

Appendix 1 Survey Directions

What is newborn screening?

- All newborns in the US are tested for between 30 and 60 medical conditions at birth
- The test uses a sample of blood from the baby's heel
- The test is performed by or under the guidance of the state health department
- Each condition that is tested for comes with a cost to the state, hospitals and insurance companies.

Why do we do newborn screening for infants at birth?

- Many of the disorders that are tested for can impact a child's normal physical and mental development
- Often the baby does not show signs of the disorder at birth, but the signs develop as the child grows
- If a child with one of these disorders is identified at birth, often there are treatments/interventions that can stop or slow the development of signs of the disorder.

Why is this study important?

- The list of conditions that are tested for is routinely evaluated by a panel of experts based on multiple criteria
- Not much is known about the public opinion about the benefits of testing for certain types of disorders
- This study aims to better understand what types of conditions the public considers most beneficial to test for on the newborn screen

Directions

- Imagine that there are new tests that can be used to test all newborns for specific health conditions. There is a very small chance that a child will be born with one of these conditions.
- The test will use the same blood sample that is already collected from all newborns at the hospital; no extra blood sample will be required, however there is a cost to the state associated with each additional test that is run
- Each of the following scenarios outlines a particular health condition and the available treatment or lack of treatment.
- The following questions ask you to give your opinions regarding the benefits of testing for each of these conditions.