further efforts and leadership are needed to define a privacy and security framework to guide the innovative uses of local data emerging in communities across the country.”

The Community as a Learning System for Health, NCVHS, December 2011, p. 19
Trust and the Community: Hearings on April 17-18, 2012

- Privacy is not an individual issue only, it’s societal and family
- Chain of trust involving the whole process from collaboration through use of data
- Participatory Governance and special obligations of data stewards to the community
- Spectrum of consent

“Trust is our Most Important Resource….and Trustworthy practices require attention to relationships and accountability.”

Kelly Edwards, PhD, Department of Bioethics and Humanities University of Washington School of Medicine
SUCCESS FACTORS IN COMMUNITY LEARNING SYSTEMS FOR HEALTH

1. A galvanizing health concern.
2. A comprehensive understanding of health and community health.
3. Collaborative culture; social capital.
4. Trust and community engagement.
5. Access to data on local health and its determinants, plus analytic capacities.
6. Data display and dissemination capacities.
7. Functioning coalitions, community engagement, agreement on priorities.
8. Organizational and technical support.
9. Political and financial support.
10. Processes and systems to translate information and priorities into action, evaluate results, and modify as needed.
Needed: Support, Shared Learning and Economies of Scale

Access + analytics + skills to make data usable and useful.

Stewardship + privacy protection + engagement + governance = Trust

Support, facilitate shared learning, and create economies of scale
Needed: An infrastructure for support, shared learning, and economies of scale.

- Privacy and security framework
- Standardized set of community health indicators
- Training, technical assistance and easy to use tools for data management, display and analysis
- Stronger local financial and human resources
- Support for public health departments to take advantage of Meaningful Use criteria
- Help with translating local knowledge into action
- Mechanisms for sharing learning beyond the community
Examples of Enabling Federal Assists

- Better bridges between clinical and public health data systems
- Standardized community health, health status, environmental and resource use indicators
- Federal and state web-based data query systems for small area data, easy analytics and visualization
- Technical assistance perhaps through existing HIT initiatives such as regional extension centers
- Longer funding periods, and transitional support for institutionalization of promising new policies and program
Questions

Contact the Executive Secretary, Marjorie S. Greenberg, MA
(301) 458-4245 Email: msg1@cdc.gov

The Community as a Learning System Report:
http://www.ncvhs.hhs.gov/111213chip.pdf

Please visit our Homepage for Meeting Information:
http://www.ncvhs.hhs.gov/
Please enter your questions or comments in the Q&A window at the bottom right of your screen.

You can also send us an email at university@nationalehealth.org, tweet a question using hashtag #NeHC, or comment on our Facebook page at www.facebook.com/nationalehealth
Before you log out...

Please take a moment to fill out the survey on the right side of your screen

Didn’t get your question answered? Join the Consumer Consortium on eHealth group in NeHC’s online community to continue the discussion:

http://www.nationalehealth.org/collaborate/groups/consumer-consortium-ehealth

Questions or Suggestions? Send us an email at university@nationalehealth.org
Thank you for your participation!

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