



How openness and transparency can improve public health

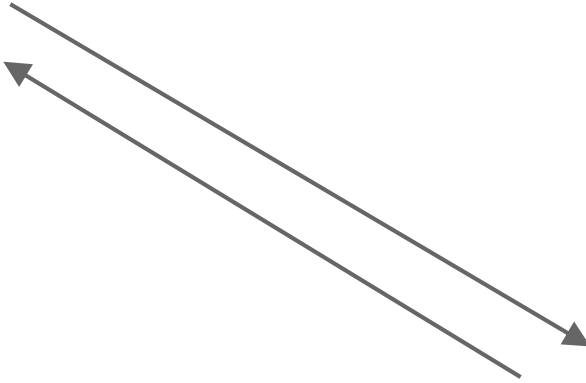
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Newborn screening saves lives and is required by law

- Within 48 hours of birth, nearly every baby born in the U.S. has blood taken for newborn screening test
- Blood samples are supposed to be sent quickly from hospitals to a public health lab where they are screened for rare, yet deadly genetic disorders
- 1 in 800 babies is born with a potentially severe or deadly disorder that can be treated if caught early
- Treatment is often simple and very effective, preventing brain damage, physical disability and death

But how do we know if it's working?

Data



Transparency

Data tells what actually happened, leads to results

- Analyzed 3 million newborn screening tests from 31 states
- Found thousands of hospitals sent babies' blood samples late to state labs
- Hospitals ignore state regulations about how they must send samples
 - In NY, 60% of samples arrived within 48 hour period required by law
 - Only two states -- Iowa and Delaware -- met the federally recommended turnaround time for 99% of blood samples
- **Results!** Major changes made in hospitals and health departments throughout country

“Hey Ellen, was it easy to get the data?”

- Requested data from 50 states and District of Columbia
 - Had to negotiate, re-file requests with every state
 - Hundreds of phone calls, emails & conversations with state officials
- *Common challenges I faced*
 - Requests, phone calls, emails ignored
 - Incorrectly cited HIPAA or state law
 - Officials had little understanding of data & their data system
 - Request incorrectly denied by newborn screening personnel
 - Officials concerned about upsetting hospitals

Here's how *you* can help

- Adopt an attitude of transparency
 - Builds trust with reporters
 - It's the right thing to do
- Get up to speed with technology
 - \$\$ is issue, but at least help staff become reasonably proficient with spreadsheets
- Be sure denials under HIPAA or state law are true concerns for privacy, not a dept. seeking to protect itself

- Make experts available to journalists
 - A press contact should facilitate conversation, not engage in a game of “Telephone”
 - Cooperation and transparency will lead to more reasonable requests from journalists
- Consider publishing more data online

"Critics are our friends, they show us our faults."

-Ben Franklin

and

Will Humble, Director of Arizona Department of Health Services

Rapid changes in Arizona

- Previously among the *worst* performers in the country, Arizona is now one of the best
- Improved state's performance by more than 30 percentage points
- In July, 99% of blood samples got to the state lab in 3 days; 100% within 4 days



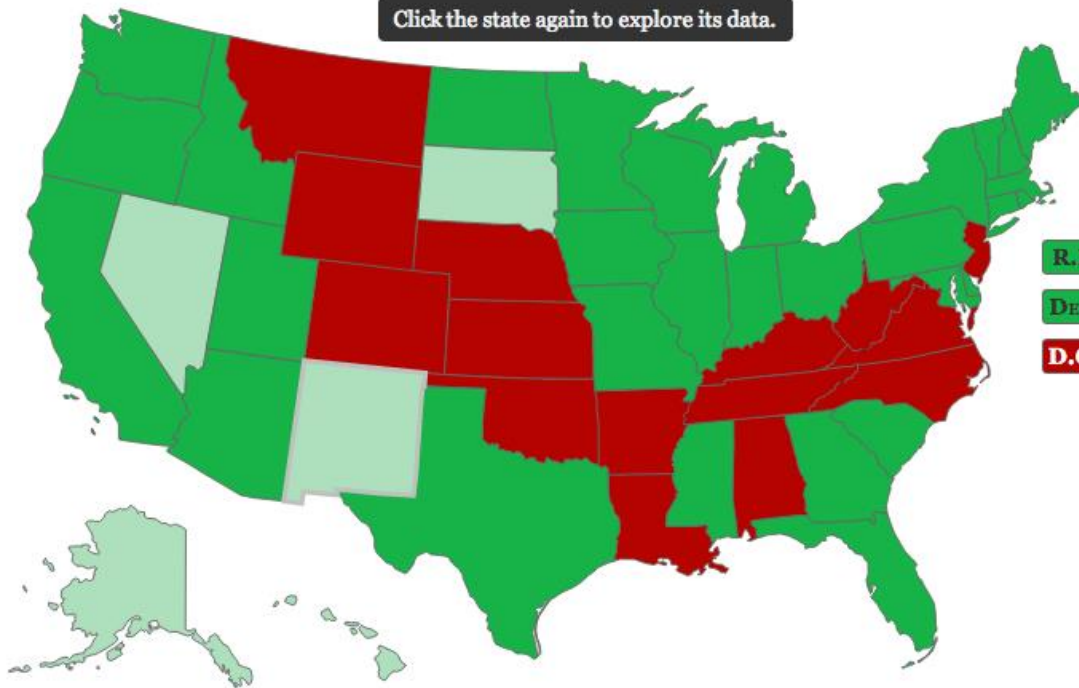


View: *Type of information released* / *Delivery guidelines* / *When labs are open*

REPORTERS SOUGHT DATA ABOUT HOW QUICKLY BLOOD SAMPLES ARRIVED AT LABS. NEW STATES ADDED DEC. 31, 2013

■ Hospital-specific information released
 ■ Statewide totals released
 ■ No information released

Click the state again to explore its data.



R.I.
DEL.
D.C.

NEW MEXICO ×

New Mexico contracts with the Oregon State Public Health Laboratory to test samples.

BROWSE RECORDS
STATEWIDE DATA ONLY

- Hospitals should send samples via courier or express mail
- Testing lab is open Monday-Friday
- Hospitals must send samples within 24 hours

Alabama
Arkansas
Colorado
District of Columbia
Kansas
Kentucky
Louisiana
Montana
Nebraska
New Jersey

North Carolina
Oklahoma
Tennessee
West Virginia
Wyoming

Statewide only

Nevada
New Mexico
South Dakota

Your work matters

Colton Hidde, Wisconsin



Garrett Saine, North Carolina



Aiden Cooper, Arkansas



Thank you!

Let me know what else we should be writing about.

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