Connecting the Dots to Combat Infant Mortality

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Department of Health and Human Services (HHS)
Health Resources and Services Administration (HRSA)
Maternal and Child Health Bureau (MCHB)

The 2014 Kansas Governor’s Public Health Conference
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Combating Infant Mortality – Outline

• Current status; current practice
• Need to change
• New and re-emerging approaches:
  o Life-course approach
  o Preconception / Interconception health
  o Collaborative Innovation Networks (COINS)
  o Collective impact
  o Backbone organizations

• Applications:
  o Currently implementing:
    ▪ The Infant Mortality COIIN
  o Under Development:
    ▪ National Maternal Health Initiative / Improving Maternal Health and Safety
    ▪ Clinical Guidelines for Well Women Visit
    ▪ Healthy Start 3.0
Infant Mortality Rate, U.S., 2000-2011


Rate per 1,000 Live Births

Year

Percentage of Births that were Very Preterm or Preterm, United States, 2000-2012

Percentage of births that were Preterm, United States 2000-2012, and Kansas 2001-2011

(10.3% increase)

USA 2006-2012 (9.8% decrease)

KS 2005 -2011 (8.2% decrease)

Percentage of Births that were Very Low Birthweight or Low Birthweight, United States, 2000-2012

(9.1% increase)

(USA 2006-2012 3.3% decrease)

Percentage of Births that were Low Birthweight, United States, 2000-2012 and Kansas 2001-2011

- USA 2006-2012 (3.3% decrease)
- KS 2005-2011 (No Change)
We made significant progress
But
We can do more!

Continuing challenges:
- Persistent health disparities
- Worse maternal outcomes
- Other countries have achieved better outcomes
Preterm births by maternal race/ethnicity United States 2012


B/W Gap USA 2012: 1.6
B/W Gap KS 2009-11: 1.54

Low birthweight births by maternal race/ethnicity - United States 2012

B/W Gap USA 2012: 1.89
B/W Gap KS 2009-11: 1.92

Infant Mortality Rates by Race/Ethnicity, United States 2007

gov/nchs/data/databriefs/db74.htm.
Black-White disparities in perinatal outcomes - United States 1980 to 2010

Year

Infant Mortality Rate
Preterm births
Low birthweight
Infant mortality rates and international rankings: Organisation for Economic Co-operation and Development (OECD) countries (27 countries), 2009

Preterm delivery rates in Very High Human Development Countries (36th of 38 countries)

<table>
<thead>
<tr>
<th>Country</th>
<th>Preterm Birth Rate (per 100 livebirths)</th>
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Source: Chang HH et al: Preventing preterm births: analysis of trends and potential reductions with interventions in 39 countries with very high human development index. Lancet. Published online November 17, 2012
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<td>Chile</td>
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<td>Costa Rica</td>
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</table>
Source: Singh GK. Maternal Mortality in the United States. A 75th Anniversary Title V Publication. HRSA 2010
Severe Maternal Morbidity

- Severe maternal morbidity increased by 75% and 114% for delivery and postpartum hospitalizations respectively from 1998-99 to 2008-09

- Rates increased during delivery hospitalizations for:
  - Thrombotic embolism (72%)
  - Respiratory distress syndrome (75%)
  - Cardiac surgery (75%)
  - Acute renal failure (97%)
  - Shock (101%)
  - Blood transfusion (183%)
  - Aneurysms (195%)

Why Are Maternal Morbidity and Mortality Rising?

- Better surveillance and improved detection
- Demographics of childbearing are changing
  - Assisted reproductive technology
  - Advances in medicine
- Women are entering pregnancy with more chronic conditions
Risk factors for adverse pregnancy outcomes among women who recently delivered a live-born baby – PRAMS 2004 – Preconception health conditions and behaviors

<table>
<thead>
<tr>
<th>Behavior /Condition</th>
<th>%</th>
<th>Behavior /Condition</th>
<th>%</th>
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</thead>
<tbody>
<tr>
<td>Overweight or obese</td>
<td>35</td>
<td>Previous preterm delivery</td>
<td>11.9</td>
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<tr>
<td>Diabetes</td>
<td>1.8</td>
<td>Tobacco (3 months bef preg)</td>
<td>23.2</td>
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<tr>
<td>Asthma</td>
<td>6.9</td>
<td>Alcohol (3 months bef preg)</td>
<td>50.1</td>
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<tr>
<td>Hypertension</td>
<td>2.2</td>
<td>Multivitamins (&gt;=4/week)</td>
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<tr>
<td>Heart problems</td>
<td>1.2</td>
<td>No contraception / not planning</td>
<td>53.1</td>
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<tr>
<td>Anemia</td>
<td>10.2</td>
<td>Pre-pregnancy counseling</td>
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<td>Previous Low Birth weight</td>
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<table>
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<tr>
<th>Behavioral</th>
<th>2003–2006 (n=275,630) Predictive marginal (95% CI)</th>
<th>2007–2010 (n=271,547) Predictive marginal (95% CI)</th>
<th>aOR (95% CI)</th>
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<td>Any alcohol use</td>
<td>55.0 (54.8–55.4)</td>
<td>52.6 (52.2–53.0)</td>
<td>0.90 (0.88–0.92)</td>
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<td>Binge drinking</td>
<td>13.3 (13.0–13.5)</td>
<td>15.4 (15.2–15.7)</td>
<td>1.20 (1.16–1.24)</td>
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<tr>
<td>Heavy drinking</td>
<td>5.3 (5.1–5.5)</td>
<td>5.0 (4.8–5.1)</td>
<td>0.94 (0.89–0.98)</td>
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<tr>
<td>Smoking</td>
<td>22.1 (21.8–22.4)</td>
<td>19.4 (19.1–19.7)</td>
<td>0.84 (0.81–0.86)</td>
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<tr>
<td>Excellent, very good, good general health</td>
<td>89.5 (89.2–89.7)</td>
<td>88.8 (88.6–89.1)</td>
<td>0.94 (0.90–0.97)</td>
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<tr>
<td>5 or more daily fruit/vegetable servings</td>
<td>25.0 (24.6–25.5)</td>
<td>25.7 (25.3–26.2)</td>
<td>1.04 (1.01–1.07)</td>
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<tr>
<td>Mental distress</td>
<td>13.1 (12.9–13.4)</td>
<td>13.3 (13.0–13.5)</td>
<td>1.02 (0.98–1.05)</td>
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<td>Social/emotional support</td>
<td>80.3 (79.9–80.8)</td>
<td>81.1 (80.8–81.4)</td>
<td>1.05 (1.02–1.09)</td>
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<tr>
<td>Moderate or vigorous activity</td>
<td>50.9 (50.4–51.5)</td>
<td>52.0 (51.5–52.6)</td>
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<td>Any medical condition</td>
<td>36.9 (36.5–37.2)</td>
<td>40.3 (39.9–40.7)</td>
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<td><strong>Clinical</strong></td>
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<td>HIV test</td>
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<td>Annual routine checkup</td>
<td>67.8 (67.3–68.3)</td>
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<td>Influenza shot</td>
<td>18.8 (18.5–19.1)</td>
<td>27.8 (27.5–28.1)</td>
<td>1.68 (1.64–1.73)</td>
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</table>

* Adjusted for race, age, marital status, education, income, employment, health insurance.

**aOR**, adjusted odds ratio.

Infant Mortality Rates for the
Five Leading Causes of Death, United States,
2000, 2005, and 2011

Source: CDC/NCHS, Mortality Data. 2011 data are preliminary.
Prepared by MacDorman for SACIM, November 2012.
Contributors to Pregnancy Outcomes

• **Current socioeconomic status:** household income, occupational status, or parental educational attainment

• **Risky behaviors:** maternal cigarette smoking, delayed and inadequate utilization of prenatal care, alcohol and drug use

• **Maternal conditions:** psychological stress, stressful life events or perceived stress or anxiety during pregnancy, perinatal infection, chronic conditions
We Currently Intervene Too Late

Critical Periods of Development

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<th>4</th>
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Missed Period

Mean Entry into Prenatal Care
Early prenatal care is not enough, and in many cases it is too late!
Combating Infant Mortality – Current Practices

- Action during and immediately after pregnancy
- Focus on single / isolated interventions
- Action follows resources – vertical funding encourages isolated interventions
- Partnerships and collaborations have limited scope
How do we proceed from here?

• Work smarter not just harder

• Change what we do and how we do it

• Adopt / adapt emerging and re-emerging evidence-based models of practice
Working smarter

• What we do - Work beyond the 9 months of pregnancy:
  ▪ Comprehensive women’s health
  ▪ Preconception / interconception
  ▪ Across the life span - “Life-course approach”

• How we do it:
  ▪ Circles of influence
  ▪ COINs
  ▪ Collective impact
To promote the health of women of reproductive age before conception and thereby improve maternal and infant pregnancy outcomes
Definition of Preconception Care

A set of interventions that aim to identify and modify biomedical, behavioral, and social risks to a woman’s health or pregnancy outcome through prevention and management, emphasizing those factors which must be acted on before conception or early in pregnancy to have maximal impact.

"The physical treatment of children should begin as far as may be practicable, with the earliest formation of the embryo; it will, therefore, necessarily involve the conduct of the mother, even before her marriage, as well as during her pregnancy."

William Potts Dewees 1825
first American textbook on Pediatrics
There Is Consensus That We Must Act Before Pregnancy

- Recommendations and clinical practice guidelines have been published by many organizations
  - MOD
  - ACOG
  - AAP
  - AAFP
  - ACNM
  - USPHS Expert Panel on the Content of PNC, 1989
  - HP 2000

More than 30 organizations worked and continue to work together to promote PCC
All health encounters during a woman’s reproductive years, particularly those that are a part of preconceptional care should include counseling on appropriate medical care and behavior to optimize pregnancy outcomes.

Preconception Interventions: Give protection

- **Folic Acid Supplements**: Reduce the occurrence of neural tube defects by two thirds

- **Rubella Immunization**: Provides protective sero-positivity and prevents the occurrence of congenital rubella syndrome

- **HIV/AIDS Screening and Treatment**: Allows for timely treatment; pregnancies can be better planned

- **Hepatitis B Vaccination**: Prevents transmission to infants in utero and eliminates the risk to women of hepatic failure, liver carcinoma, cirrhosis, and death.
**Diabetes Management:** Reduces the 3-fold increase in birth defects among infants of women with type 1 and type 2 diabetes.

**Hypothyroidism Management:** Adjusting the dosage of Levothyroxine early in pregnancy protects proper neurological development.

**Maternal PKU Management:** Low phenylalanine diet before conception and throughout pregnancy prevents mental retardation in infants born to mothers with PKU.

**Obesity Control:** Reduces the risks of neural tube defects, preterm birth, diabetes, c-section, hypertensive and thromboembolic disease.

**STDs Screening and Management:** Reduce the risk of ectopic pregnancy, infertility, PID, and chronic pelvic pain; also reduce the risk to the fetus of fetal death, or physical and developmental disabilities, including mental retardation and blindness.
Preconception Interventions: Avoid Teratogens

- **Alcohol use:** Fetal alcohol syndrome (FAS) and other alcohol-related birth defects can be prevented.
- **Anti-epileptic drugs:** Some anti-epileptic drugs are known teratogens – changing to a less teratogenic treatment regimen reduces harmful exposure.
- **Accutane use:** Use of Accutane in pregnancy results in miscarriage and birth defects – avoiding pregnancy or ceasing Accutane use before conception eliminates harmful exposure.
- **Oral anticoagulants:** Warfarin is a teratogen; medications can be switched before the onset of pregnancy.
- **Smoking:** Completing smoking cessation before pregnancy can prevent smoking-associated adverse outcomes include preterm birth, low birth weight.
The lifecourse approach proposes that disparities in birth outcomes are the consequences of differential developmental trajectories set forth by early life experiences and cumulative allostatic load over the life course.

Lifecourse Perspective to Improve Pregnancy Outcomes

Scientific evidence from two leading longitudinal models:

- **The early programming model** - exposures in early life could influence future reproductive potential

- **The cumulative pathways model** - decline in reproductive health results from cumulative wear and tear to the body’s allostatic systems

- These two models are not mutually exclusive

Low Birthweight is associated with Syndrome X (Type 2 diabetes, hypertension and hyperlipidaemia)


Low Birthweight is associated with hypertension

<table>
<thead>
<tr>
<th>Birth weight (lbs)</th>
<th>Systolic Blood Pressure</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;=5.5</td>
<td>170</td>
</tr>
<tr>
<td>5.6-6.5</td>
<td>165</td>
</tr>
<tr>
<td>6.6-7.5</td>
<td>160</td>
</tr>
<tr>
<td>7.6-8.5</td>
<td>175</td>
</tr>
<tr>
<td>&gt;8.5</td>
<td>155</td>
</tr>
</tbody>
</table>

- Men 64-70
- Women 64-70
Low Birthweight is associated with non-fatal coronary heart disease

Contributors to Pregnancy Outcomes

• **Current socioeconomic status:** household income, occupational status, or parental educational attainment

• **Risky behaviors:** maternal cigarette smoking, delayed and inadequate utilization of prenatal care, alcohol and drug use

• **Maternal conditions:** psychological stress, stressful life events or perceived stress or anxiety during pregnancy, perinatal infection, chronic conditions
Lifecourse Perspective to Improve Pregnancy Outcomes

A 12-point plan to close the Black-White gap in birth outcomes - 1:

Address the needs of AA women for **quality healthcare across the lifespan:**

1. Provide **interconception** care to women with prior adverse pregnancy outcomes,
2. Increase access to **preconception** care to AA women,
3. Improve the quality of **prenatal** care, and
4. Expand healthcare access over the life course
Lifecourse Perspective to Improve Pregnancy Outcomes

A 12-point plan to close the Black-White gap in birth outcomes - 2:

Enhance family and community systems that may influence the health of pregnant women, families, and communities.

5. Strengthen father involvement in AA families,
6. Enhance coordination and integration of family support services,
7. Create reproductive social capital in AA communities, and
8. Invest in community building and urban renewal
A 12-point plan to close the Black-White gap in birth outcomes - 3:

Address the social and economic inequities that underlie much of health disparities:

9. Close the education gap,
10. Reduce poverty among AA families,
11. Support working mothers and families, and
12. Undo racism
Circles of Influence*

- Infant
- Infant's Family
- Infant's Health Care Providers
- Infant's School
- Police, Fire, and Safety
- National Officials and Policy Makers
- Local Officials and Policy Makers
- Community and faith agencies
- Health Program Directors
- Transportation

* Courtesy of Dr. Magda Peck, CityMatCH
• Support the development of clinical preventive health guidelines for well woman visit

• Compile the guidelines into a succinct resource

• Disseminate these guidelines and promote their adoption into standard clinical practice among women’s health care providers
Women’s and Maternal Health - HRSA Initiatives
National Maternal Health Initiative

• Promote coordination and collaboration within HRSA, across HHS agencies and with professional and private organizations.

• Five priorities:
  ▪ Improve women’s health before, during, and after pregnancy
  ▪ Improve systems of maternity care including clinical and public health systems
  ▪ Improve public awareness and education
  ▪ Improve research and surveillance
  ▪ Improve the quality and safety of maternity care
Women’s and Maternal Health - HRSA Initiatives
Improving Maternal Health and Safety

• Purpose: reduce the number of maternal deaths and/or preventable severe morbidities

• Goal: engaging health care providers, State leaders, hospitals, payers, and consumers

• Strategies:
  o Promote knowledge of and access to preconception and interconception care through a provider education campaign
  o Engage stakeholders in efforts to reduce primary cesarean delivery
  o Facilitate the adoption of the maternal safety bundle through development of a CoIIN of early adopter states
A CoIN, or Collaborative Innovation Network, is a team of self-motivated people with a collective vision, enabled by the Web to collaborate in achieving a common goal by sharing ideas, information, and work.
"If you and I swap a dollar, you and I still each have a dollar. If you and I swap an idea, you and I have two ideas each."

By openly sharing ideas and work, a team's creative output is exponentially more than the sum of the creative outputs of all the individual team members.

Key Elements of a CoIN

• Being a “cyber-team”

• Innovation

• Work patterns characterized by meritocracy, transparency, and openness

The Infant Mortality CoILIN
The Collaborative *Improvement* & Innovation Network to Reduce Infant Mortality

- Designed to help States innovate and improve their approaches to improving birth outcomes

- Initiated March 2012 as a mechanism to support the adoption of collaborative learning and quality improvement principles and practices to reduce infant mortality and improve birth outcomes.
COIN: Strategies & Structure

5 Strategy Teams

1. Reducing early elective deliveries <39 weeks (ED);
2. Enhancing interconception care in Medicaid (ICC);
3. Reducing SIDS/SUID (SS);
4. Increasing smoking cessation among pregnant women (SC);
5. Enhancing perinatal regionalization (RS).

Teams

- 2-3 Leads (Content Experts);
- Data and/or Method Experts
- Staff support (MCHB & partner organizations)
- State representatives
- Shared Workspace
- Data Dashboard
Non-Medically Indicated Early Term Deliveries Among Singleton, Term Deliveries*

25% total decline translating to ~50,000 early, elective deliveries averted since 2011 Q1

* Based on provisional birth certificate data; excludes women with pre-existing conditions
Smoking During Pregnancy*

8% total decline translating to ~8,000 fewer women smoking in pregnancy since 2011 Q1

Based on provisional birth certificate data reflecting smoking in any trimester; 3 States using unrevised birth certificate; 1 State excluded that did not report 2013 data
Other COIIN Accomplishments

- **Interconception Care**: 7 out of 8 states introduced policies to improve interconception care access or content

- **Perinatal Regionalization**: several states are working together to address levels of care designations

- **Safe Sleep**: monthly collaborative learning sessions to share best practices and innovations
Collective Impact

A systemic approach to social impact that focuses on the relationships between organizations and the progress toward shared objectives.

Collective Impact Initiatives are:

- Long-term commitments
- By a group of important actors
- From different sectors
- To a common agenda
- For solving a specific social problem

Accessed March 2014
Collective Impact

“The power of collective impact lies in the heightened vigilance that comes from multiple organizations looking for resources and innovations through the same lens, the rapid learning that comes from continuous feedback loops, and the immediacy of action that comes from a unified and simultaneous response among all participants.”

Preconditions for Collective Impact

1. An influential champion to bring cross-sector leaders together and keep their active engagement over time

2. Adequate financial resources to last for at least two to three years

3. Urgency for change around an issue

Accessed March 2014
Conditions of Collective Success

1. A common agenda
2. Shared measurement systems
3. Mutually reinforcing activities
4. Continuous communication, and
5. Backbone support organizations

Accessed march 2014
Keeping collective impact alive

Two key elements:

• Backbone Organization
• Cascading Levels of Linked Collaboration

Backbone organizations require two main ingredients:

1. Strong adaptive leadership

2. Sufficient resources to propel collective impact efforts

Backbone organizations serve six essential functions:

1. Providing overall strategic direction
2. Facilitating dialogue between partners
3. Managing data collection and analysis
4. Handling communications
5. Coordinating community outreach, and
6. Mobilizing funding

Backbone Organization

Effective Backbone Leadership:

1. Visionary
2. Results oriented
3. Collaborative, relationship builder
4. Focused, but adaptive
5. Charismatic and influential communicator
6. Politic
7. Humble

Healthy Start programs are uniquely situated to:

- Champion the infant mortality cause in their communities
- Serve as backbone organizations to ensure collective impact
- Implement the main functions of a backbone organization

THE NATIONAL HEALTHY START PROGRAM
History

• Established in 1991 as a presidential initiatives
• Started as a 5-year demonstration project
• Targets communities with high infant mortality rates and other adverse perinatal outcomes
• Initially focused on community innovation and creativity
• Today, HRSA supports 105 grants in 196 counties, in 39 States, DC, Puerto Rico
• In 2010, over 90% of all healthy start sites were implementing all 9 core components of the program

• Most offered additional services:
  Home visiting, breastfeeding support and education, smoking and other tobacco use cessation, healthy weight services, male and family involvement, domestic/intimate partner violence screening, and child abuse screening or services
• Perinatal outcomes significantly improved:
  • IMR = 4.78 compared with 6.15 nationally, 11.63 for African Americans
  • Low birth-weight rate = 10% compared with 8.1% nationally, and 13.53% for African Americans
  • Very low birth-weight rate 1.7% compared with 1.45% nationally, and 2.98% for African Americans
Why Change Healthy Start?

- Recommendations of external evaluations

- Recommendations of the Secretary’s Advisory Committee on Infant Mortality

- To keep pace, align with, coordinate efforts, and support current Department and Agency programs and priorities

- To integrate current and emerging evidence-based approaches to improving perinatal outcomes
Main Changes to Healthy Start
Healthy Start Approaches

- Improve Women’s Health
- Promote Quality Services
- Strengthen Family Resilience
- Achieve Collective Impact
- Increase Accountability through Quality Improvement, Performance Monitoring, and Evaluation
Implementing Healthy Start 3.0

• Two new programs are being launched:

  • Supporting Healthy Start Performance Project
  
  • Healthy Start Information System
Supporting Healthy Start Performance Project

- SHSPP will promote the uniform implementation of Healthy Start by:
  - Ensuring skilled, well qualified workers at all levels of the program
  - Identifying and better defining effective services and interventions
  - Offering mentoring, education, and training to staff delivering these interventions and services
  - Providing shared resources
Healthy Start Information System

- Data Dashboard for real-time monitoring of progress of activities

- Individual client data, program data, and community outcome data for:
  - Continuous quality improvement
  - Provision of targeted technical assistance, and
  - Ongoing local and national evaluations
Healthy Start CAN Drive Collective Impact

Healthy Start programs are uniquely situated to:

• Champion the infant mortality cause in their communities

• Serve as backbone organizations to ensure collective impact

• Implement its six main functions of a backbone organization:
  o Provide overall strategic direction
  o Facilitate dialogue between partners
  o Manage data collection and analysis
  o Handle communications
  o Coordinate community outreach, and
  o Mobilize funding

For More Information

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Roles and Scope of Work

NIH
Research
Clinical and basic research
Training

HRSA
Access to Care
Provides essential access to care
Reimbursement & financial issues

AHRQ
Quality of Care
Supports health services research initiatives that seek to improve the quality of health care

FDA
Regulatory
Assures product safety and efficacy
New product approval

CDC
Prevention and Control
Monitoring, investigation, research, program development, implementation and evaluation, health promotion, training and capacity building