

Recent and prospective mothers' attitudes and preferences regarding newborn genetic screening: a survey of 2,266 U.S. women

**Secretary's Advisory Committee on Heritable Disorders
in Newborns and Children
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Goals of Newborn Screening Survey

- Measure knowledge & understanding in the general public
- Assess support
- Assess information needs
- Test whether severity of disease, age of onset, and positive predictive value influence support



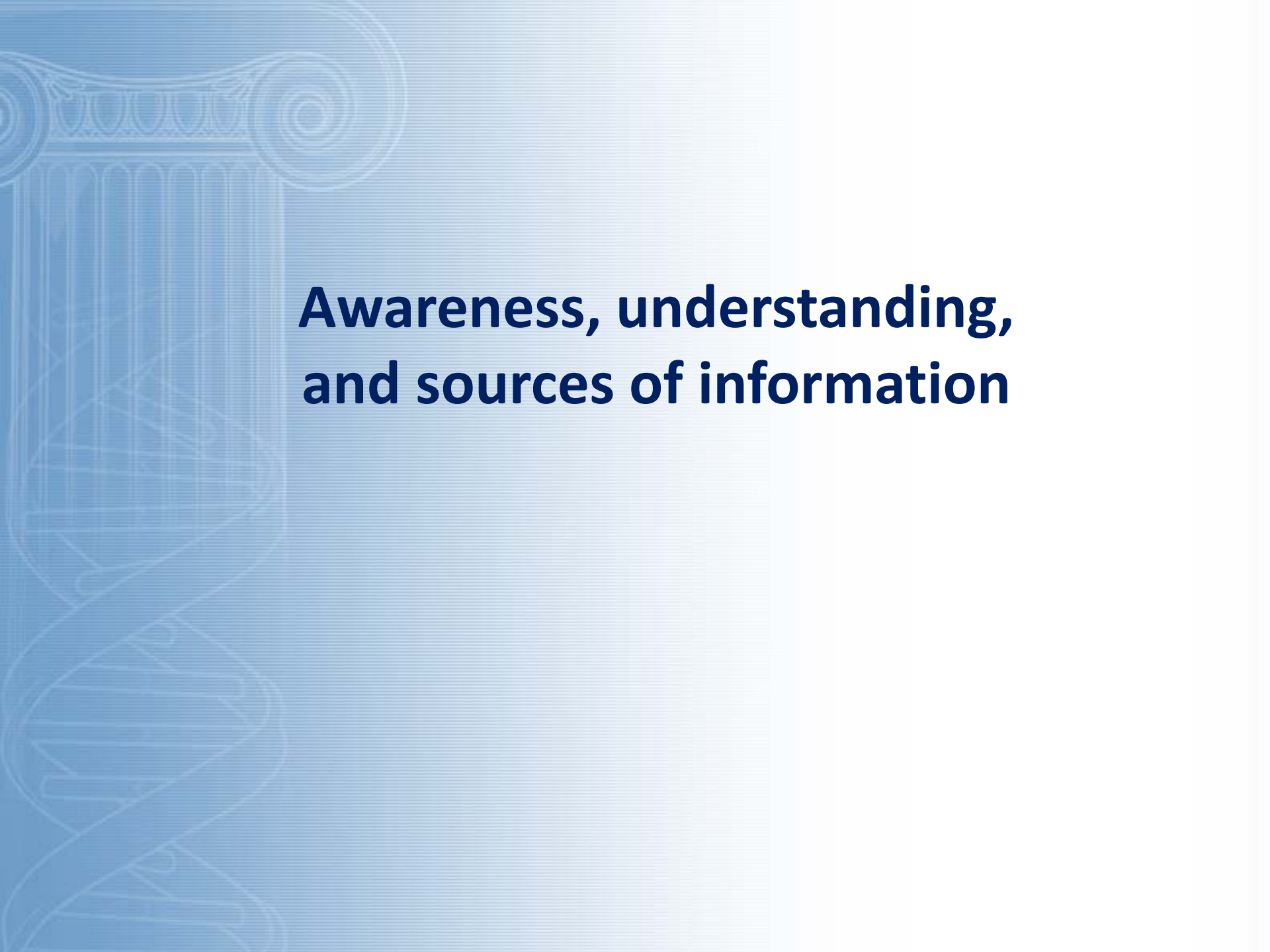
Survey Methods

- Conducted online (11 minutes)
- National, random sample (N=2,266)
- Women age 18-45
 - who gave birth in the past 3 years (N=1,258)
 - who plan to have biological child in the next 3 years (N=1,008)
- 46 questions asked of both groups
- Recent mothers asked 10 questions about experience
- Randomized to view one of four testing scenarios



Survey Demographics

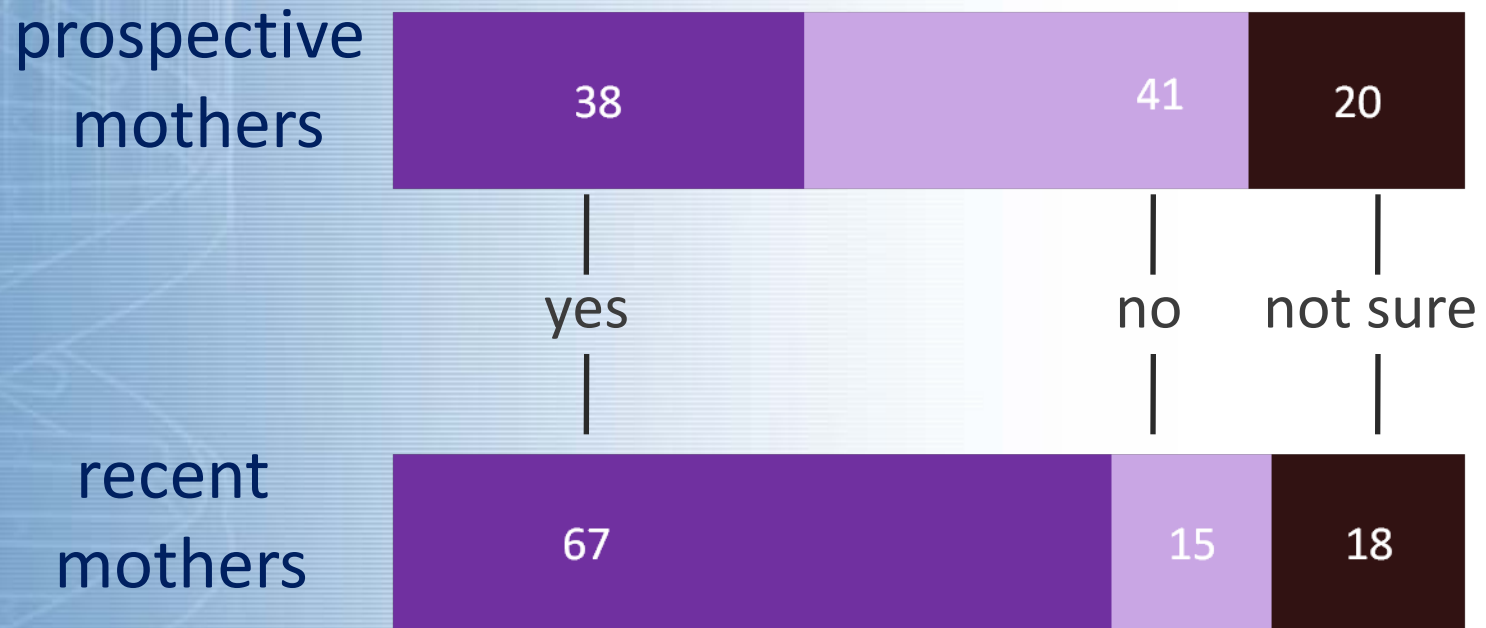
	Recent Mothers (n=1,258)	Prospective Mothers (n=1,008)
	%	%
Age 18-24	18	27
Age 25-29	32	31
Age 30-34	26	22
Age 35-39	18	14
Age 40-44	6	7
White non-Hispanic	62	58
Black non-Hispanic	12	16
Hispanic	18	16
Other race, non-Hispanic	8	10
< 12 yrs school	8	4
High School	21	23
Some college	36	34
B.A.	35	40
HH income <\$25K	11	11
HH income \$25K-\$50K	27	28
HH income \$50K-\$75K	27	23
HH income \$75K+	33	38



**Awareness, understanding,
and sources of information**

Nearly two-thirds of prospective mothers and one-third of recent mothers had not heard of NBS

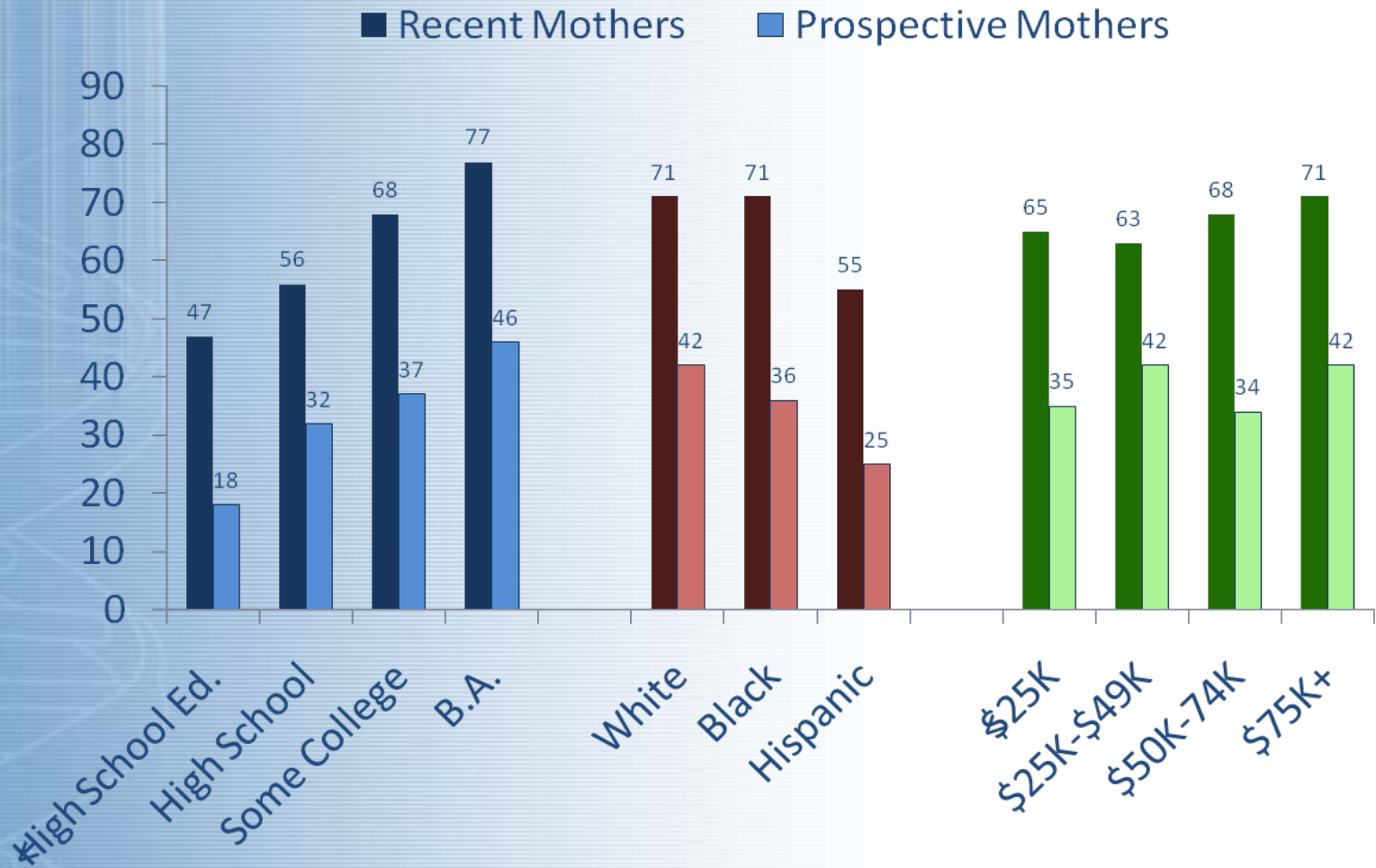
‘Before today had you heard of newborn screening?’



Awareness of NBS, by Demographic Group

‘Before today had you heard of newborn screening?’

(% who said yes)

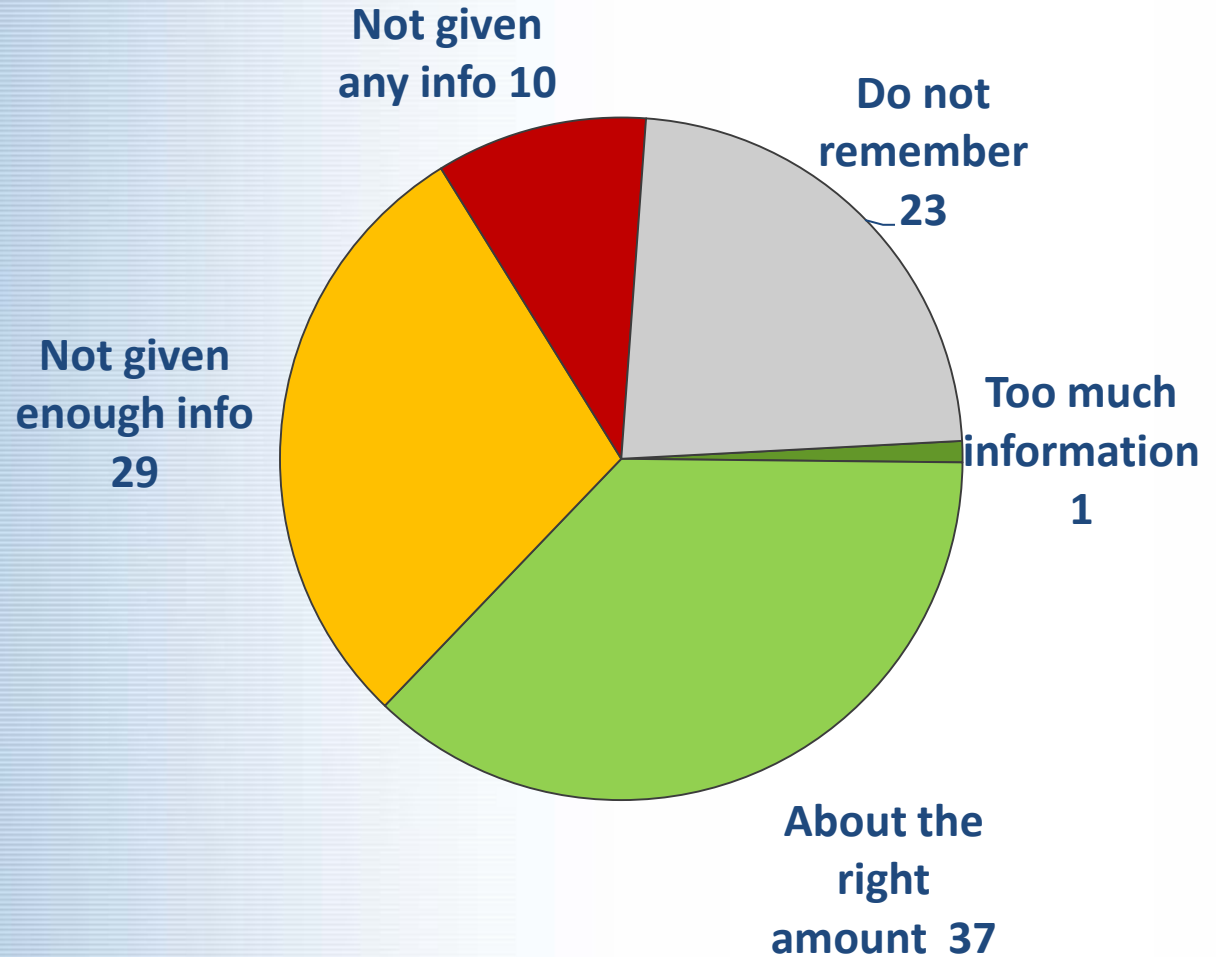


Many recent mothers were unaware of NBS during their last birth

- 39% said they received too little information on NBS
- 65% knew their baby had screening done at the time
- 44% remembered getting the results of NBS
- 24% felt they had a good understanding of NBS

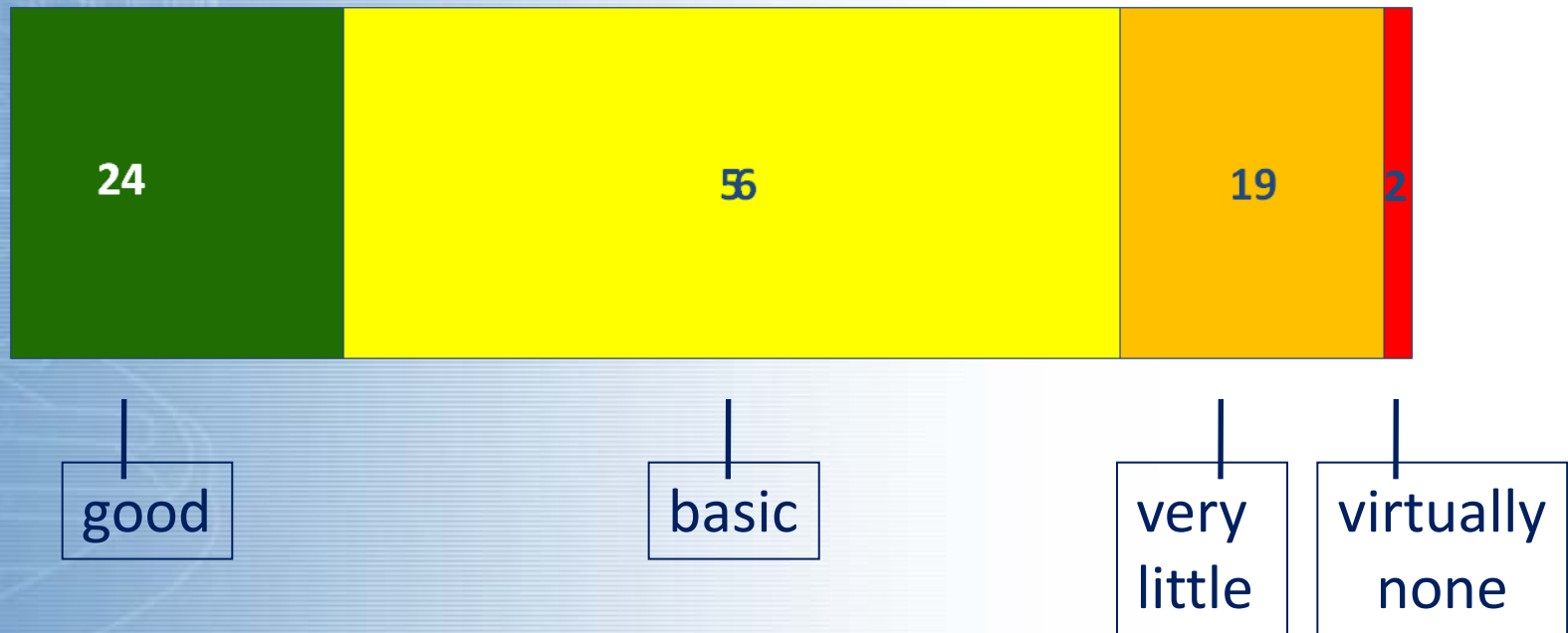
Recent mothers

“Which of the following best describes the information you got about newborn screening during your pregnancy?”

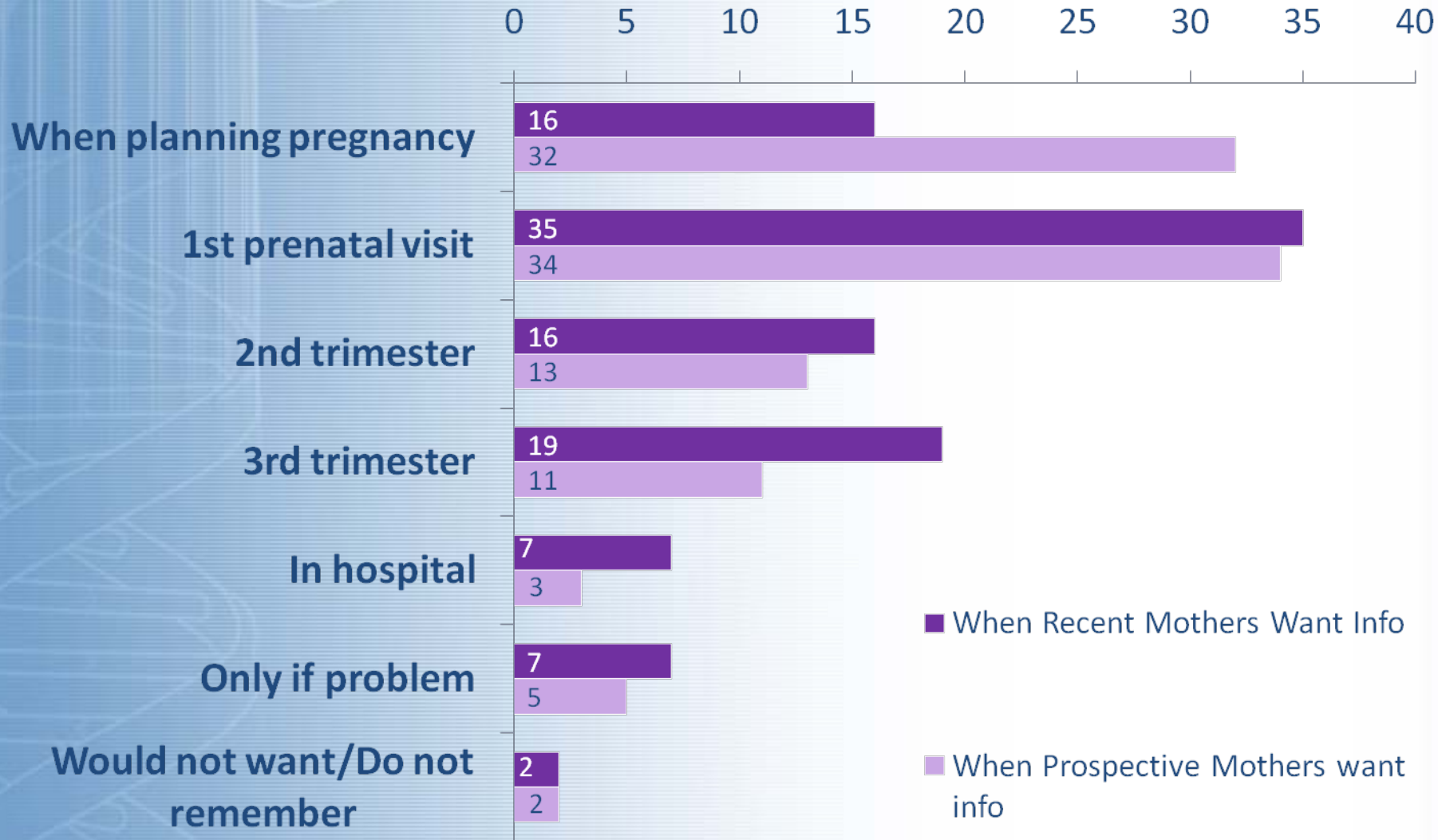


Recent Mother's Understanding

'From the information you received during your last pregnancy about NBS how would you rate your understanding of NBS?'



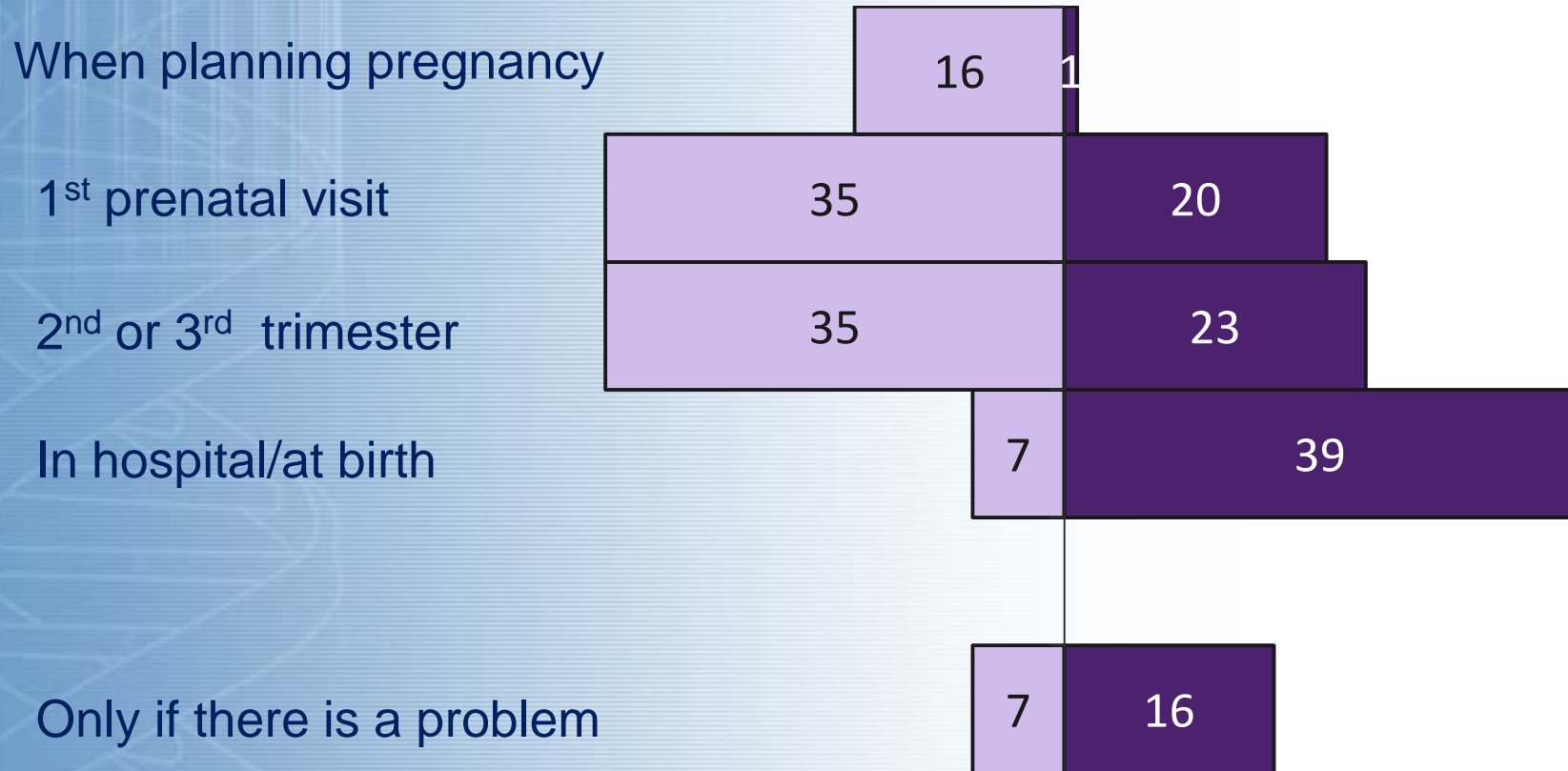
When would you first want to get information about NBS?



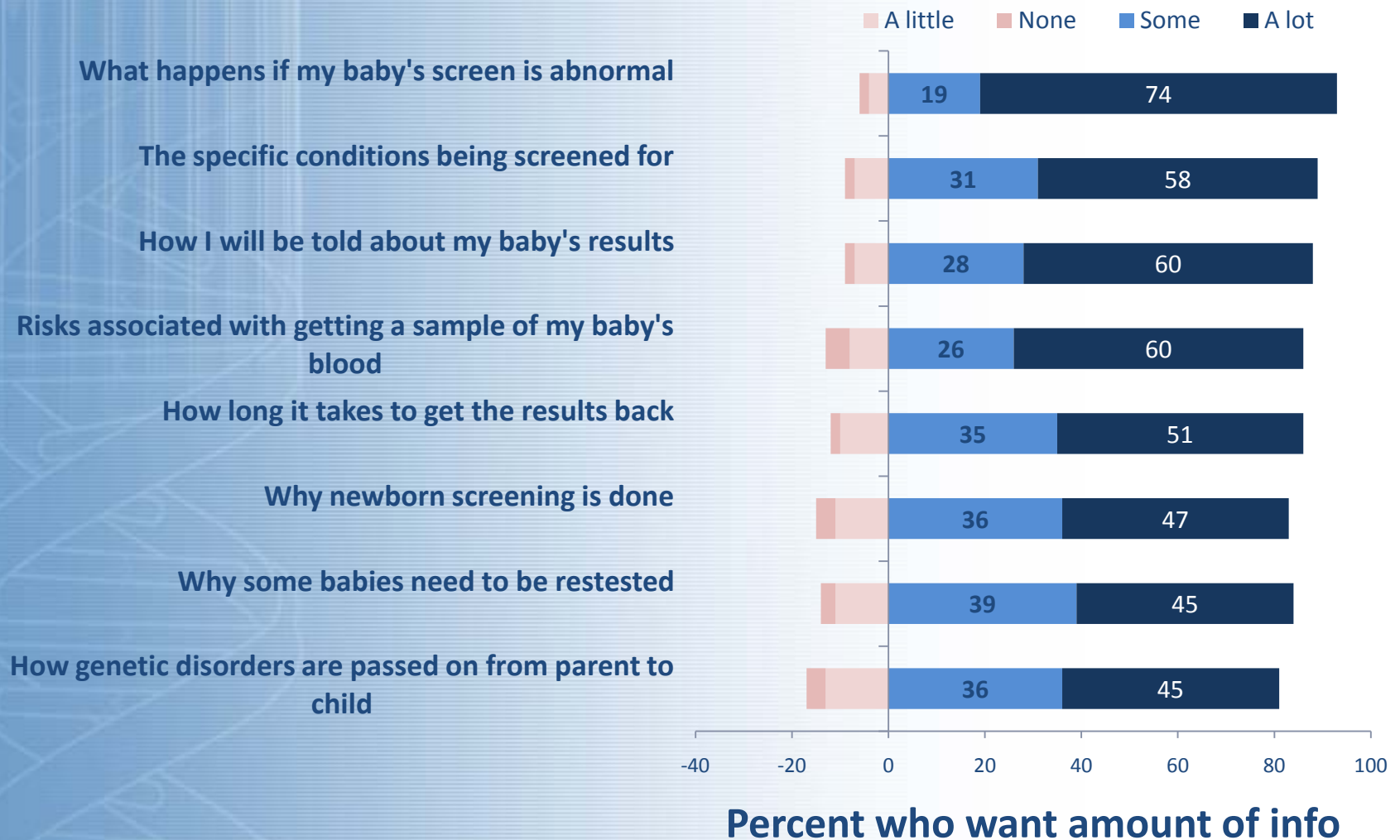
Women are getting info on NBS later than they would like

When recent mothers **wanted** to get first info on NBS:

When recent mothers **actually** got first info on NBS:



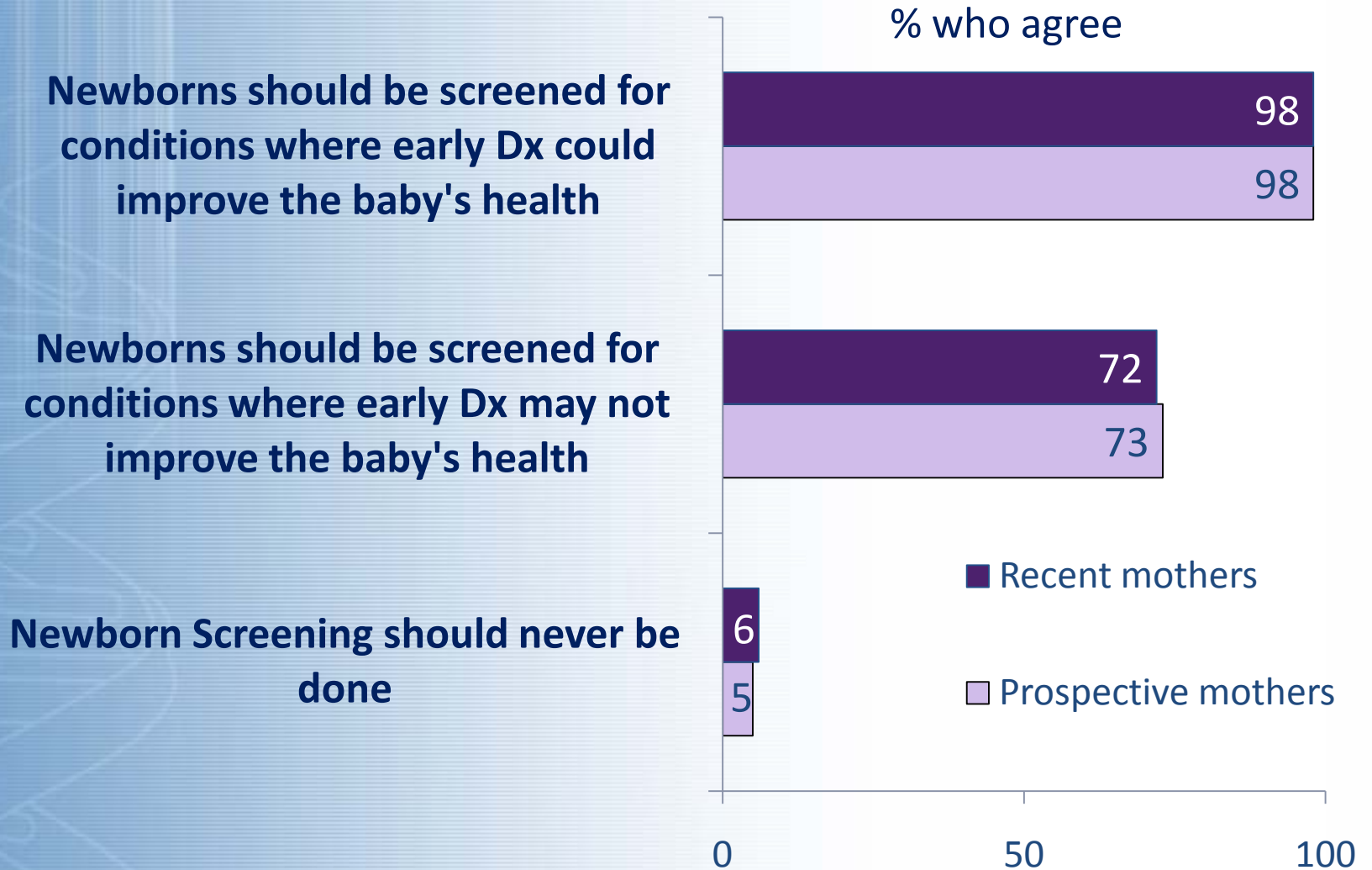
Practical information is some of the most important





Opinions and concerns about newborn screening

After being provided a definition of NBS, women expressed wide support for it.

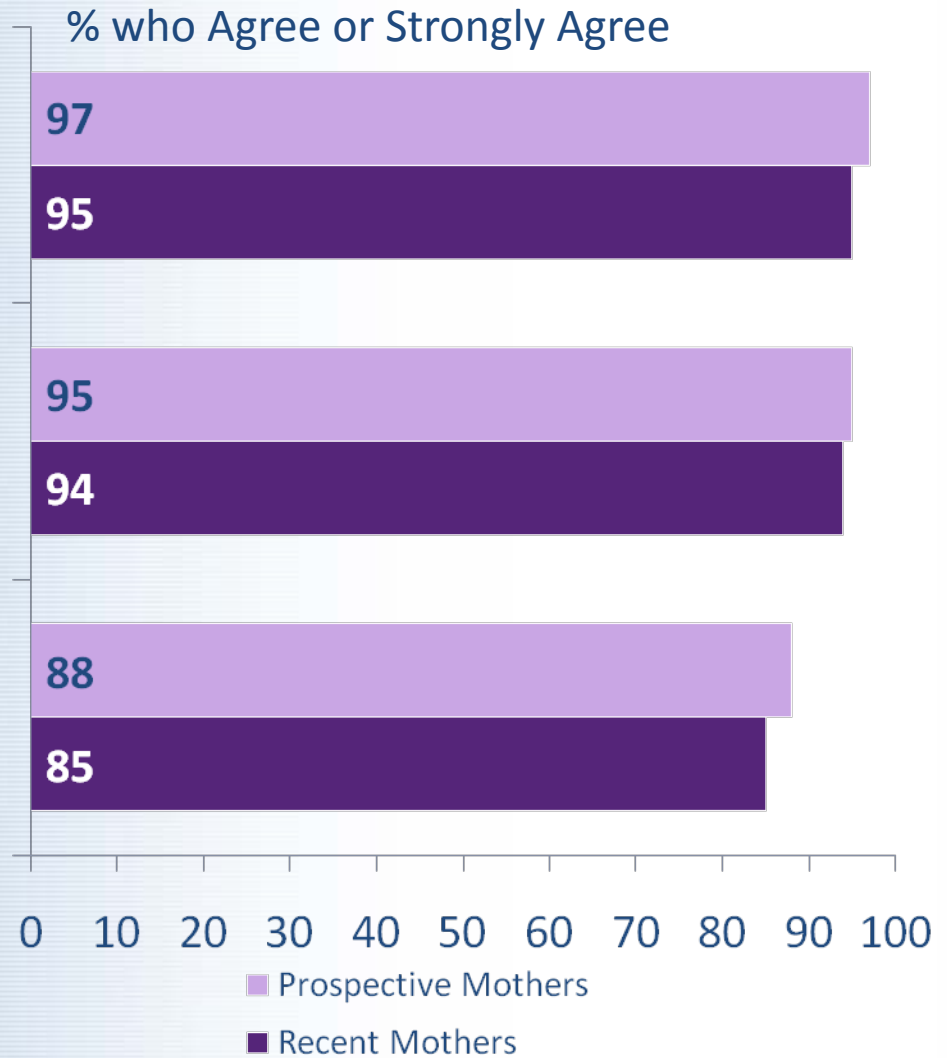


NBS is important....

So parents can prepare to care for a child with a condition

To improve the health of babies

So parents can learn if they are at risk to have another child w/ a condition



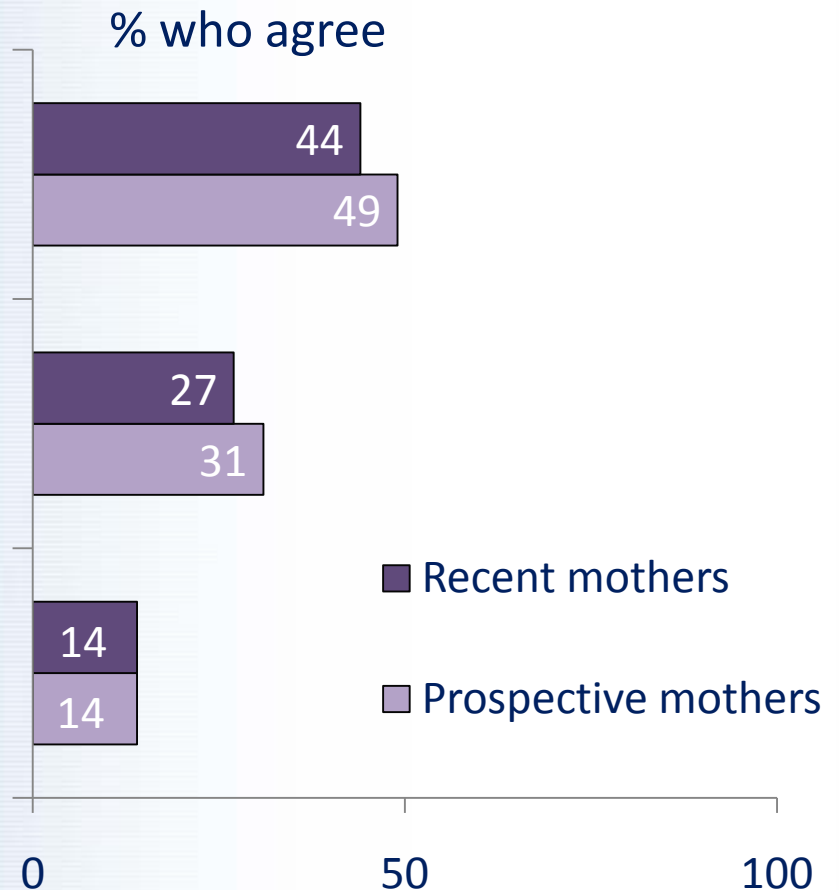
The greatest concern was about the accuracy of test results

“I worry that....”

NBS might not provide accurate info

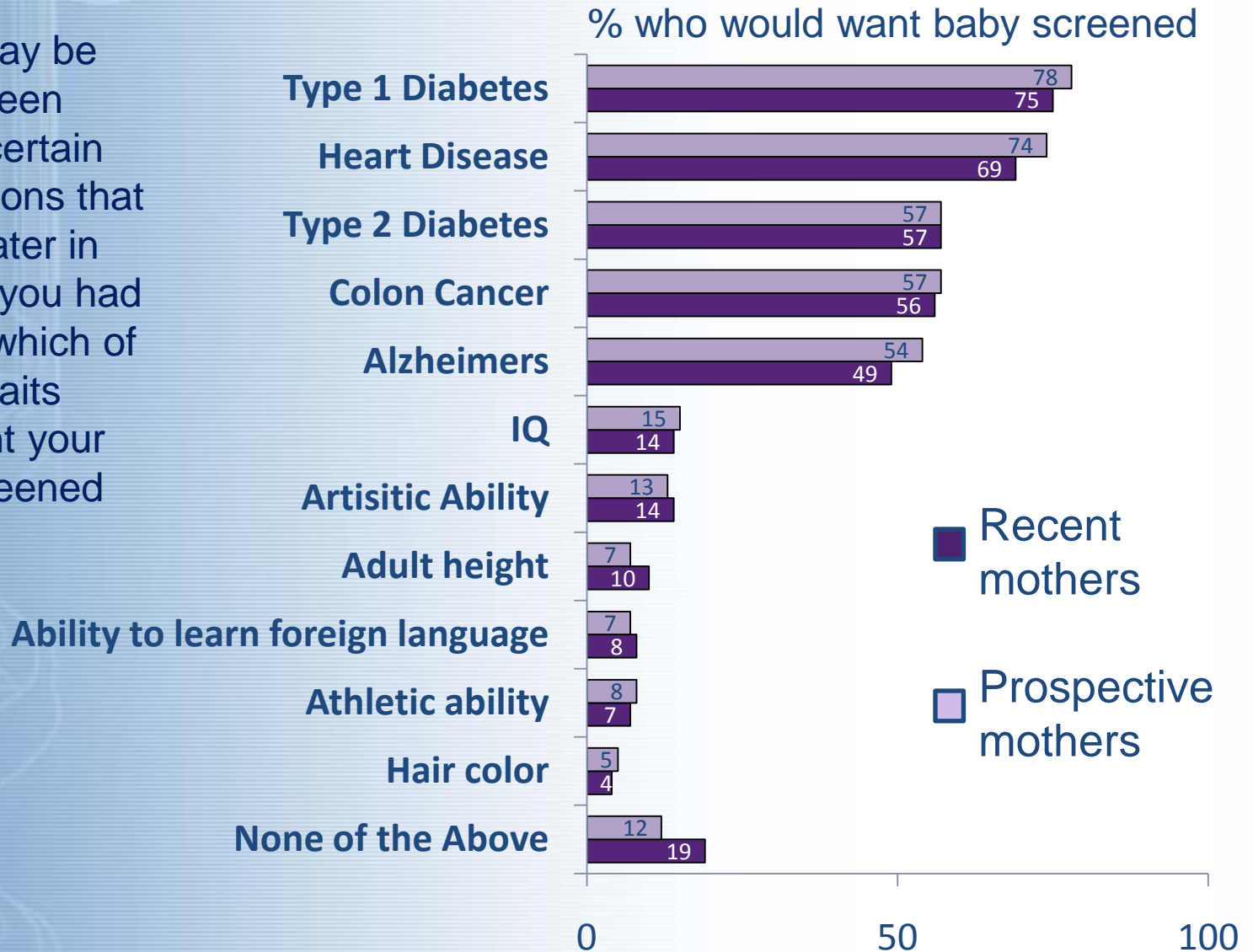
NBS causes too much anxiety for parents

NBS takes money away from other health care needs



Interest in NBS for adult onset diseases and traits

“Someday it may be possible to screen newborns for certain traits or conditions that may develop later in life. Assuming you had a baby today, which of the following traits would you want your baby to be screened for?”





**Influence of Positive Predictive Value,
Severity of the Disease, and Age of Onset
on Support for Screening**

Each person randomized to one of four versions of a fictional, unnamed, incurable, rare genetic disease:

Age of onset:

“symptoms start to appear between 12 and 15 years” **or**
“symptoms start to appear between 3 and 5 years”

Severity

“There is no cure, eventually the disease causes death” **or**
“There is no cure, the disease continues to get worse with age”

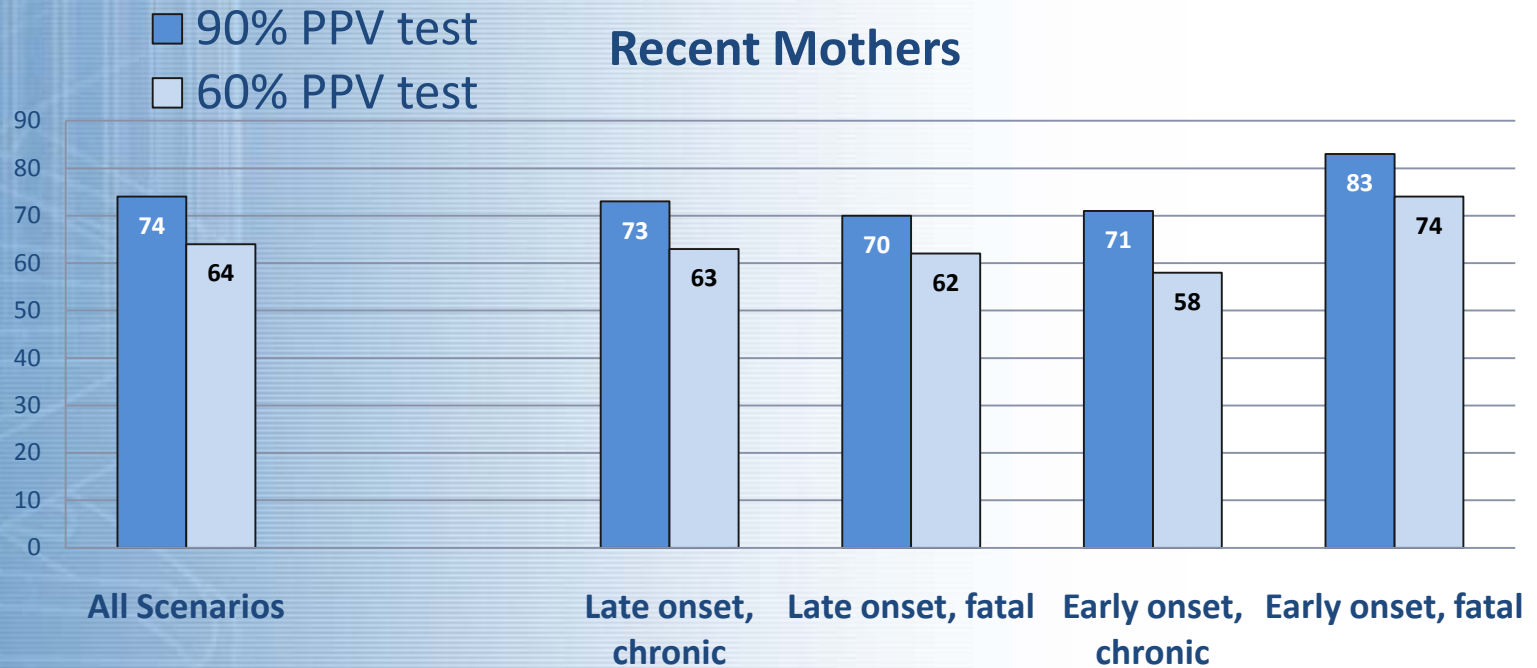
For the assigned scenario:

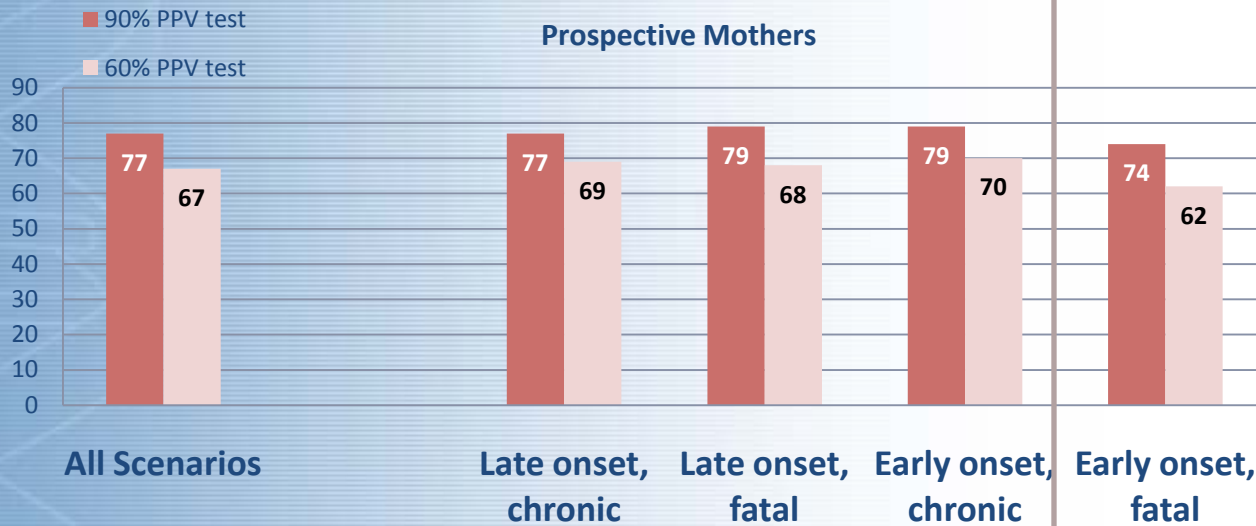
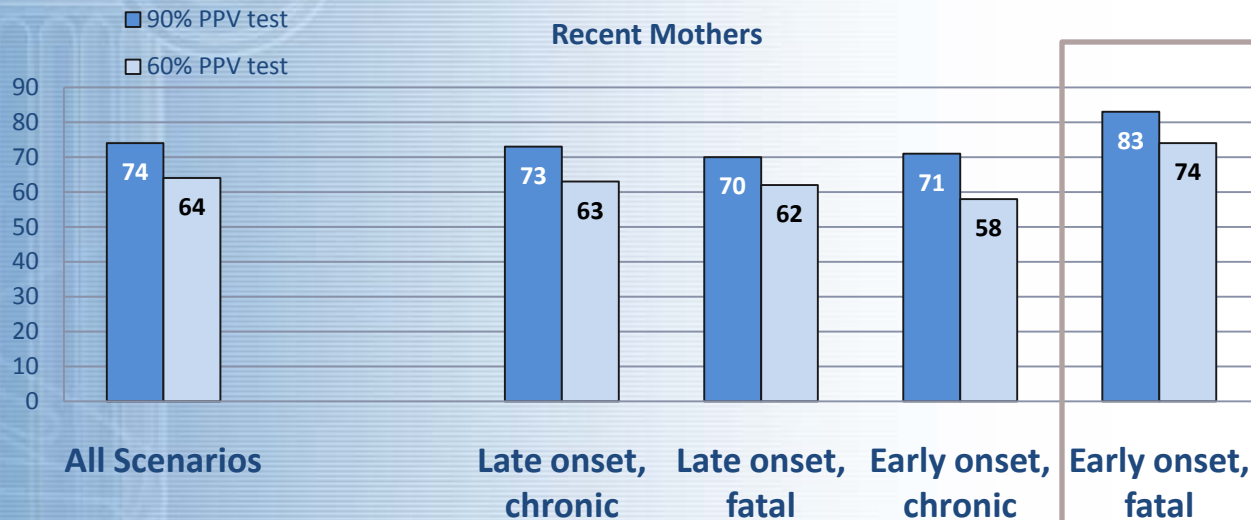
- Asked about that disease, assuming test had 90% PPV
- Then asked again, assuming the test had 60%

People were asked questions about NBS for the disease using a test that had 90% PPV.

They were then asked the questions again, assuming 60% PPV.

Support for screening for the disease varied most when PPV of the test changed





Conclusions

The public needs & wants information on NBS

- Awareness is low
- Too little education is occurring, and too late
- Unfamiliarity with NBS means patients won't ask about it
- Concise, practical information
- Offered at multiple junctures
- Hispanics, women <25, those who have not completed college

NBS is viewed very positively

- Prospective mothers > Recent Mothers

Accurate information is highly valued

- Worry about inaccuracy
- Support increases with PPV, though majorities supported all scenarios

Majorities interested in testing for adult onset diseases

Low but measurable interest in testing for traits

Study Limitations

- **What people say in a survey does not always correspond to what they will do**
- **Required English literacy**
- **High income and education – adjusted or stratified analyses**

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Consumer Task Force

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