



Survey on Electronic Data Collection and Newborn Screening System Information Needs Assessment

National Coordinating Center for the Regional Genetic and Newborn Screening Service Collaboratives



May 13, 2010

Advisory Committee on Heritable Disorders in Newborns and Children

Developed by: CORN Newborn Screening Committee (and subsequently by NNSGRC NBS Advisory Committee)

- **Listing of program contacts (laboratory and follow-up)**
- **A summary listing of conditions for which newborns are/were screened in each state.**
- **A summary of laboratories providing screening services within a jurisdiction (no. and type).**
- **A summary of newborn's age at time of screening (i.e. number screened at 0-12 hrs, 13-24 hrs, 2 days, 3 days, 4 days, 5 days, 6 days, 7 days, over 7 days).**
- **Summary of program fees, collection mechanism and program elements covered by fee.**

- **Number of newborns receiving a subsequent screen because of: (1) a statutory requirement; (2) resolution of initial screening results.**
- **Number of newborns reported with a "not normal" (out-of-range) screening result for each condition.**
- **Number of out-of-range reports confirmed with a diagnosis for each condition screened – subdivided by: (1) diagnosis (classical form or a condition-variant);(2) race/ethnicity; (3) sex; (4) time from birth until treatment was initiated**
- **Number of "not normal" reports for which the patient could not be located (i.e. 'lost to follow-up').**

- **Definition for each condition reported as diagnosed in (level of biochemical markers defining condition).**
- **Laboratory methodology used for each condition including the screening levels used to define the need for: (1) immediate clinical follow-up (serum confirmation) (2) repeat DBS screening.**
- **Total number of specimens received (initial and subsequent) and number of births.**
- **Percentage of specimens considered unacceptable for analysis.**
- **Number of newborns receiving an initial screening NBS test.**



◆ Goal

- Plan for the future expansion of the National Newborn Screening Information System (NNSIS)

◆ Design

- Drafted and reviewed by team from HRSA, NICHD, NNSGRC, Genetic Alliance, CDC, APHL, ACMG-NCC & NBSTRN-CC, and selected state newborn screening programs (NBS)

◆ Participants

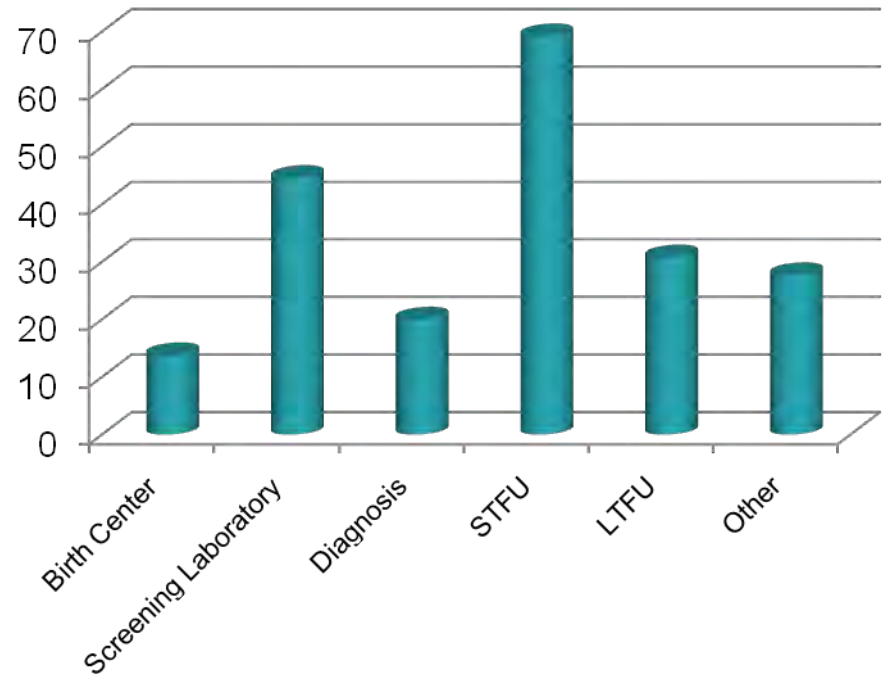
- Current users of NNIS
- Two from each state and territory
 - Laboratory
 - Short-Term Follow-Up (STFU)

◆ Timing

- Administered April 2010 to May 2010
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- ◆ **Survey emailed to 87 individuals**
- ◆ **Each state represented**
- ◆ **Responses from 64 individuals (74%)**
- ◆ **50% provided contact information**
- ◆ **Majority of respondents work in either screening laboratory or short-term follow-up**





Communication of Screening Results

◆ Response Rate – 98%

Answer Options	Response Percent
PCP	79.4%
Birth Facility	66.7%
Ordering Physician	66.7%
NNSIS	57.1%
Other Database (Stork, etc)	52.4%
STFU	33.3.%
Parent (Urgent Results)	20.6%
Parents (Urgent Results for Selected Conditions)	17.5%
Parents (All Results including Normal)	7.9%



Tools Used to Communicate Screening Results

◆ Response Rate – 92%

Answer Options	Response Percent
FAX to submitter or primary care provider	83.1%
Phone to submitter or primary care provider	72.9%
Regular mail to submitter	61.0%
Phone to specialty care consultant	57.6%
Regular mail to primary care provider if different from submitter	52.5%
Phone to follow-up coordinator	28.8%
Phone to parent	27.1%
Regular mail to parent	25.4%
FAX to follow-up external contractor	22.0%



Communication of Confirmatory Diagnosis

◆ Response Rate – 59%

Answer Options	Response Percent
NNSIS	80.5%
Pediatrician/Primary Doctor	48.8%
Specialist/Subspecialist	41.5%
Other database	36.6%
Local case registry	22.0%
State birth defects registry	19.5%
Parents	14.6%
Other	14.0%
Birth hospital	9.8%



Tools Used to Communicate Confirmatory Diagnosis

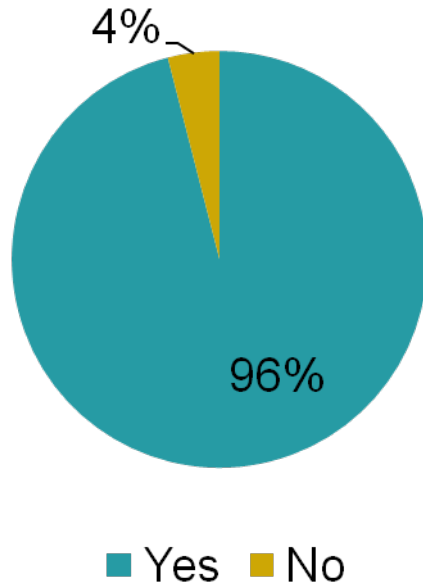
◆ Response Rate – 59%

Answer Options	Response Percent
Phone	57.9%
FAX	52.6%
Email	50.0%
Electronic download (internet bulletin board and/or transfer)	34.2%
Regular mail	31.6%
Other	23.60%
Certified mail	2.6%
Courier	2.6%



NNSIS Data Entry & Frequency

◆ Response Rate – 76%



Answer Options	Response Percent
Monthly < 10 hours	30.8%
Annually < 10 hours	20.5%
Monthly < 1 hour	17.9%
Do Not Enter Data	17.9%
Annually > 10 hours	10.3%
Monthly < 20 hours	2.6%



NNSIS Data Entry Cost Estimate

- ◆ **Estimate \$72K annual cost**
- ◆ **Range \$0 to \$3600**

Percent	Monthly	Annual
10%	\$0	\$0
10%	\$60	\$720
50%	\$30	\$360
30%	\$300	\$3600



NNSIS Website Use

◆ Response Rate – 53%

Answer Options	Response Percent
Monthly	50.0%
When requested	25.0%
Quarterly	21.9%
Yearly	12.5%
Daily	9.4%
Never	6.3%



NNSIS Information Type Utilized

◆ Response Rate – 81%

Answer Options	Response Percent
Number of diagnosed cases	84.6%
Amount of NBS fee	71.2%
Laboratory method in use	55.8%
Number of births	53.8%
Number of tests reported on initial screens	50.0%
Number of unsatisfactory specimens	50.0%
Time from birth to treatment/diagnosis (depending on condition)	48.1%
Number of not normal results on initial screens	48.1%
Number of tests reported on subsequent screens	34.6%
Number of not normal results on subsequent screens	30.8%
Race/ethnicity of diagnosed cases	26.9%
Other (please specify)	21.2%
Sex of diagnosed cases	19.2%

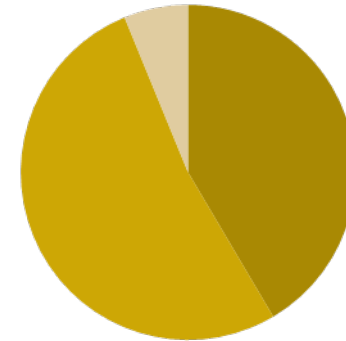


NNSIS Information Uses for Programs

◆ Response Rate – 100%

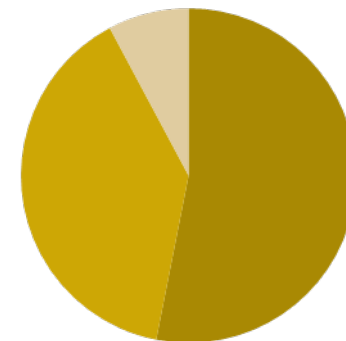
Answer Options	Response Percent
Program evaluation and/or development	53.7%
Daily, weekly, monthly or yearly reports.	42.6%
Other (please specify)	29.6%
Quality assurance.	27.8%

Internal



■ Yes ■ No ■ Unsure

External

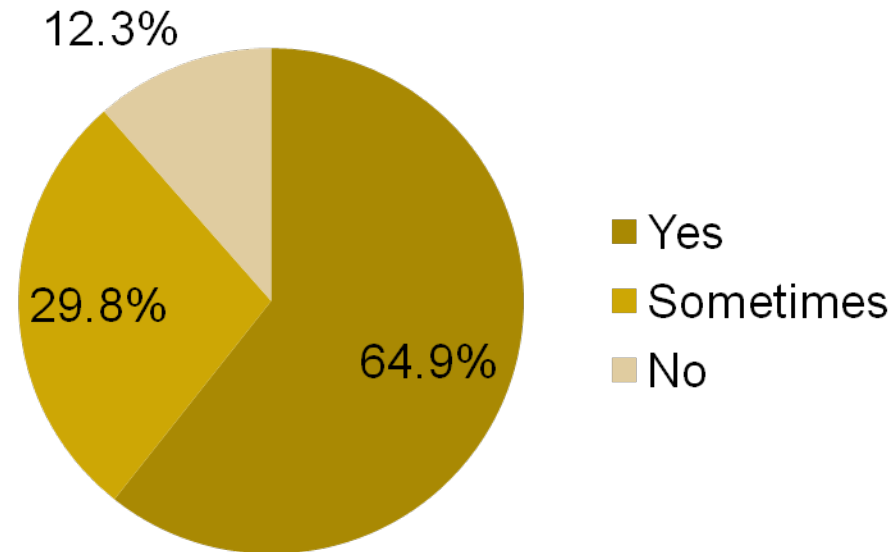


■ Yes ■ No ■ Unsure



◆ Response Rate – 100%

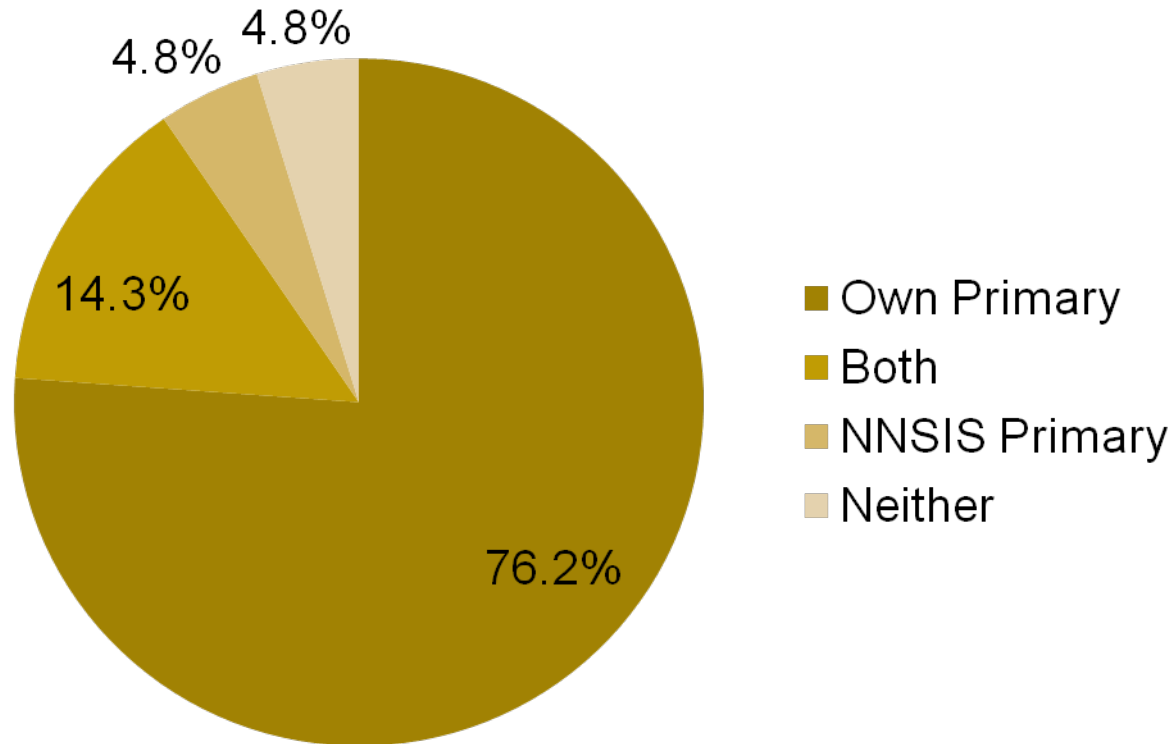
Useful





Program Database Types and Usage

◆ Response Rate – 98%





◆ Response Rate – 42%

Answers Provided

Include Maternal Data

Ability to Edit Individual Case

Expanded Analytics

Expanded Diagnostic Categories

Improved Classification of Disorders

Incorporate National Standards

◆ Response Rate – 50%

Answers Provided

LTFU

Link NBS & Vital

Real Time Linkage

Automatic Downloads

HL7 Data Exchange

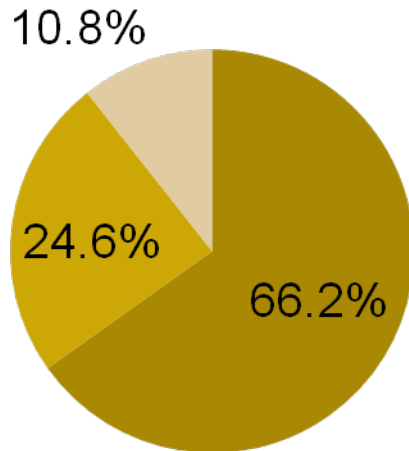
Electronic Communication with Providers



NNSIS Case Definition

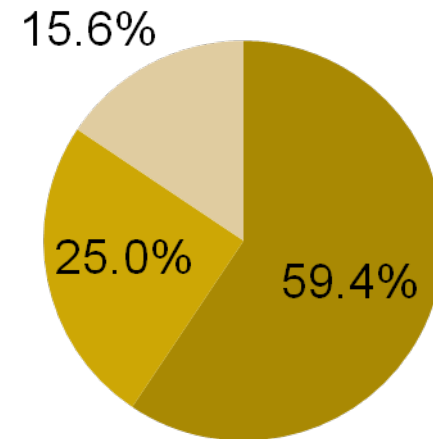
◆ Response Rate – 100%

Clinically Diagnosed



■ Yes ■ No ■ I don't know

TP Definition

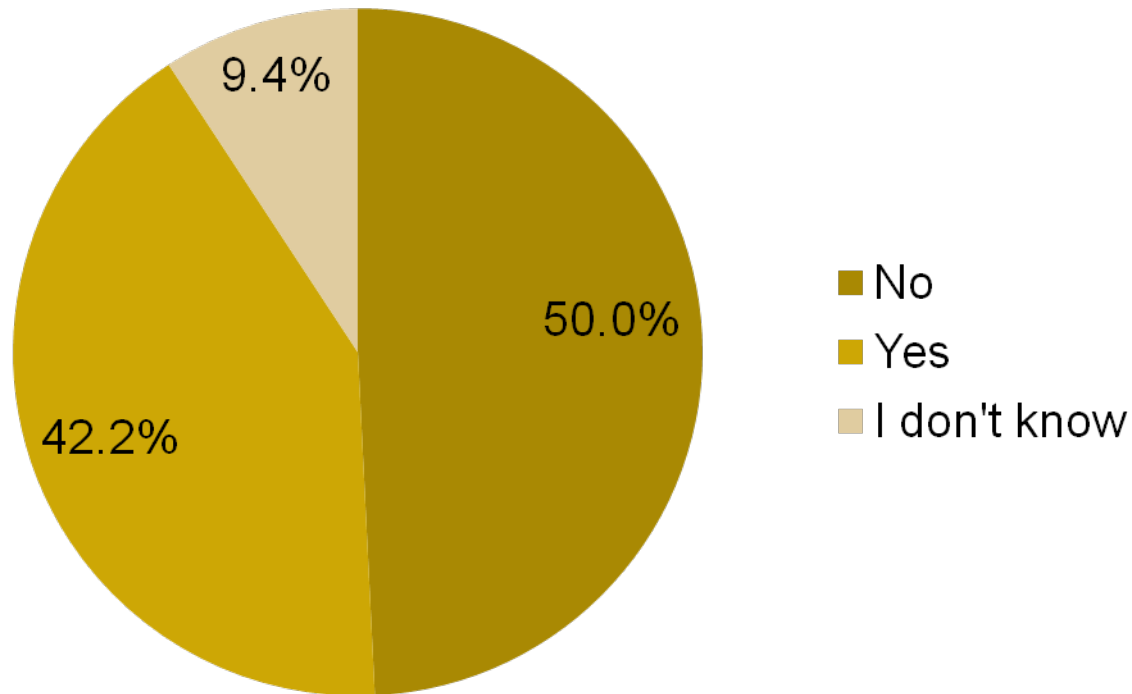


■ Yes ■ No ■ I don't know



Demographic Information Confirmation

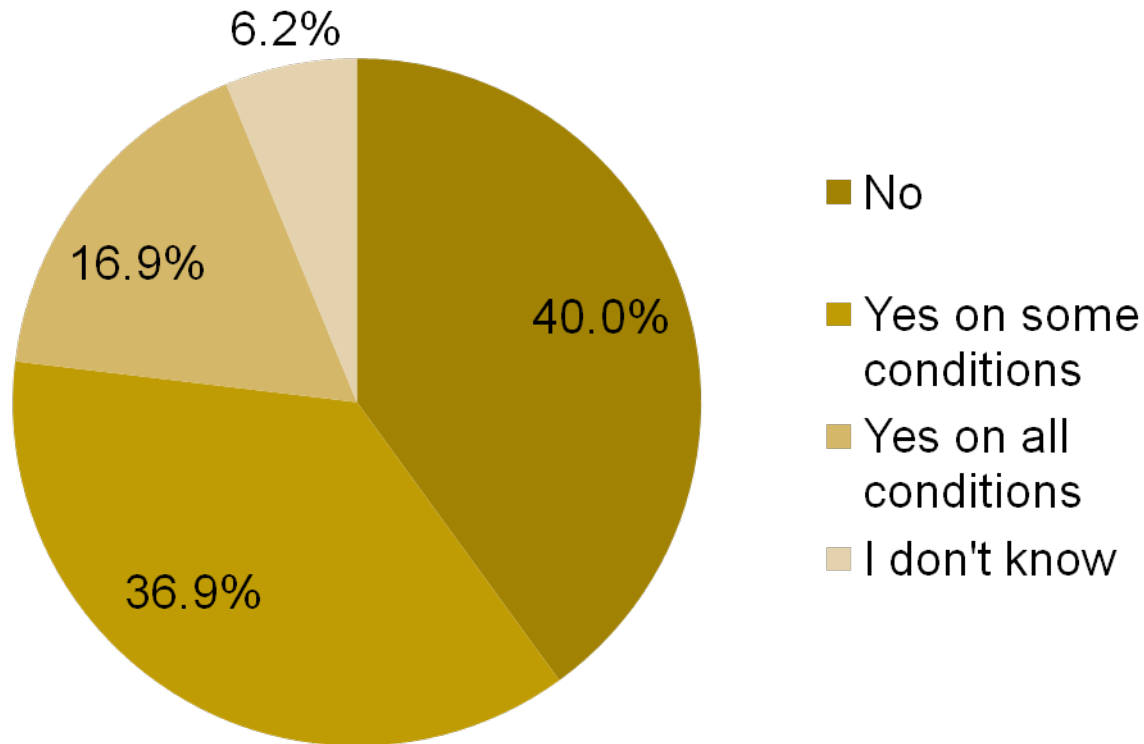
◆ Response Rate – 100%





Long-Term Follow-Up

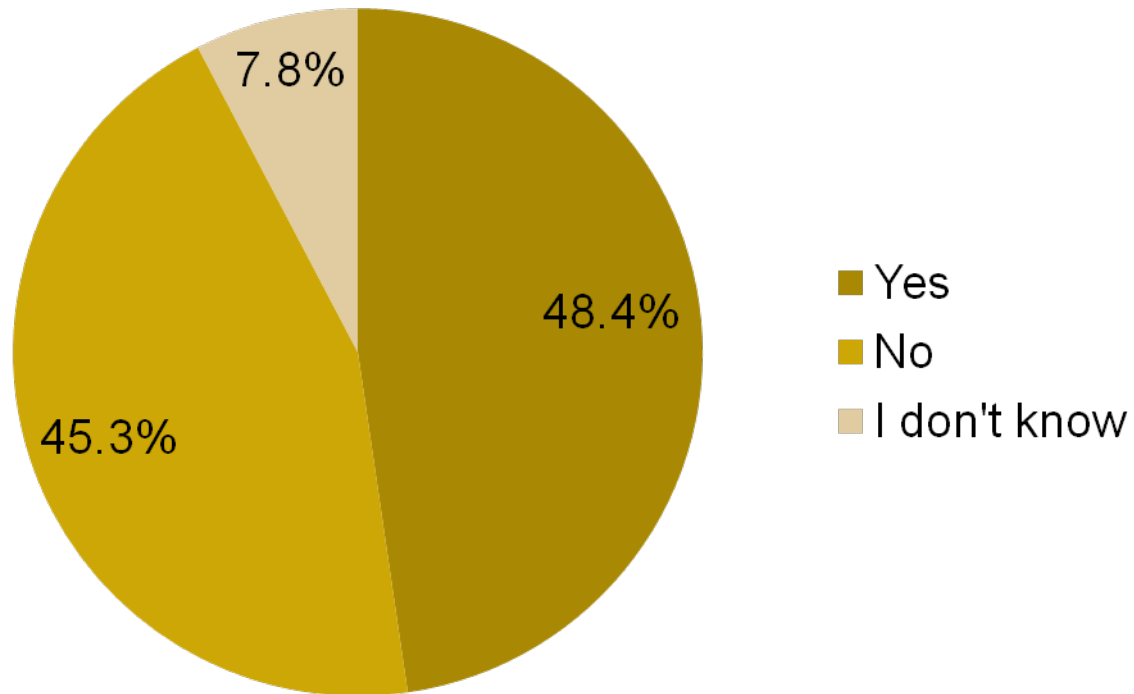
◆ Response Rate – 100%





Screening Confirmation

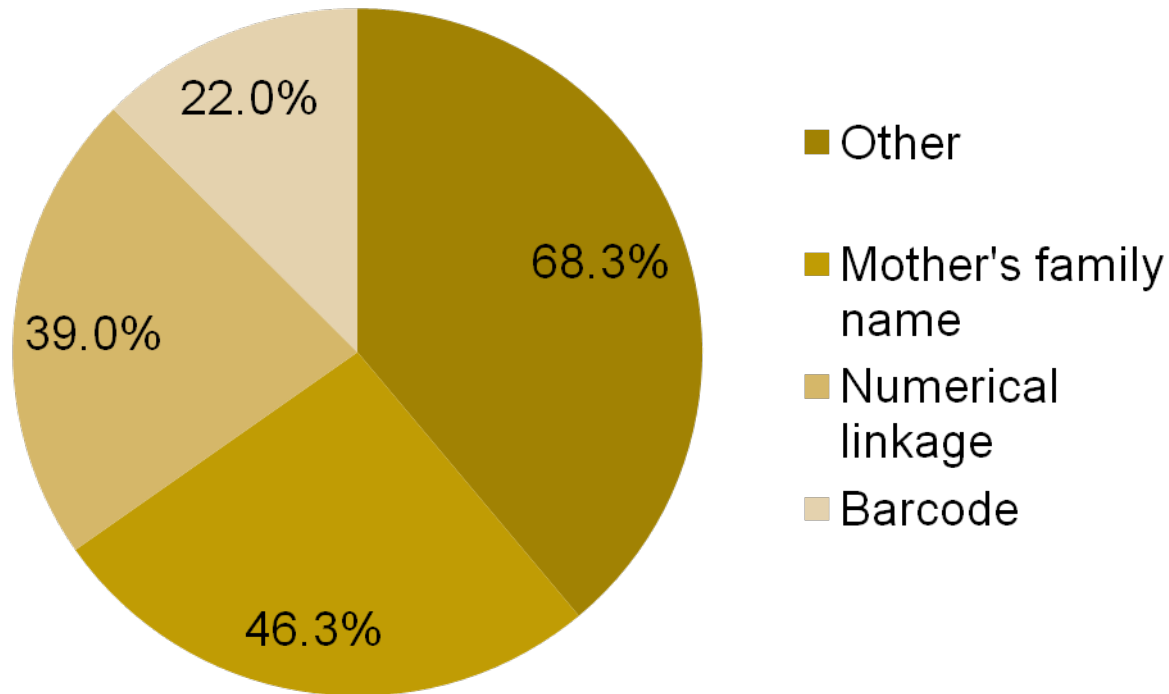
◆ Response Rate – 100%





Second Screen Linkage

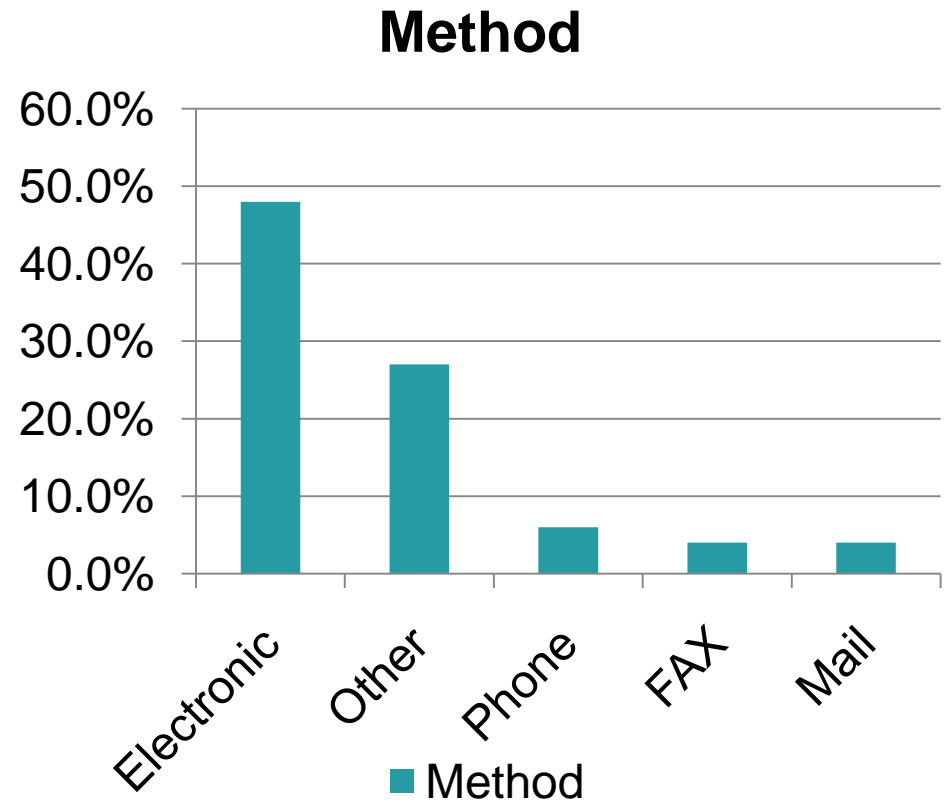
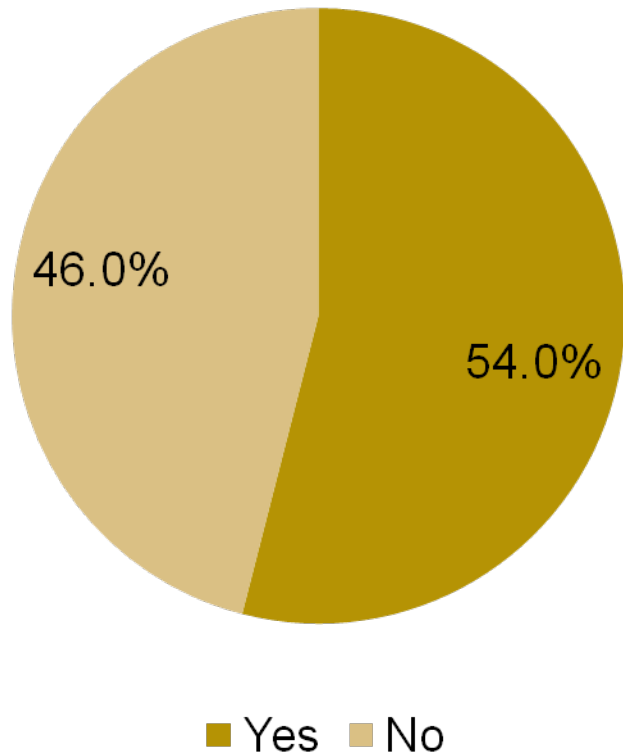
◆ Response Rate – 60%





NBS and NBH Data Exchange

◆ Response Rate – 78%





Barriers to Information Technology Expansion & Type of Support Needed

◆ Response Rate – 78%

Answers Provided

Compliance

Funding

Staffing

Lack of Buy In

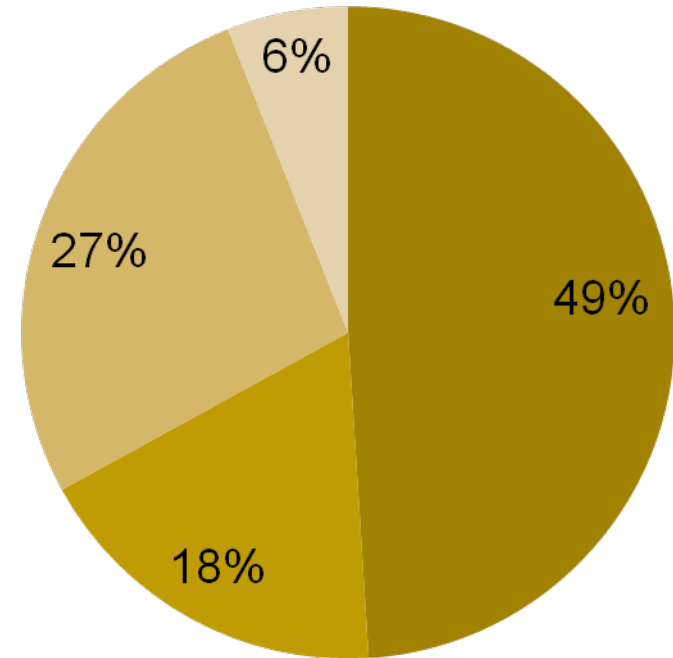
Confidentiality Concerns

Lack of Expertise

Not a Priority

Lack Legal Authority

Political Issues

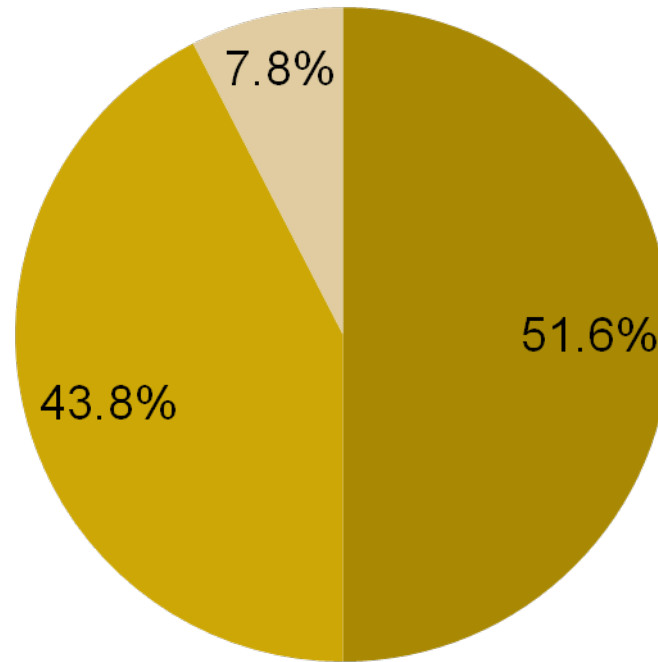


- Funding
- Staffing
- Both Funding & Staffing
- Access



Concerns About Information Sharing

◆ Response Rate – 100%

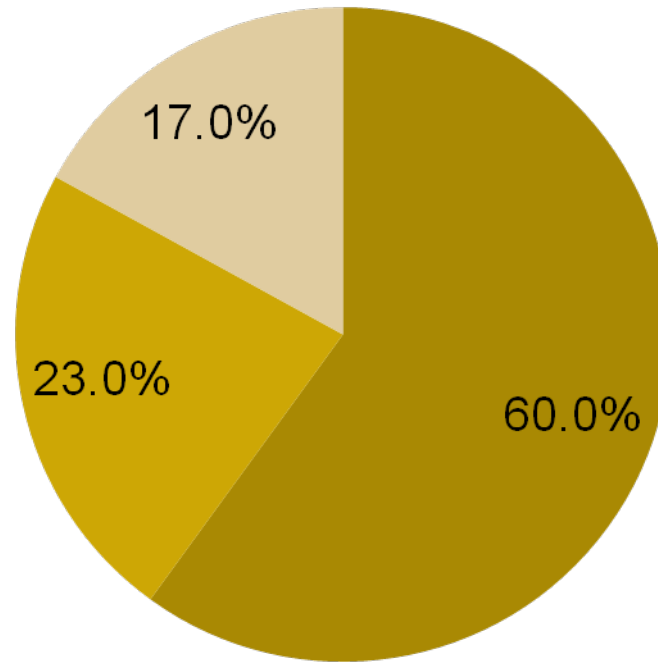


■ Yes ■ No ■ Unsure



Expanded Information Concerns

◆ Response Rate – 100%



■ Yes ■ No ■ Unsure



- ◆ **Discussion**
 - **Survey Feedback**
 - **Results Feedback**
 - **Use of Survey Results**
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Acknowledgements

- ◆ **HRSA**
 - ◆ **NICHD**
 - ◆ **CDC**
 - ◆ **Regional Collaboratives**
 - ◆ **Genetic Alliance**
 - ◆ **APHL**
 - ◆ **NNSGRC**
 - ◆ **State NBS Programs**
 - ◆ **ACMG/NCC**
 - ◆ **ACMG/NBSTRN-CC**
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