

NewSTEPs Data Repository: A Resource for the Newborn Screening Community

www.newsteps.org

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APHL is collaborating with the Colorado School of Public Health to implement NewSTEPs.



NewSTEPs

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Voluntary Data Repository

NewSTEPS Data Repository

The innovative [Data Repository](#)® will serve as a central link for access to newborn screening information, data, and resources across the country.

Purpose: Provide tools to state newborn screening systems to adequately evaluate, analyze, and benchmark the performance of their tests and the quality of their newborn screening programs



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How Can I Access It?



NBS Laboratory, Follow-Up, and Medical Personnel ▾ Parents and Caregivers Policy Makers and Administrators

NewSTEPS Data Repository

The innovative Data Repository serves as a central link for access to newborn screening information, data, and resources across the country.

About NewSTEPS

The Newborn Screening Technical assistance and Evaluation Program (NewSTEPS), funded through a cooperative agreement to the Association of Public Health Laboratories (APHL) by the Genetic Services Branch of the Health Resources and Services Administration (HRSA), provides quality improvement initiatives, an innovative data repository and technical resources for newborn screening programs.



STATE PROFILES

Check out map explorer for your state's data

Explore profiles



DATA REPOSITORY

Access data and more with NewSTEPS Data Repository

Visit Data Repository



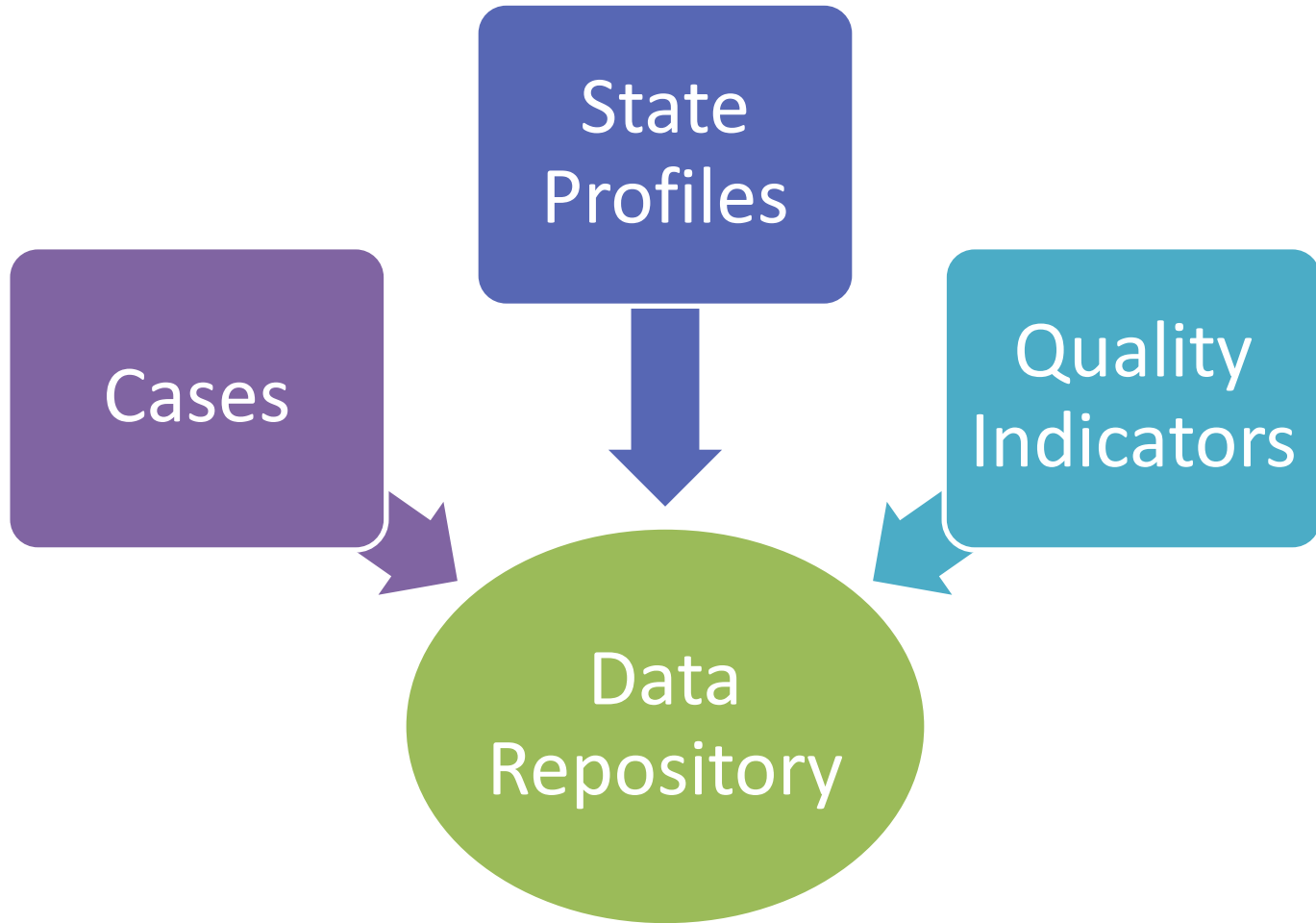
TECHNICAL ASSISTANCE

Evaluation Site Visits, Model Practices, and more.

Learn more



Components of Data Repository

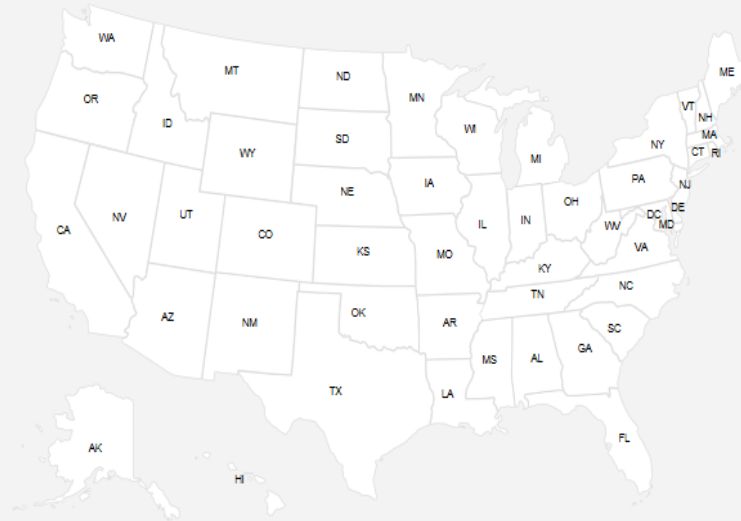


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Select a state or click [here](#) to view aggregate reports.



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- RI
- MD
- NH
- CT
- DC
- MA
- NJ
- DE
- PR
- GU

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California State Profile

<< Back to Map

Demographics

Disorders

Policies

Adding to NBS Panel

Fees

Program Structure

Contacts

Advisory Committee

IT Support

Year: [?]

2012

Name of State NBS

Program: [?]

California Newborn Screening
Program/Genetic Disease
Screening Program

Region: [?]

Western States Genetic Services
Collaborative (WSGSC)

Website:

<http://www.cdph.ca.gov/programs/NBS/Pages/default.aspx>

Annual Births: [?]

510,000



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Reports



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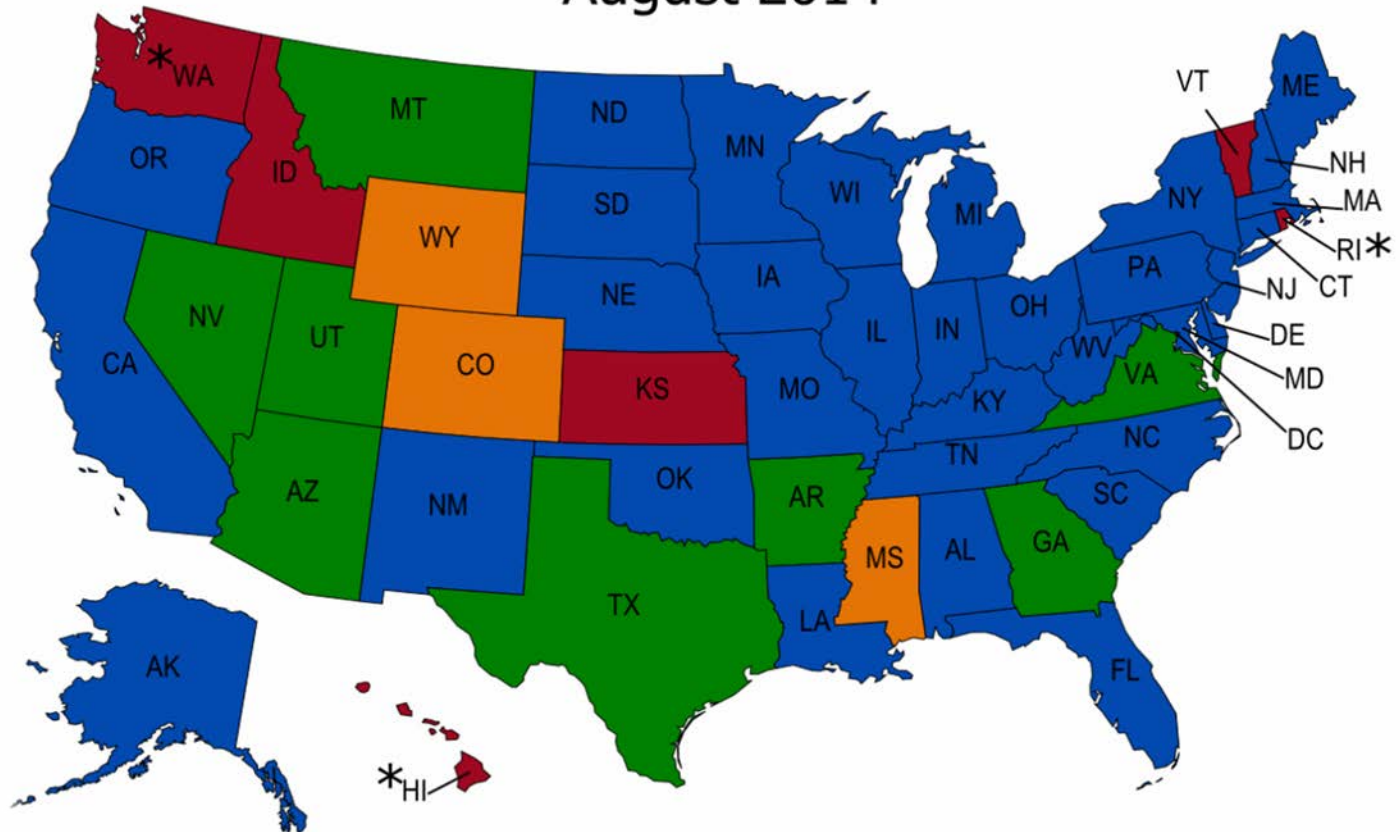
Range of Initial Newborn Screening Fees in the United States



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CCHD Screening Status August 2014



Screening Status

- Universally required by law or rule and fully implemented
- Required by law or rule but not yet fully implemented
- Being considered via legislation/statute/rule change but not yet approved
- Supported as standard of care without a law

*Universally offered

Interactive Reports and Queries



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Screened Conditions Report

Core

Secondary

Other

Condition	Universally Required	Universally Offered	Offered Select	Considered	Req Not Implemented	Likely Detected	Pilot Tested
Other Disorders							
Biotinidase deficiency - BIOT	51						
Critical congenital heart disease - CCHD	27	5	5	4	9		
Cystic fibrosis - CF	50				1		
Classic galactosemia - GALT	51						
Hearing loss - HEAR	38	9	4				
Severe Combined Immunodeficiencies - SCID	21	1	6	4	2		

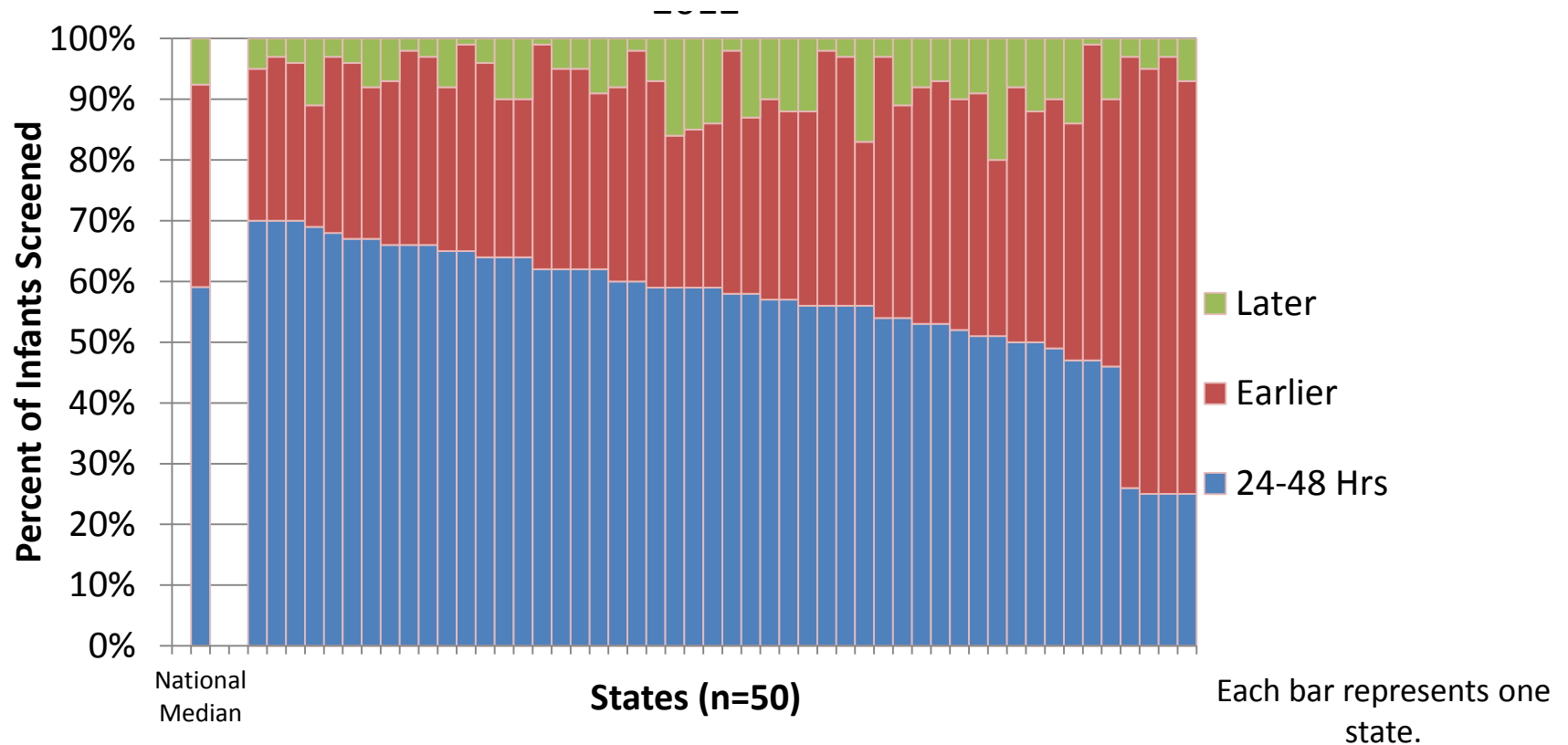


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Sample Report Graphic: Quality Indicators

Percent of infants receiving screening in specified time intervals



All data portrayed in this sample report are fictitious. Data do not represent actual outcomes from any newborn screening program. Any resemblance to real data from a real newborn screening program is completely coincidental.



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Making Data Entry Easier

Current

- Manual Data Entry

IN PROGRESS

- Pilot with NBS Programs
- Working with LIMS vendors*

Future

- Electronic Data Transfer
- Reports from state LIMS

*PerkinElmer, Natus/Neometrics, StarLIMS, OZ Systems



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You Have Control!



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Technical Assistance: HIT

Webinars | Work Group | Implementing Data Standards

- Workgroup goals:
 - Serve as a resource for NBS programs as they navigate through HIT
- Webinars ongoing every other month
- Support the integration of health information technology frameworks, including HL7 messaging
- Support technical assistance for NBS program in development of data standards



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Conclusion

- Reports, access to aggregate and individual information
- Inform quality improvement activities
- Continuous quality improvement



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Newborn Screening
50 Years of Saving Babies' Lives

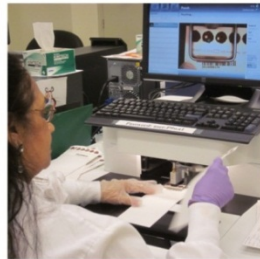


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