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
<table>
<thead>
<tr>
<th></th>
<th>Recent Mothers (n=1,258)</th>
<th>Prospective Mothers (n=1,008)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>%</td>
<td>%</td>
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<tr>
<td>Age 18-24</td>
<td>18</td>
<td>27</td>
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<tr>
<td>Age 25-29</td>
<td>32</td>
<td>31</td>
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<td>Age 30-34</td>
<td>26</td>
<td>22</td>
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<tr>
<td>Age 35-39</td>
<td>18</td>
<td>14</td>
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<tr>
<td>Age 40-44</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>White non-Hispanic</td>
<td>62</td>
<td>58</td>
</tr>
<tr>
<td>Black non-Hispanic</td>
<td>12</td>
<td>16</td>
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<tr>
<td>Hispanic</td>
<td>18</td>
<td>16</td>
</tr>
<tr>
<td>Other race, non-Hispanic</td>
<td>8</td>
<td>10</td>
</tr>
<tr>
<td>&lt; 12 yrs school</td>
<td>8</td>
<td>4</td>
</tr>
<tr>
<td>High School</td>
<td>21</td>
<td>23</td>
</tr>
<tr>
<td>Some college</td>
<td>36</td>
<td>34</td>
</tr>
<tr>
<td>B.A.</td>
<td>35</td>
<td>40</td>
</tr>
<tr>
<td>HH income &lt;$25K</td>
<td>11</td>
<td>11</td>
</tr>
<tr>
<td>HH income $25K-$50K</td>
<td>27</td>
<td>28</td>
</tr>
<tr>
<td>HH income $50K-$75K</td>
<td>27</td>
<td>23</td>
</tr>
<tr>
<td>HH income $75K+</td>
<td>33</td>
<td>38</td>
</tr>
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</table>
Awareness, understanding, and sources of information
Nearly two-thirds of prospective mothers and one-third of recent mothers had not heard of newborn screening.

Before today had you heard of newborn screening?

-prospective mothers
  -yes: 38
  -no: 41
  -not sure: 20

-recent mothers
  -yes: 67
  -no: 15
  -not sure: 18
Awareness of NBS, by Demographic Group

‘Before today had you heard of newborn screening?’ (% who said yes)

<table>
<thead>
<tr>
<th>Education Level</th>
<th>Recent Mothers</th>
<th>Prospective Mothers</th>
</tr>
</thead>
<tbody>
<tr>
<td>High School Education</td>
<td>47</td>
<td>18</td>
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<tr>
<td>Some College</td>
<td>56</td>
<td>32</td>
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<tr>
<td>B.A.</td>
<td>68</td>
<td>37</td>
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<td></td>
<td>77</td>
<td>46</td>
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<td>White</td>
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<td>42</td>
</tr>
<tr>
<td>Black</td>
<td>71</td>
<td>36</td>
</tr>
<tr>
<td>Hispanic</td>
<td>55</td>
<td>25</td>
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</table>

<table>
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<tr>
<th>Income Level</th>
<th>$25K</th>
<th>$25K-$49K</th>
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<tr>
<td></td>
<td>65</td>
<td>35</td>
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<td>34</td>
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<tr>
<td></td>
<td>71</td>
<td>42</td>
</tr>
</tbody>
</table>
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?”

- About the right amount: 37
- Too much information: 1
- Not given enough info: 29
- Not given any info: 10
- Do not remember: 23
Recent Mother’s Understanding

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

- 24: good
- 56: basic
- 19: very little
- 2: virtually none
When would you first want to get information about NBS?

- **When planning pregnancy**: 16 (Recent Mothers) / 32 (Prospective Mothers)
- **1st prenatal visit**: 35 (Recent Mothers) / 34 (Prospective Mothers)
- **2nd trimester**: 16 (Recent Mothers) / 13 (Prospective Mothers)
- **3rd trimester**: 19 (Recent Mothers) / 11 (Prospective Mothers)
- **In hospital**: 7 (Recent Mothers) / 3 (Prospective Mothers)
- **Only if problem**: 7 (Recent Mothers) / 5 (Prospective Mothers)
- **Would not want/Do not remember**: 2 (Recent Mothers) / 2 (Prospective Mothers)
Women are getting info on NBS later than they would like

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

- When planning pregnancy: 16
- 1\textsuperscript{st} prenatal visit: 35
- 2\textsuperscript{nd} or 3\textsuperscript{rd} trimester: 35
- In hospital/at birth: 7
- Only if there is a problem: 7

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

- When planning pregnancy: 1
- 1\textsuperscript{st} prenatal visit: 20
- 2\textsuperscript{nd} or 3\textsuperscript{rd} trimester: 23
- In hospital/at birth: 39
- Only if there is a problem: 16
Practical information is some of the most important

What happens if my baby's screen is abnormal
- A little: 19
- None: 74
- Some: 58
- A lot: 60

The specific conditions being screened for
- A little: 31
- None: 58
- Some: 58
- A lot: 60

How I will be told about my baby's results
- A little: 28
- None: 60
- Some: 60
- A lot: 60

Risks associated with getting a sample of my baby's blood
- A little: 26
- None: 60
- Some: 60
- A lot: 60

How long it takes to get the results back
- A little: 35
- None: 51
- Some: 51
- A lot: 60

Why newborn screening is done
- A little: 36
- None: 47
- Some: 47
- A lot: 51

Why some babies need to be restested
- A little: 39
- None: 45
- Some: 45
- A lot: 51

How genetic disorders are passed on from parent to child
- A little: 36
- None: 45
- Some: 45
- A lot: 51
Opinions and concerns about newborn screening
After being provided a definition of NBS, women expressed wide support for it.

Newborns should be screened for conditions where early Dx could improve the baby's health.

Recent mothers: 98%
Prospective mothers: 98%

Newborns should be screened for conditions where early Dx may not improve the baby's health.

Recent mothers: 72%
Prospective mothers: 73%

Newborn Screening should never be done.

Recent mothers: 6%
Prospective mothers: 5%
NBS is important....

So parents can prepare to care for a child with a condition
- % who Agree or Strongly Agree
  - Prospective Mothers: 97
  - Recent Mothers: 95

To improve the health of babies
- % who Agree or Strongly Agree
  - Prospective Mothers: 95
  - Recent Mothers: 94

So parents can learn if they are at risk to have another child with a condition
- % who Agree or Strongly Agree
  - Prospective Mothers: 88
  - Recent Mothers: 85
The greatest concern was about the accuracy of test results

“I worry that….”

- NBS might not provide accurate info
  - Recent mothers: 44%
  - Prospective mothers: 49%

- NBS causes too much anxiety for parents
  - Recent mothers: 27%
  - Prospective mothers: 31%

- NBS takes money away from other health care needs
  - Recent mothers: 14%
  - Prospective mothers: 14%

The greatest concern was about the accuracy of test results.
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?”

- Type 1 Diabetes: 78% (Recent mothers), 75% (Prospective mothers)
- Heart Disease: 74% (Recent mothers), 69% (Prospective mothers)
- Type 2 Diabetes: 57% (Recent mothers), 57% (Prospective mothers)
- Colon Cancer: 57% (Recent mothers), 56% (Prospective mothers)
- Alzheimers: 49% (Recent mothers), 54% (Prospective mothers)
- IQ: 15% (Recent mothers), 14% (Prospective mothers)
- Artisitic Ability: 13% (Recent mothers), 14% (Prospective mothers)
- Adult height: 7% (Recent mothers), 10% (Prospective mothers)
- Ability to learn foreign language: 7% (Recent mothers), 8% (Prospective mothers)
- Athletic ability: 8% (Recent mothers), 7% (Prospective mothers)
- Hair color: 5% (Recent mothers), 4% (Prospective mothers)
- None of the Above: 12% (Recent mothers), 19% (Prospective mothers)
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”  
“symptoms start to appear between 3 and 5 years”

**Severity**

“There is no cure, eventually the disease causes death”  
“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.

Recent Mothers

- 90% PPV test
- 60% PPV test

Support for screening varied when the PPV of the test changed. The graph shows the percentages for different scenarios:

- All Scenarios
- Late onset, chronic
- Late onset, fatal
- Early onset, chronic
- Early onset, fatal

The percentages for these scenarios are as follows:

- All Scenarios: 74% (90%), 64% (60%)
- Late onset, chronic: 73% (90%), 63% (60%)
- Late onset, fatal: 70% (90%), 62% (60%)
- Early onset, chronic: 71% (90%), 58% (60%)
- Early onset, fatal: 83% (90%), 74% (60%)
All Scenarios

Recent Mothers

Prospective Mothers

Early onset,
chronic

90% PPV test
60% PPV test

Late onset,
chronic

Late onset,
fatal

Early onset,
chronic

Early onset,
fatal

90% PPV test
60% PPV test

90% PPV test
60% PPV test

90% PPV test
60% PPV test

90% PPV test
60% PPV test

All Scenarios

Late onset,
chronic

Late onset,
fatal

Early onset,
chronic

Early onset,
fatal
Conclusions

The public needs & wants information on NBS

• Awareness is low
• Too little education is occurring, and too late
• Unfamiliarity with NBS means patients wont 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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