New Estimates of the Economic Benefits of Newborn Screening for Congenital Hypothyroidism in the US

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Why New Economic Estimates for CH?

- **Newborn screening saves lives *and* saves money**
  - Some screening tests save lives but not money
  - Other tests save money but not lives
  - A few tests may both save lives and save money
- **Congenital hypothyroidism is the most common NBS disorder**
  - Screening prevents cognitive impairment and disability
  - Cost savings from CH drive savings for NBS overall
- **Published cost savings estimates are outdated**
  - Based on old estimates of frequency of CH and disability
  - Don't take into account value of preventing mild cognitive impairment

Challenges in Estimation of Outcomes of NBS

- **Need for outcomes data for representative sample of children with disorder in absence of newborn screening**
  - Cannot compare with untreated cohort (natural history)
  - Spectrum bias –ascertainment of clinically apparent cases
  - Referral bias – academic medical centers more likely to see severely affected children
- **Sources of unbiased data on unscreened cohorts**
  - Population-based surveillance studies
    - Controls for referral bias but not spectrum bias
  - Retrospective screening of stored DBS with follow-up

Grosse SD. Assessing the clinical utility of newborn screening. In: *Human Genome Epidemiology, 2nd Ed.*, edited by MJ Khoury et al. New York: Oxford. 2009, 517–32.

Cognitive Outcomes in CH

- **Based on population surveillance studies**
  - 20–30% of those diagnosed with CH had IQ <70
  - Mean shift to the left of 20–25 IQ points
- **Retrospective screening study from Sweden**
  - 32 of 100,239 stored DBS specimens positive for CH (TSH > 20 mU/l whole blood) (1 in 3,100)
    - 15 had clinical CH (1 in 6,700)
    - 22 had permanent CH (1 in 4,600)
  - Among 7 children with subclinical CH, mean reduction in 7-8 points relative to euthyroid children

Grosse SD, Van Vliet G. Prevention of intellectual disability through screening for congenital hypothyroidism: how much and at what level? *Arch Dis Child*. 2011;96:374–9.

Alm J, Hagenfeldt L, Larsson A, et al. Incidence of congenital hypothyroidism: retrospective study of neonatal laboratory screening versus clinical symptoms as indicators leading to diagnosis. BMJ 1984;289:1171–75.

Projecting Long-term Cognitive Outcomes of CH

- **2000 infants diagnosed and treated for CH each year in US (1 in 2,000 births)**
  - 1,170 children with permanent CH by old TSH cutoff (1 in 4,600)
    - 630 children would have had clinical CH (1 in 6,700 births)
      - 160 (25%) would have had intellectual disability (IQ <70) – 8% of CH diagnoses
      - 470 other children would have had IQ lower by 22 points
    - 540 children would have mild, subclinical permanent CH
      - IQ lower by 8 points on average
  - 830 children would have had no predictable cognitive impairment in absence of treatment

Economic Benefit of Preventing Cases of Intellectual Disability

- **Lifetime direct and indirect cost of $1.3 M for each child born with intellectual disability (IQ <70)**
  - Based on RTI-CDC cost analysis (MMWR 2004)
  - Present value calculated with 3% discount rate
  - 80% represents indirect cost of lost productivity
  - Adjusted for inflation to 2010 dollars
- **Avoided cost of roughly $200 M from 160 avoided cases of intellectual disability**

CDCCDC. MMWR 2004; 53(3):57–59

Economic costs associated with mental retardation, cerebral palsy, hearing loss, and vision impairment — United States, 2003. MMWR 2004; 53(3):57–59

Economic Benefit of Preventing Loss of Cognitive Potential Due to CH

- From each year's birth cohort, 1,100 children with IQ scores in normal range are projected to avoid aggregate loss of 14,900 IQ points
- IQ predicts education, employment, and earnings
- Earnings used to approximate average productivity
- Economists have estimated the impact of IQ differentials on earnings
  - Each additional IQ point raises earnings by 1-2%
  - 1% increase in lifetime earnings is $13,000
- Value of 14,900 IQ points is roughly $200 M

Grosse SD. How much is an IQ point worth? Implications for regulatory impact analyses. AERE Newsletter. 2007; 27(2):17-21

Grosse, SD Krueger KV, Mvundura M. Economic productivity by age and sex: 2007 estimates for the United States. Med Care. 2009; 47:S94–S103

What is the Net Economic Benefit of Screening for CH in the US?

- **Cost of newborn blood spot screening in US estimated in 2003 to be $35 per infant in 2010 dollars, or $140 M for US**
- **Cost of laboratory testing for CH alone estimated in 2002 at about $5 in 2010 dollars or $20 M for US**
- **Economic benefits of CH screening about $400 M per year**
  - 20 times the cost of lab screening for CH
  - Greater than the total cost of NBS in US

United States General Accounting Office. Newborn Screening: Characteristics of State Programs. 2003.
PriceWaterhouseCoopers. Newborn Screening Programs: An Overview of Cost and Financing. 2002..

Limitations

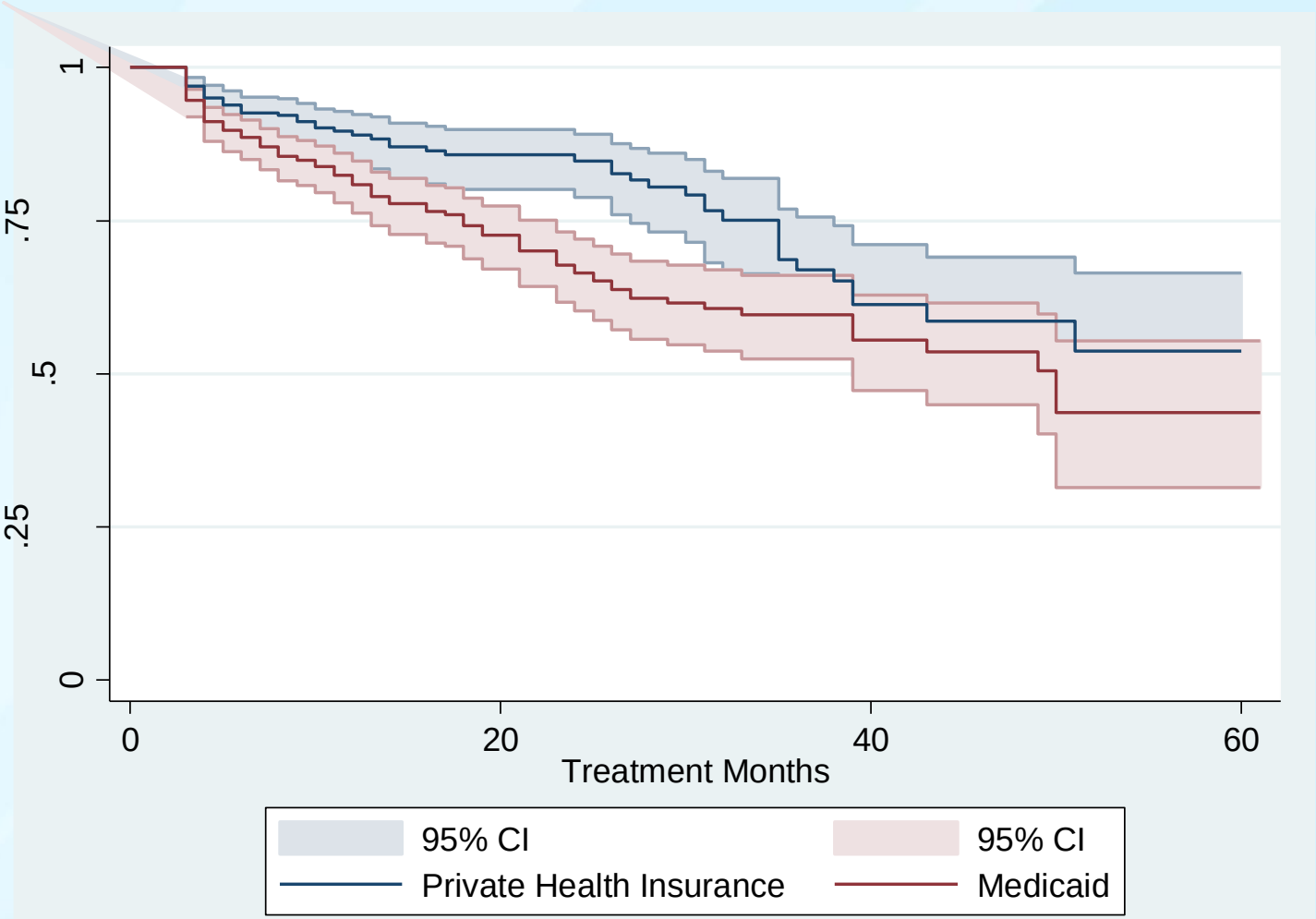
- **Wide range of estimates of economic value of IQ**
  - Conservative estimate used, lower than used by US EPA
- **Congenital hypothyroidism includes other, behavioral outcomes not included in economic evaluation**
  - Total economic benefit likely to be larger than reported
- **Societal economic benefit not the same as reduction in direct costs**
  - Most of the economic benefit from CH screening consists of avoided productivity losses
  - Reduction in special educational costs less than the cost of screening, hence not "cost-saving" in technical sense
  - Cannot be used for a budget impact analysis

Other Limitations

- **Economic benefit estimates all derive from identification of permanent CH cases using a relatively high TSH threshold**
- **No evidence of cognitive impairment among children with transient CH or permanent CH below threshold**
  - Absence of evidence not equal to evidence of absence
- **Unclear how many children in US diagnosed with CH actually have permanent CH**
  - Lack of systematic long-term follow-up for CH in US
  - Many children diagnosed with CH go off treatment without apparent ill effects (Kemper et al. 2010; Korzeniewski, unpublished)

Kemper, AR Ouyang L, Grosse SD. Discontinuation of thyroid hormone treatment for US children with congenital hypothyroidism: Findings from health insurance claims data. . BMC Pediatrics 2010; 10:9

Continuation of hormone treatment for children with CH by insurance type (Kemper et al. 2010)



CDC Public Health Grand Rounds
Newborn Screening: Improving Outcomes

Archive of August 19 Public Health Grand Rounds

http://www.cdc.gov/about/grand-rounds/archives/2011/august2011.htm

1-hour video

3 Mb file with presentation slides

5 presenters

- R. Rodney Howell
- Sharon Terry
- Carla Cuthbert
- Scott Grosse
- V. Fan Tait