

Child Health and Healthcare Measures in the National Center for Health Statistics Data Systems

IOM meeting on Pediatric Health and Health Care
Quality Measures – December 14th, 2009

Alan E. Simon, MD
National Center for Health Statistics
Centers for Disease Control and Prevention



SAFER • HEALTHIER • PEOPLE™

Outline

- ∅ Discuss National Center for Health Statistics data systems with child health and health care data
 - | Data gaps of each system
- ∅ Discuss data (and gaps) in our systems as they relate to previous IOM framework for child health and health care measurement

National Vital Statistics System

- ∅ National and state statistics on births and deaths
 - | Births - low birthweight, preterm births, prenatal care, teen births
 - | Deaths – leading causes, injury deaths by mechanism and intent, fetal and perinatal mortality
- ∅ Subgroups
 - | Births/Infant deaths – mother’s age, race/ethnicity, education attainment, marital status, state of residence
 - | Deaths - age, sex, race/ethnicity, state of residence
- ∅ Publicly available
 - | *National Vital Statistics Reports, VitalStats*
 - | Annual data files for all events

Data Gaps

∅ Vital Statistics birth and fetal death files

- | Lack of national data on key items because data are collected by states in a non-comparable manner:
 - prenatal care
 - educational attainment
 - smoking during pregnancy
 - delivery and vaginal birth after cesarean delivery (VBAC)

∅ Many new data items cannot be obtained from states because of budget constraints

- | infertility treatment, ruptured uterus, infections during pregnancy

National Health and Nutrition Examination Survey

- ∅ Interview and examination survey continuous since 1999
 - | Public release every 2 years
- ∅ Information on health status from dietary report, biochemical tests, physical measurements and clinical assessments
- ∅ Measures
 - | Overweight, serum cotinine, blood lead, dental caries
- ∅ Subgroups
 - | N=4,500 <18 every 2 years
 - | race/ethnicity, age, sex, family income, insurance
- ∅ Data gap: Sample size makes estimation of specific populations with particular diagnoses difficult

National Health Interview Survey

- ∅ Continuous household interview survey
- ∅ Information on illnesses, injuries, chronic conditions, use of health services
- ∅ Subgroups
 - | N=20,000 <18 in sample annually
 - | N=9,000 <18 years old detailed child interviews
 - | age, race/ethnicity, sex, family income, family structure, geographic region, location of residence, health insurance status
- ∅ Publicly available
 - | Annual public release
 - | *Summary Health Statistics of U.S. Children* (annual)

NHIS measures

∅ Health status

- | Respondent-assessed health status
- | Limitation of activity caused by chronic conditions
- | Developmental disabilities – learning disability; ADHD; mental retardation; speech, hearing and vision impairments; cerebral palsy, autism, seizures
- | Emotional and behavioral difficulties

∅ Health care

- | Health insurance coverage
- | Health care utilization
- | Dental care
- | Prescription medication use
- | Seasonal and H1N1 flu vaccination

Data Gaps for NHIS

- ∅ National level estimates.
 - | State level estimates available for approximately 20 largest states only
- ∅ Small sample does not allow estimates for some subpopulations
- ∅ Data on many topics are at a fairly high level, and do not get at detailed enough information.
 - | Mental health
 - | Oral health
 - | Access
 - | Prescription drug use

National Survey of Family Growth

- ∅ Household survey of men and women ages 15-44
 - | Continuous since 2006
 - | Data released every 2-3 years
- ∅ Data on sexual activity, marriage, cohabitation, contraceptive use, pregnancy, infertility, men's roles in raising and supporting children
- ∅ Measures related to infant & child health:
 - | Birthweight, breast-feeding, prenatal care,
 - | teen pregnancy
 - | intendedness of births,
 - | HIV testing during pregnancy.

National Immunization Survey (NIS) and State and Local Area Integrated Telephone Survey (SLAITS)

∅ Telephone Surveys

- | Contacts over 1 million households annually

∅ Can estimate to state level and some local areas

∅ SLAITS is funded from sponsorship of specific modules

- | more than 6 different SLAITS surveys with child health relevance have been fielded
- | Content is sponsor driven

∅ NIS immunization questions are stable with occasional supplemental topics

National Immunization Survey


- ∅ NIS is a list-assisted random-digit-dialing national telephone survey followed by a mailed survey to children's immunization providers
 - ∅ In the past year, the NIS Provider Study Immunization History Questionnaire was sent to approximately 30,000 medical providers.
- ∅ Measures vaccination coverage among children 19-35 months and 13-17 years of age
- ∅ Release data annually

National Survey of Children's Health

- ∅ Fielded in 2003/2004 and 2007/2008
 - | Planned for 2011
- ∅ Telephone survey of parents of children 0-17 years of age
- ∅ Subgroups:
 - | N=91,642 completed child-level interviews
 - | Age, race, income, insurance, parental education, MSA status

Measures of NSCH

- ∅ Health status
 - | Child health status – E/VG/G/F/P
 - | Oral health status
 - | Prevalence of conditions
 - | Breastfeeding
 - | Problem social behaviors
 - | Missed school days

 - ∅ Health care
 - ∅ School and activities
 - ∅ The Child's Family
 - ∅ The Child and Family's Neighborhood
- 

National Survey of Children with Special Health Care Needs

- ∅ Fielded 2001, 2005/6, and 2009/10
- ∅ Children less than 18 years of age with special health care needs as identified using the Children with Special Health Care Needs Screener
 - | 13.9% prevalence
- ∅ Screener covers 5 concepts
 - | Limitation of activities
 - | Need for or use of prescription medication
 - | Need for or use of specialized therapies
 - | Above routine need or use of medical, mental health, or education services
 - | Need for or receipt of treatment or counseling for an emotional, behavioral, or developmental problem
- ∅ N=40,840 completed special needs interviews in the main sample; 6,113 completed interviews with children in the referent sample (to compare to those without special health care needs).

National Survey of Children with Special Health Care Needs topic areas

- ∅ Health and Functional Status
- ∅ Access to Care
 - | Utilization
 - | Unmet Need
- ∅ Care Coordination
- ∅ Family Centered Care, Transition Issues, and Ease of Service Use
- ∅ Health Insurance
- ∅ Adequacy of Health Care Coverage
- ∅ Impact on the Family
- ∅ Family Composition
- ∅ Income and Other Demographics

National Health Care Surveys

∅ National Hospital Discharge Survey (NHDS)

- | National sample of discharges from hospitals
- | NHDS (N=69,000 of which 40,000 are newborns in 2006, should be about ½ of this for 2008)
- | Diagnoses, procedures, age, sex, length of stay, expected source of payment

∅ National Ambulatory Medical Care Survey (NAMCS)

- | National sample of visits to private physicians' offices
- | N=6,084 < 18/yr
- | Age, sex, race, diagnoses, procedures ordered, drugs prescribed and being taken by patient, height, weight, expected source of payment
- | Provider characteristics


National Health Care Surveys

- ∅ National Hospital Ambulatory Medical Care Surveys (NHAMCS)
 - | National sample of visits to hospital outpatient departments
 - N = 7112 <18 yr
 - | National sample of visits to emergency departments
 - N= 7929<18 yr

- ∅ National Survey of Ambulatory Surgery (NSAS)
 - | National sample of ambulatory surgeries
 - | NSAS to be folded into this NHAMCS

- ∅ Annual public release of data
- ∅ National Health Statistics Reports

Data Gaps

- ∅ Visit level data, not patient level
 - | Estimation of patients from # of visits in last year
 - ∅ Dental care/orthodontia
 - ∅ Mid-level practitioners (NP/PA) in private offices
 - ∅ Psychologists
- 

Youth Risk Behavior Surveillance System

- ∅ Not NCHS, but CDC
- ∅ Only survey with the child as respondent
- ∅ National Survey (N=14,000) and separate state/local surveys
- ∅ School-based survey of 9th -12th graders
- ∅ Public release every 2 years
- ∅ Measures
 - | Behaviors contributing to unintentional injuries and violence
 - | tobacco, alcohol and other drug use
 - | sexual behaviors
 - | unhealthy dietary behaviors and physical inactivity
 - | Obesity

Framework for Measures of Child Health and Health Care

From Children's Health the Nation's Wealth (IOM, 2004)

- ∅ Children's Health Conditions
- ∅ Measures of Child Health Status, Functioning, and Health Potential
- ∅ Measures of Family and Community Influences on Health
- ∅ Health System Influences on Health
 - | Quality of care of health system

Children's Health Conditions, cont.

∅ Diagnoses

| Measured and Patient Report—

- National Health and Nutrition Examination Survey (NHANES)

| Parent Report--

- National Health Interview Survey (NHIS)
- National Survey of Child Health (NSCH)
- National Survey of Children with Special Health Care Needs (NSCSHC)

| Physician View--

- National Ambulatory Medical Care Survey (NAMCS)
- National Hospital Ambulatory Medical Care Survey (NHAMCS)
- National Hospital Discharge Survey (NHDS)

Data Gaps

- ∅ Population based data are largely participant report
 - | “Has a doctor ever told you that you have....”
 - | Estimates cannot be made for diseases that are not asked about
- ∅ Establishment survey data measures visits, not people
 - | Estimates cannot easily be made for less common diseases.

Data Gaps, cont.

- ∅ Diagnosis reporting is access dependent
 - ∅ Developmental assessments
 - ∅ Mental health
 - ∅ Oral health
 - ∅ Food allergies
- 

Measures of Child Health Status, Functioning, and Health Potential

- Ø In general, how would you describe the child's health? Would you say [his/her] health is excellent, very good, good, fair, or poor? (NSCH, NHIS, NHANES)
- Ø Functional disability in children (NHIS—Patricia Pastor)
- Ø Positive well-being (NSCH—Kris Moore, Child Trends)
- Ø Children with Special Health Care Needs Screener (NSCH, NSCSHCN)—Proxy of disability
- Ø Health related quality of life (NSCH—Simon)

Data Gaps

- ∅ No universally accepted summary measures of health and well-being included in the surveys (HRQoL, disability, etc..)
- ∅ Lack of other non-health well-being indicators for children in our surveys prevents examination of how they interact with health well-being
- ∅ School Readiness
 - | broadly defined domains
 - Physical well-being and motor development
 - Social and emotional development
 - Approaches to learning
 - Language development
 - Cognition and general knowledge

Measures of Family and Community Influences on Health

- ∅ Measures of community exist on NSCH: Social cohesion, safety, perceptions of neighborhood
 - | Do sidewalks or walking paths exist in your neighborhood
 - | "We watch out for each other's children in this neighborhood."
 - | How often do you feel [he/she] is safe at school?

- ∅ Measures of family exist on NSCH
 - | During the past week, how many days did you or other family members read to your child?
 - | During the past week, how many days did you or other family members tell stories or sing songs to your child?

Data Gaps

- ∅ Relating these to health is challenging because of lack of summary health measures
- ∅ Questions are about parents' perception of neighborhood/community quality
- ∅ Objective measures of neighborhoods are usually linked in from ZIP-Code level census data at best.
 - | No census block level information available.

Health System Influences on Health/Quality of Care of Health System

- ∅ Insurance (NSCH, NHIS, NHANES, NAMCS, NHAMCS, NHDS)
- ∅ Underinsurance
 - | Questions on NSCSHCN and NSCH about adequacy of insurance
 - Does the child's health insurance offer benefits or cover services that meet [his/her] needs?
 - Does the child's health insurance allow [him/her] to see the health care providers [he/she] needs?
 - Not including health insurance premiums or costs that are covered by insurance, do you pay any money for the child's health care?
 - How often are these costs reasonable?
- ∅ Medical home (NSCH, NSCSHCN)

Data Gaps

- | Portion of year that someone was insured/uninsured is unknown
- | Questions on adequacy of insurance may provide better information for some groups (parents of children with special health care needs)
- | No real information on what is covered. People don't know how good their insurance is until they try to use it.

Quality of Care

∅ NHDS –Pediatric Patient Safety Indicators

- | Larger sample available from the KID database from AHRQ
- | Although both have limited clinical data

∅ NAMCS/NHAMCS

- | Quality Indicators have been developed using these (Randall Stafford, et al.)
 - Inappropriate antibiotic use for URI
 - Corticosteroids for asthma
 - Appropriate antibiotic use for acute otitis media
 - Diet and exercise counseling
 - Routine blood pressure check at well-check
- | Most are not in children—more development could be done here

Data Gaps

- ∅ Lack of longitudinal data makes quality difficult to assess
 - | Unsure what was done at other visits for the same patient
- ∅ Even when only a single visit is needed, quality can be difficult to ascertain for many issues
 - | Contraindications to specific treatments (allergies to a specific antibiotic)
 - | Severity of condition can dictate appropriate treatment (asthma and inhaled corticosteroids)

Data Gaps that Apply to All of Measure Groups

∅ Longitudinal data

- | NCHS data are cross-sectional only

∅ Small area data

- | More actionable

∅ Race/ethnicity categorizations and estimation

- | Vital statistics does better than most surveys

Ongoing Changes

- ∅ National Hospital Discharge Survey being redesigned for 2010
 - | More clinical data
 - | Potential oversamples
 - | More outcomes
 - | Hospital level variables
- ∅ NAMCS/NHAMCS
 - | Beginning to collect lab values

Potential Improvements

- ∅ Oversample of children for NHIS or NHANES
 - | Would result in more estimable groups
- ∅ NAMCS/NHAMCS could:
 - | Explore other visits in chart of sampled visit
 - Longitudinal data
 - | Conduct more provider level data collection
- ∅ Developmental work for measures of child health to be used in national surveys