

Prenatal Education about Newborn Screening and Dried Bloodspot Policy



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Ethical and Policy Challenges

- Parental Education
 - Education is primarily through brochures provided in the birthing facility
 - Widely recognized that current approaches are largely ineffective
 - Brochures are not read
 - Providers do not consistently address NBS
 - Perinatal period is not conducive to education about low-risk issues
 - Little incentive for better education

Ethical and Policy Challenges

- Parental Education
 - Surveys of parents consistently show a strong interest in education about NBS in the prenatal period
 - Evidence suggests that few prenatal care providers offer information about NBS

AAP Task Force (2000)

- *“Prospective parents should receive information about newborn screening during the prenatal period. Pregnant women should be made aware of the process and benefits of newborn screening and their right of refusal before testing, preferably during a routine third trimester prenatal care visit.”*

Serving the Family From Birth to the Medical Home. Newborn Screening: A Blueprint for the Future A Call for a National Agenda on State Newborn Screening Programs. Pediatrics 2000 106: 389-422.

ACOG

- Committee Opinion #481, March 2011
- *“The Committee on Genetics recommends that obstetric care providers make resources regarding newborn screening available to patients during pregnancy. Information can be disseminated through informational brochures, electronic sources, or through discussion during prenatal visits.”*

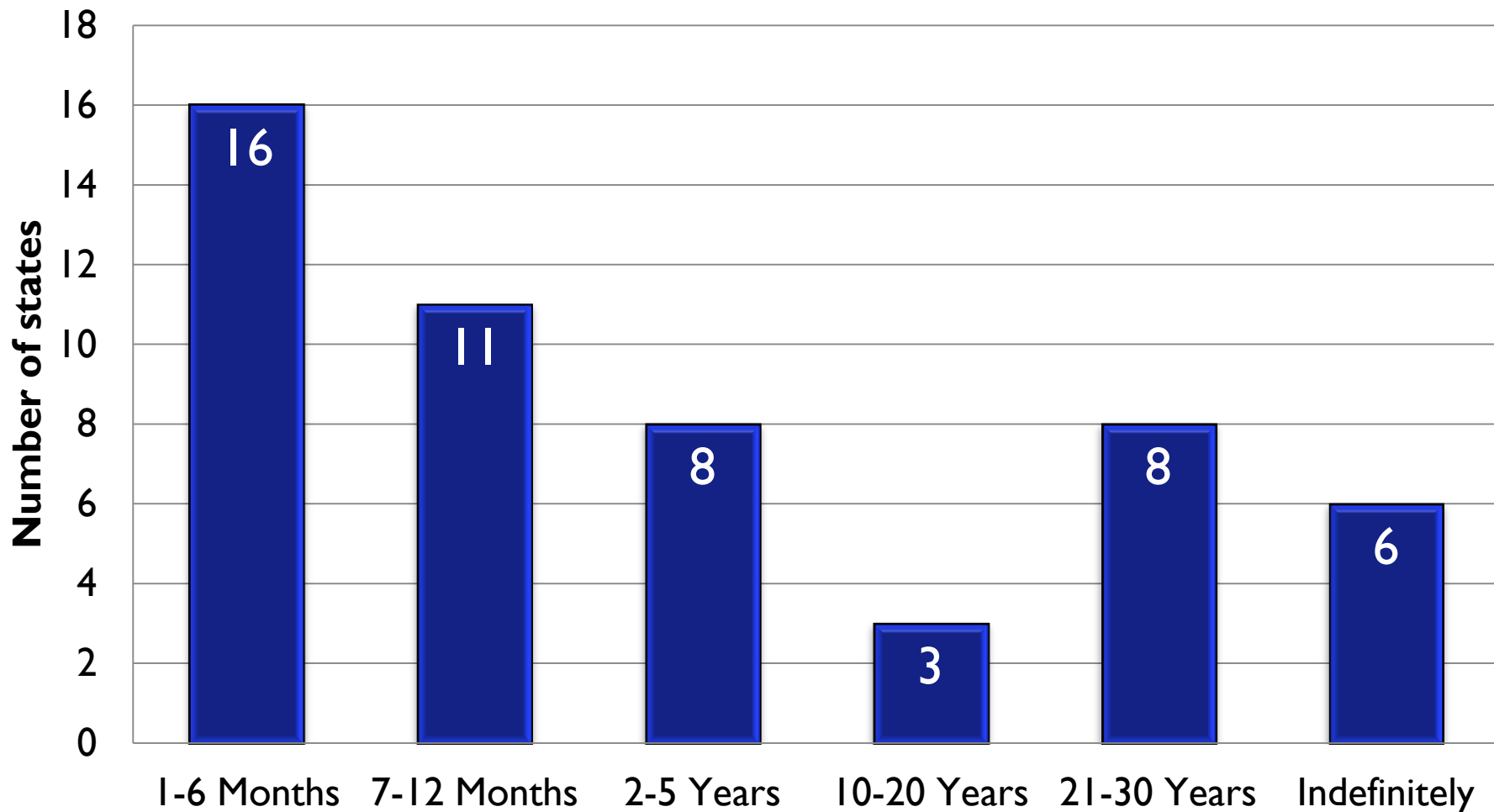
Parental Education

- What do parents want to know about NBS?
- “7 things” Davis et al (Pediatrics 2006;117:S326)
 - All newborns are required by the state to get tested for some rare disorders before they leave the hospital.
 - Babies with these disorders may look healthy at birth.
 - Serious problems can be prevented if we find out about these problems right away.
 - To do the test, a nurse will take a few drops of blood from your baby’s heel.
 - Your baby’s health professional and hospital will get a copy of the test results. Ask about your baby’s test results when you see your health professional.
 - Some babies need to be retested. If your baby needs to be retested, you will be notified. It is very important to get retested quickly.
 - Talk to your baby’s health professional if you have questions.

Residual Dried Bloodspots (DBS)

- Newborn screening conducted on 4 million infants per year in the US
- Residual blood is available on virtually every baby screened
- Many states retain residual bloodspots for:
 - Quality improvement for existing tests
 - Forensic uses
 - Biomedical research
- Controversy relates primarily to research use

State Dried Blood Spot Retention Times



From: NewSTEPS, Sontag, August 2015

Research applications

- Residual bloodspots have high value due to coverage of the entire population of newborns and children
 - Genetic epidemiology
 - Infectious agent exposure in pregnant women
 - HIV infection
 - CMV infection
 - Prenatal exposure to environmental agents
- Literature Review: ~1900 publications in the English language with use of DBS from NBS

Current Project

- *“Parental Education about Newborn Screening and Bloodspot Retention”*
- NHGRI, 4 year award
- Collaboration between
 - University of Utah (Botkin – PI)
 - Intermountain Healthcare (Nancy Rose)
 - UCSF (Miriam Kuppermann)
 - Albert Einstein (Siobhan Dolan)

Study Team

University of Utah

- Rebecca Anderson, RN, PhD (Manager)
- Erin Rothwell, PhD
- Bob Wong, PhD
- Louisa Stark, PhD

University of California at San Francisco

- Allison O'Leary
- Rachel Freyre
- Elizabeth Doyle

Albert Einstein College of Medicine

- Sarah Hreyo
- Isha Kalia
- Setul Pardanani, MD
- -Medical Director

Intermountain Health

- Beth Fedor

State Policies

- **Utah, California, and New York**
 - Provide information about NBS and DBS in brochures distributed in post-partum period
 - Retained residual bloodspots
 - Permit parents to opt-out

Specific Aims

- **Specific Aim 1)** To determine what pregnant women, young mothers, and their partners want to know regarding the retention and use of residual bloodspot samples
- **Specific Aim 2)** To create multimedia educational tools to be used in the prenatal care environment that will provide basic information about NBS and DBS.

Specific Aims

- **Specific Aim 3)** To determine the impact of the prenatal education intervention on parental knowledge, attitudes, and decisions regarding NBS services and DBS
- **Specific Aim 4)** To examine the normative/ethical implications of the results

What do parents want to know about residual bloodspots?

- Some states save leftover bloodspots after newborn screening is complete.
- Leftover bloodspots can be used to improve the public's health in many ways.
- No extra heel pricks are done to collect blood for other potential uses of the spots.
- Safeguards are in place to protect the privacy of babies and families and to ensure the ethical conduct of research.

What do parents want to know about residual bloodspots?

- The baby's name or other identifiable information is not attached to the leftover bloodspots used in most research.
- Because most research with leftover bloodspots is done anonymously, parents will usually not get results back from the research.
- A parent may request that their baby's bloodspot not be used in research after newborn screening.

Theoretical Basis for Interventions

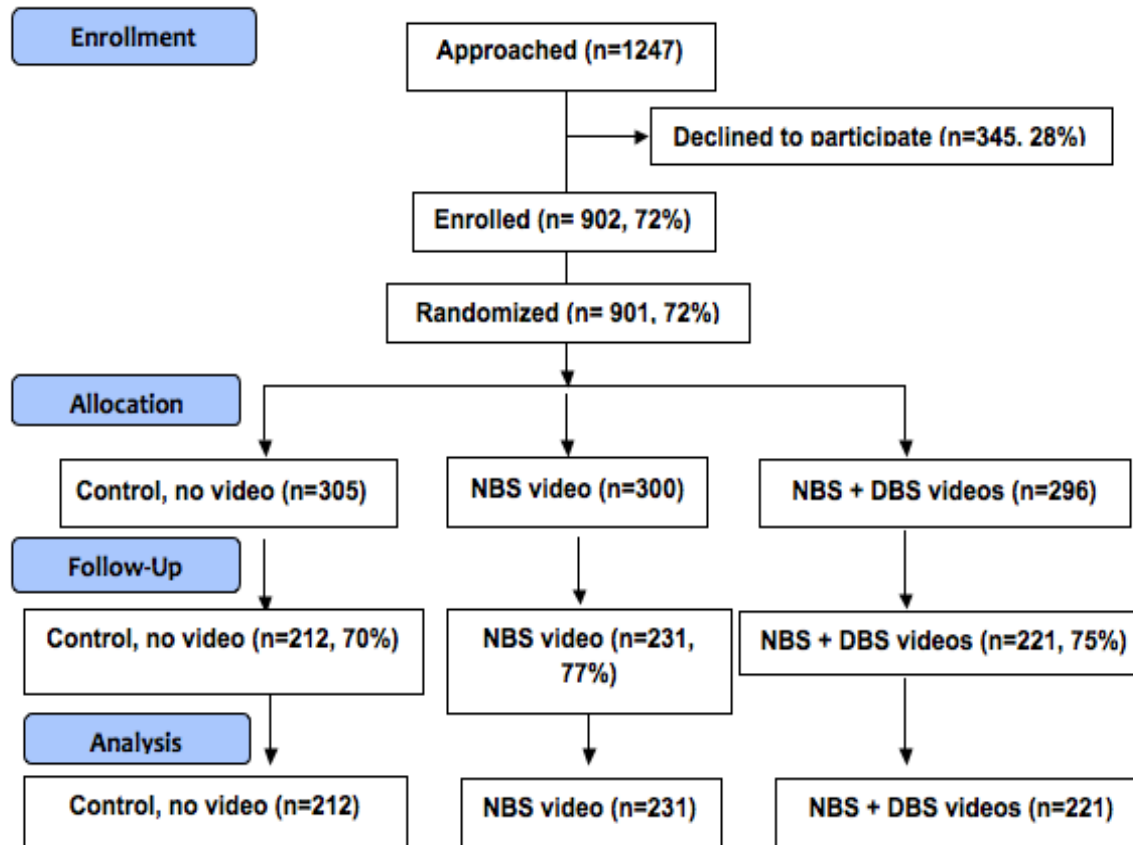
- Principles of Multimedia Learning Theory
 - Multiple presentation (words+pictures>words)
 - Contiguity (corresponding words and pictures)
 - Split attention (words as auditory narration)
 - Individual difference (first three principles apply more to low knowledge individuals)
 - Coherence principle (few rather than many words)
- Adult learning => people can remember 7 ± 2 items

The Movies!



Consort flow diagram

CONSORT Flow Diagram



Demographics

- **N=664** 36 – 40 weeks gestation
- **Age** = 31 yrs (SD 5.6)
- Weeks enrollment to survey = 7.2 (SD 3.3)
- **Given Birth Before**
 - 54.4% Yes
 - 45.6% No
- **Race**
 - 17.0% Black or African American
 - 48.6% White
 - 7.9% Asian
 - 5.9% Multi-racial
 - 1.2% Native Hawaiian or Pacific Islander
 - 0.5% American Indian or Alaska Native
 - 14.2% Other
- **Ethnicity**
 - 27.9% Hispanic
 - 72.1% Non-Hispanic
- **Language**
 - 93.7% English
 - 6.3% Spanish
- **Marital Status**
 - 83% Married or living with partner
- **Income**
 - 33.4% Under \$50,000
 - 22.5% Over \$100,000
- **Education**
 - 23.2% High School or Less
 - 57.2% College graduate
 - 19.6% Professional or graduate degree

The Results!

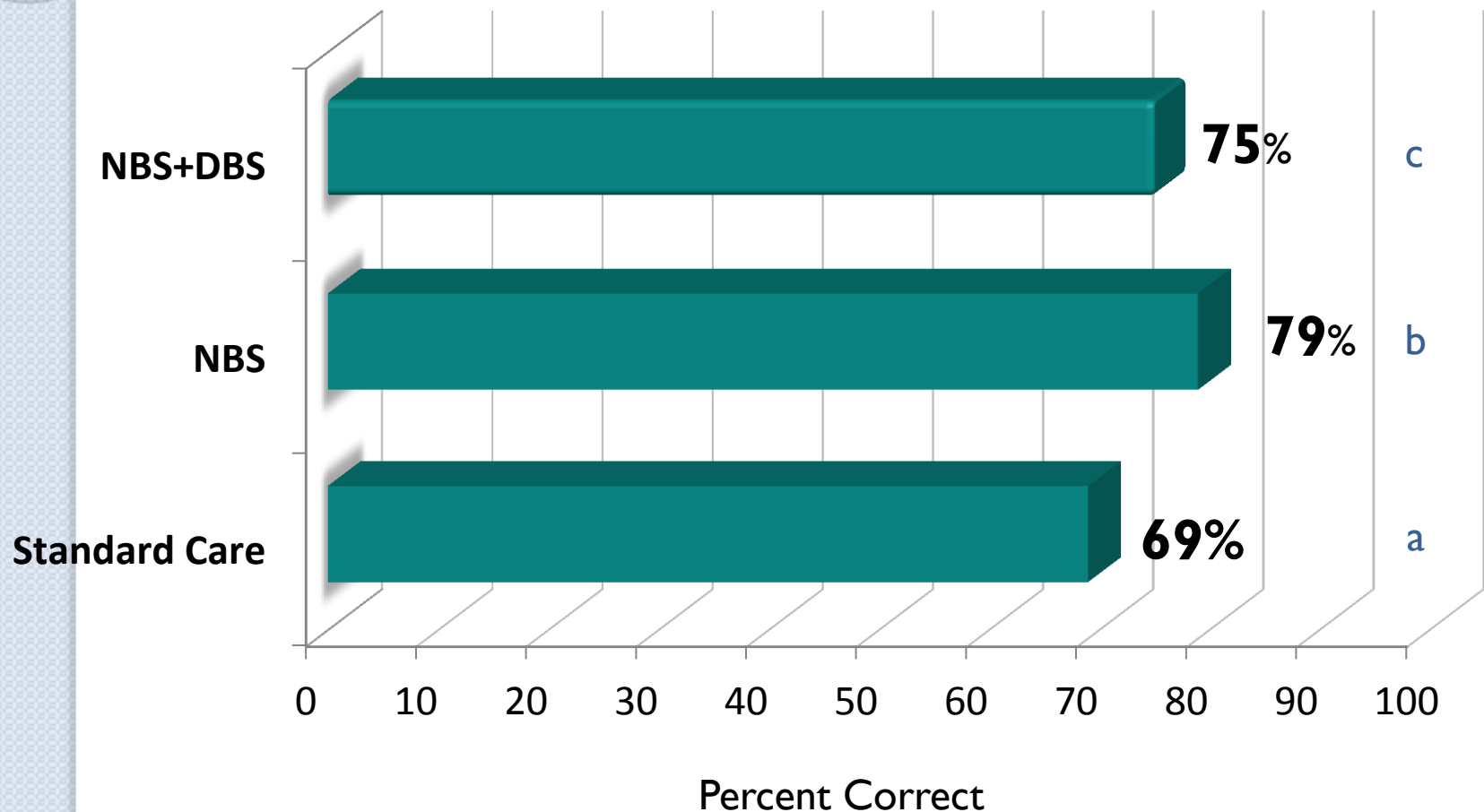


Botkin JR, Rothwell E, Anderson RA, Rose NC, Dolan SM, Kuppermann M, Stark LA, Goldenberg A, Wong B. Prenatal education of parents about newborn screening and residual dried bloodspots. JAMA Pediatrics 2016 Apr 4. doi: 10.1001/jamapediatrics.2015.4850.

Knowledge about NBS

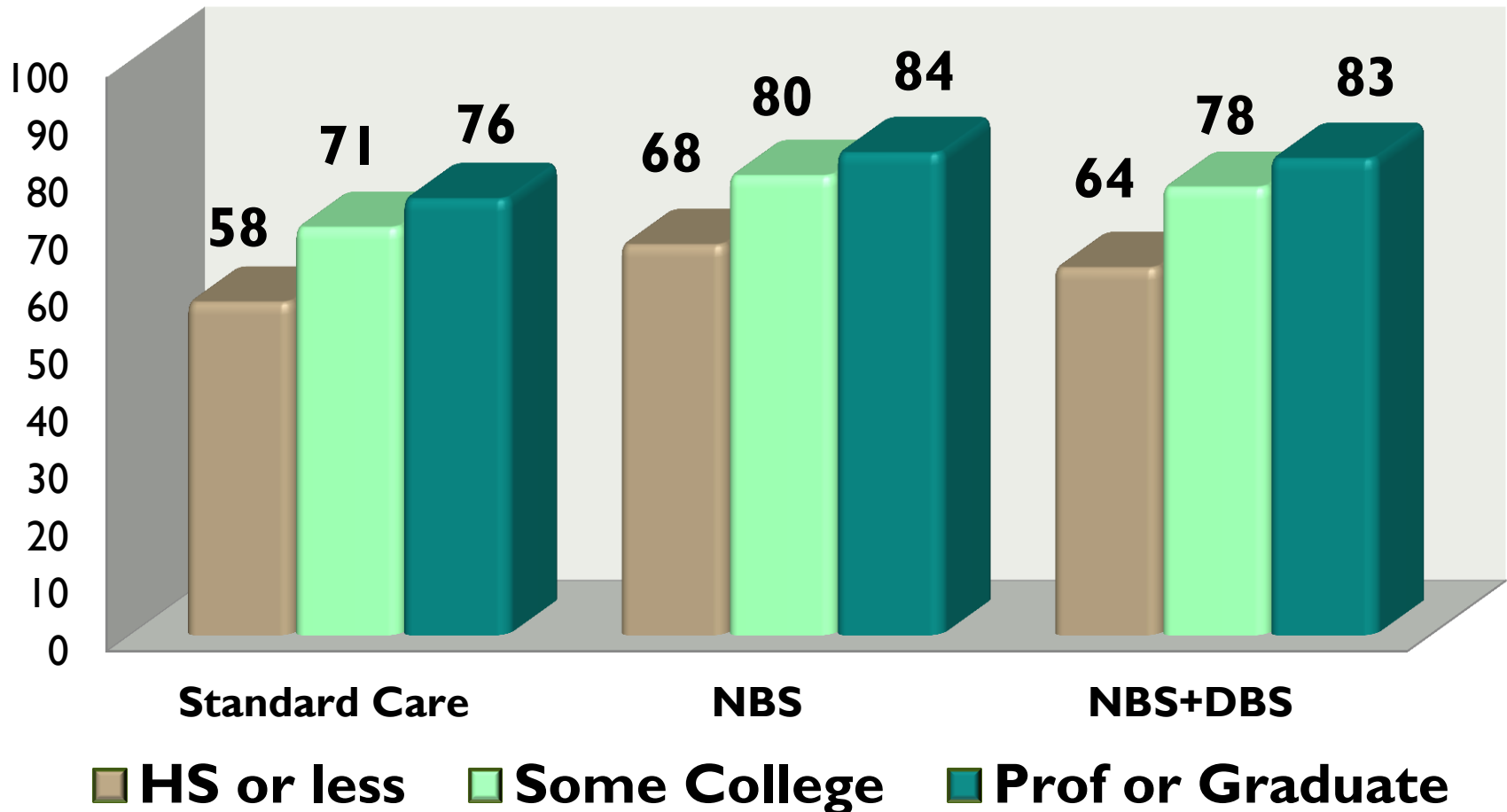
Knowledge scores

Statistically
Different Subsets



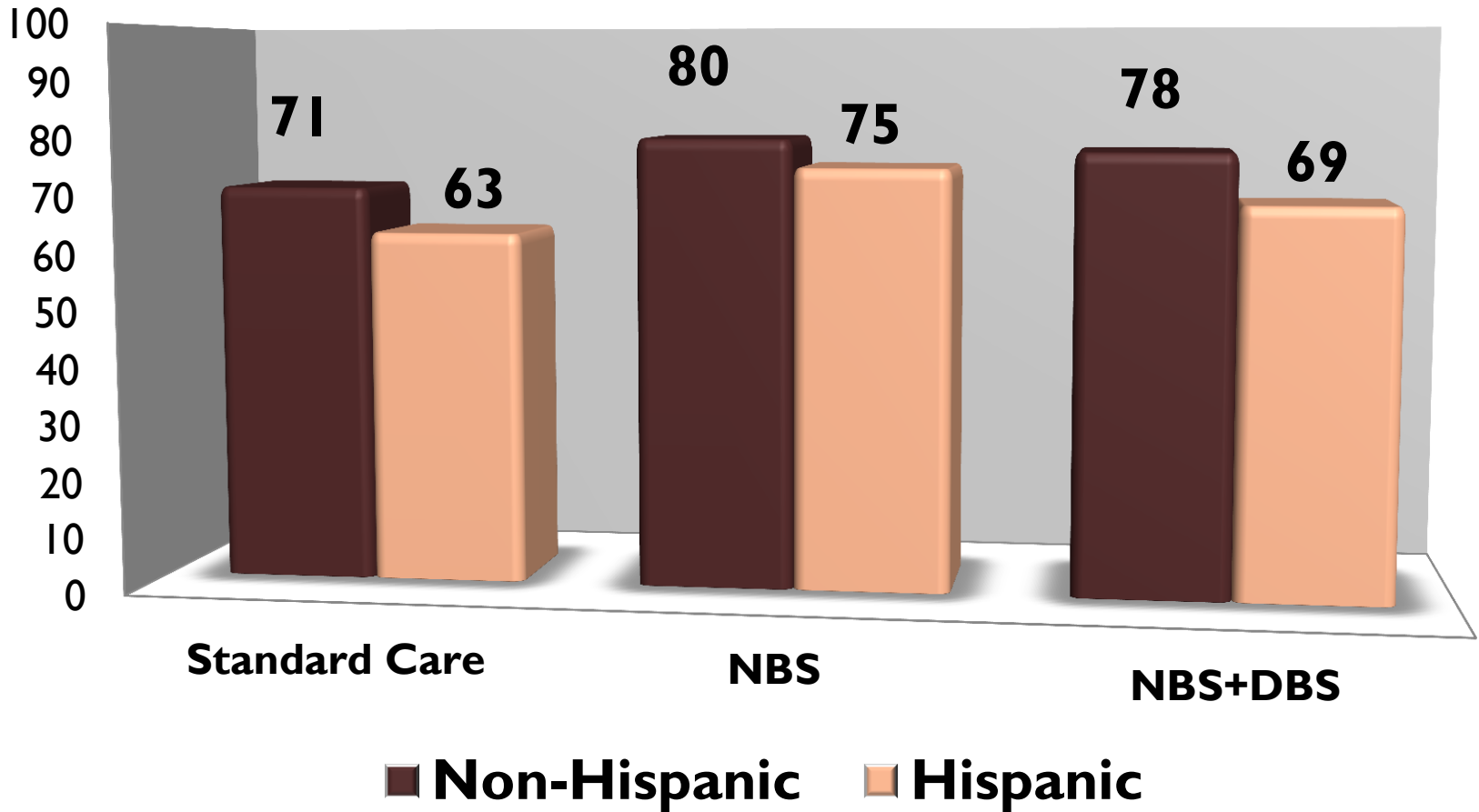
Knowledge about NBS by Education

Percent Correct

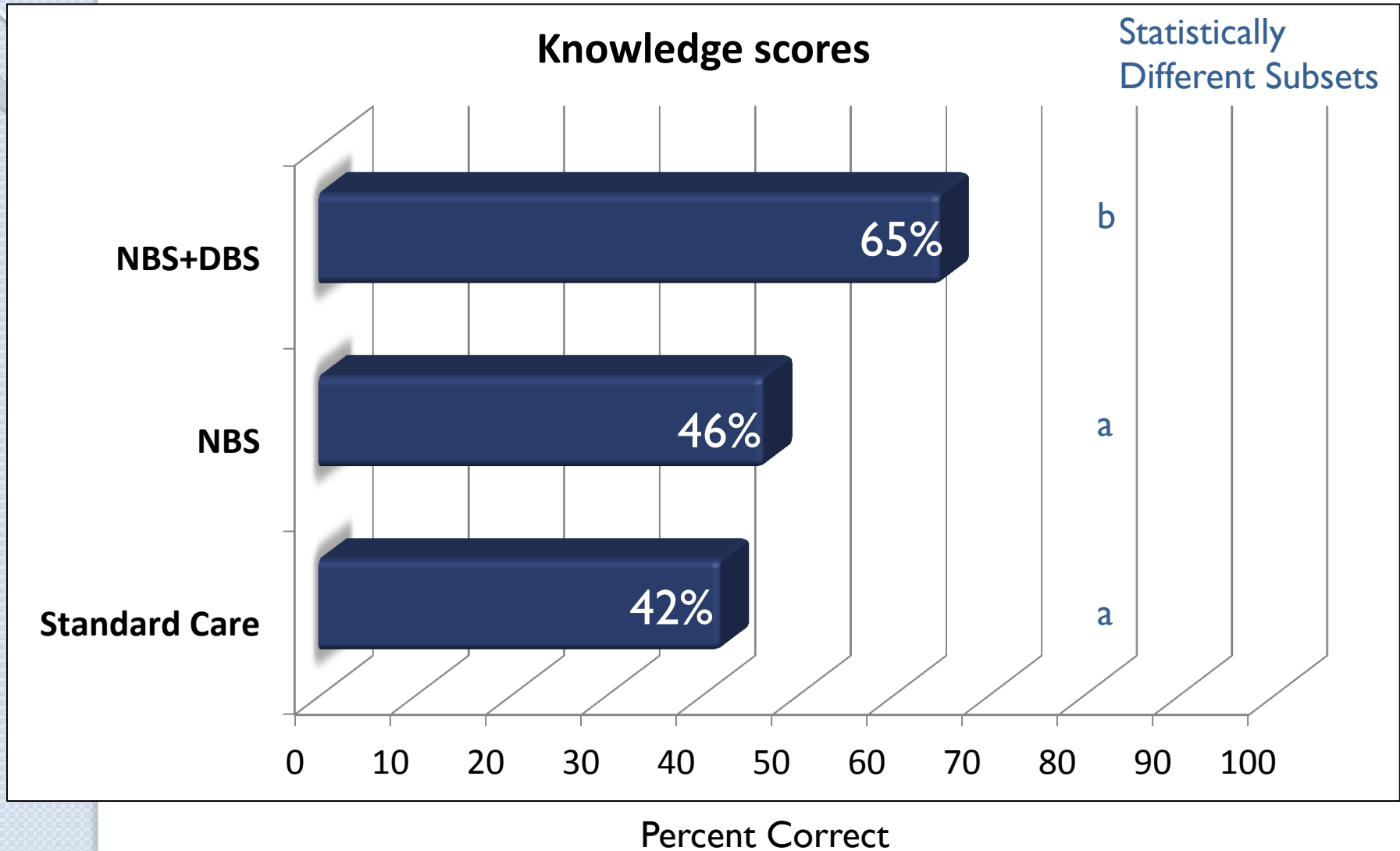


Knowledge about NBS by Ethnicity

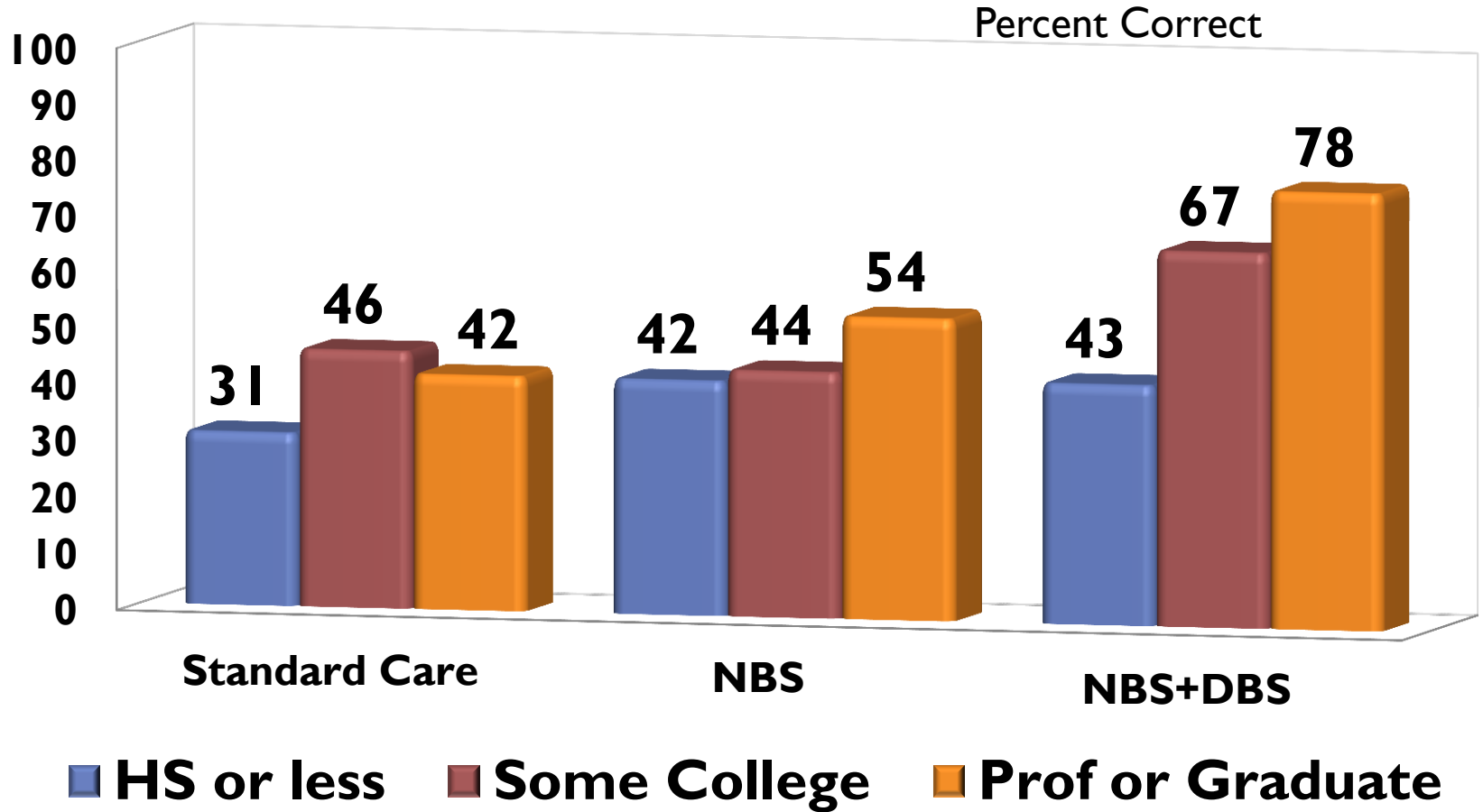
Percent Correct



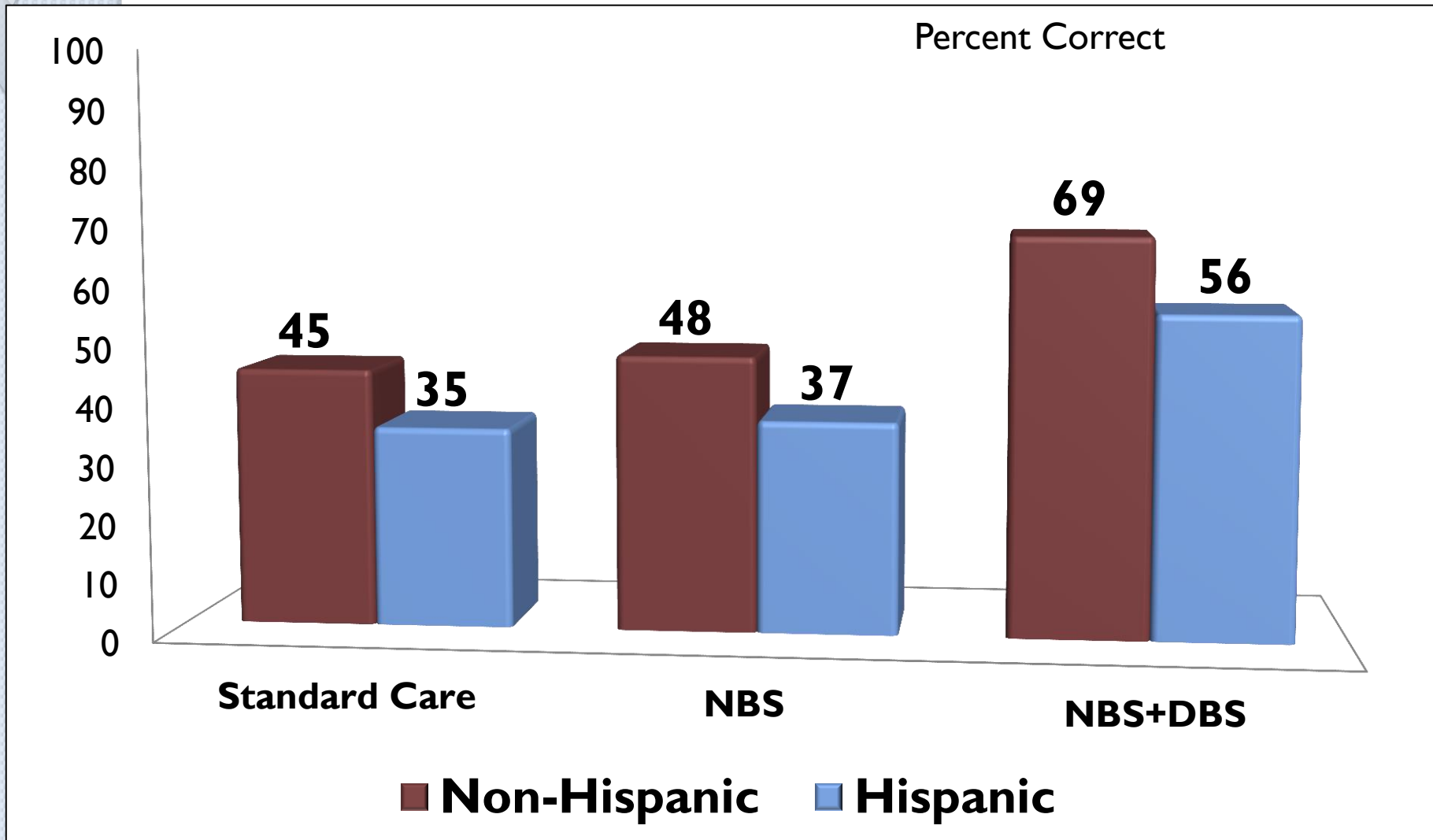
Knowledge about DBS



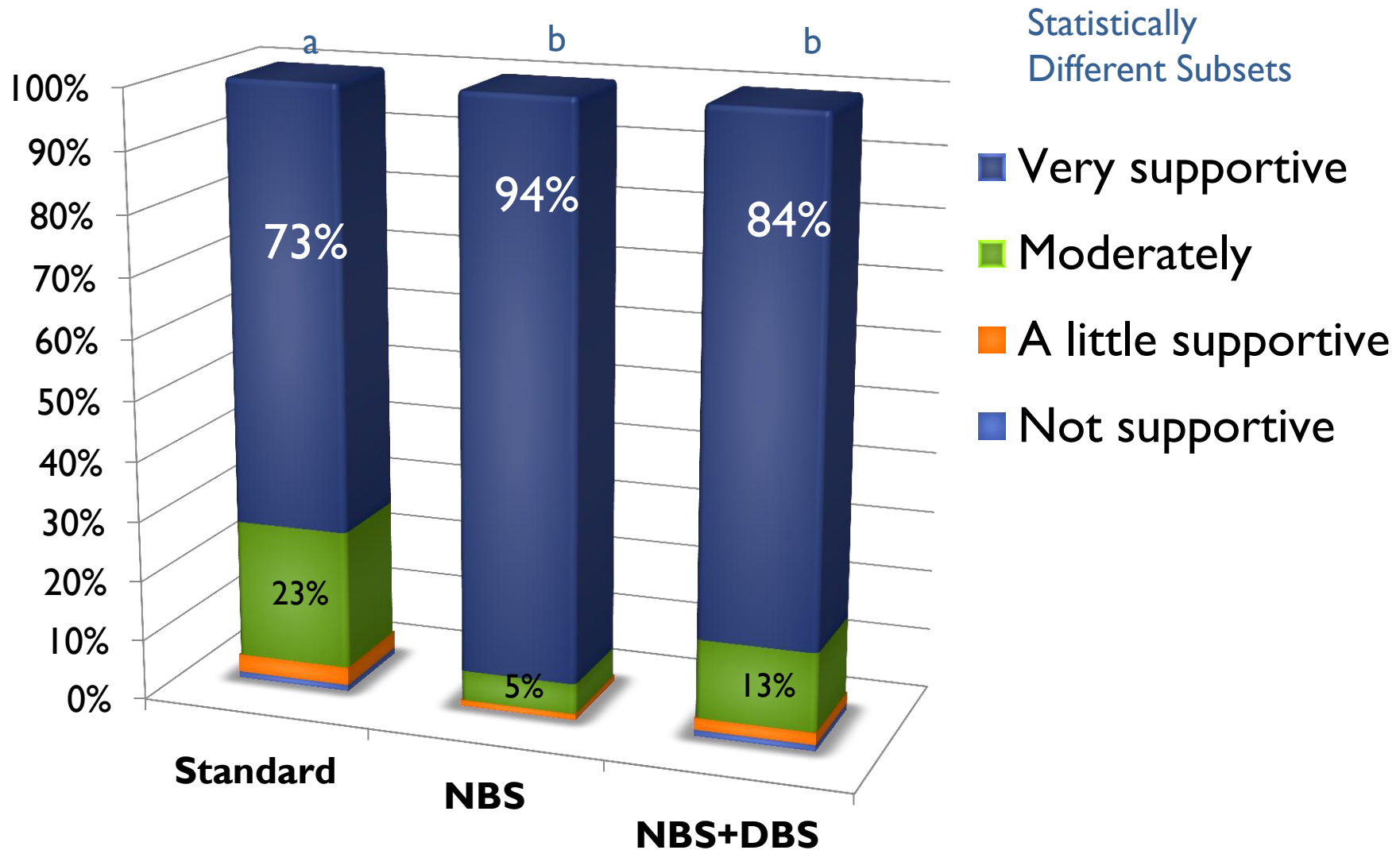
Knowledge about DBS by Education



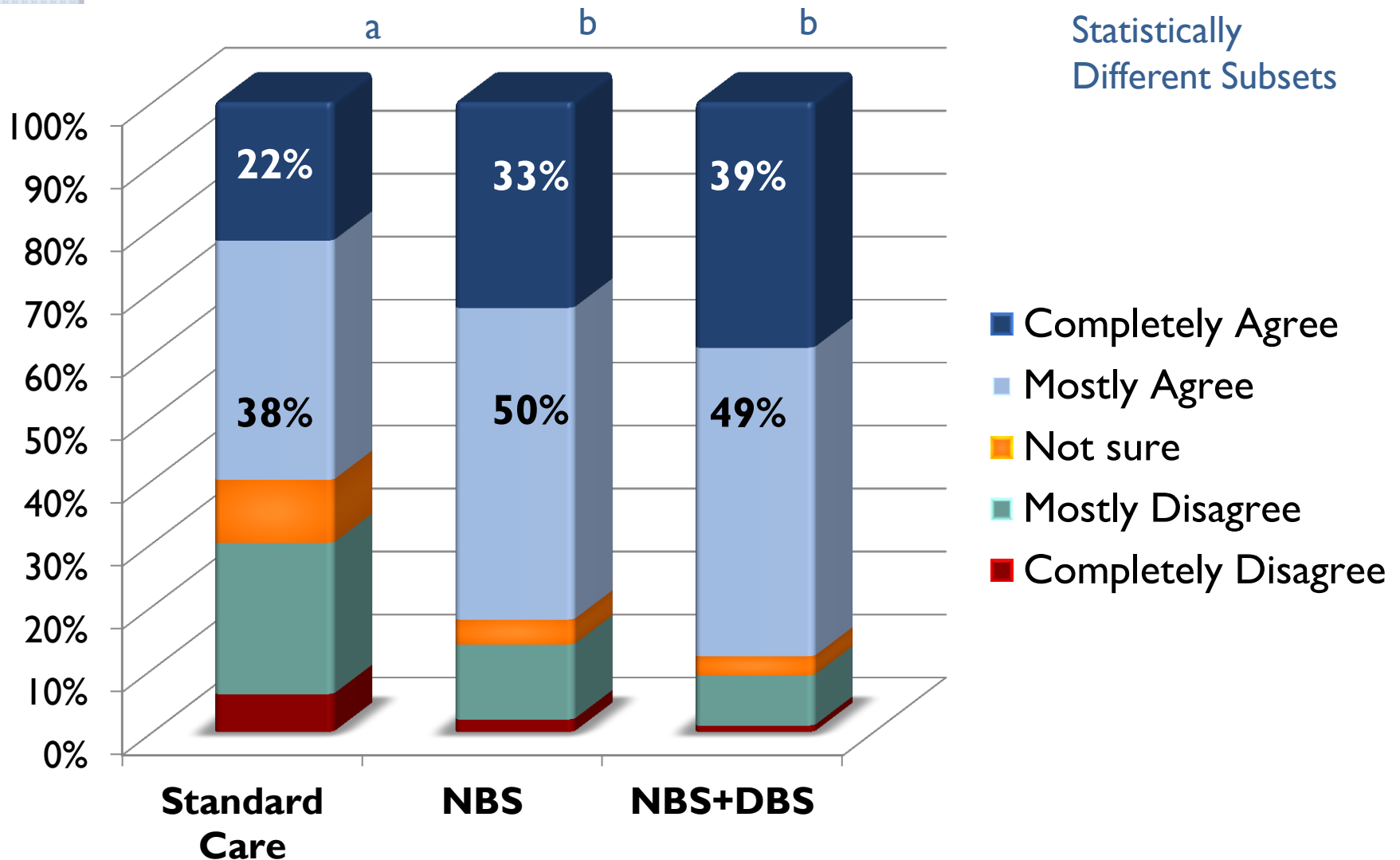
Knowledge about DBS by Ethnicity



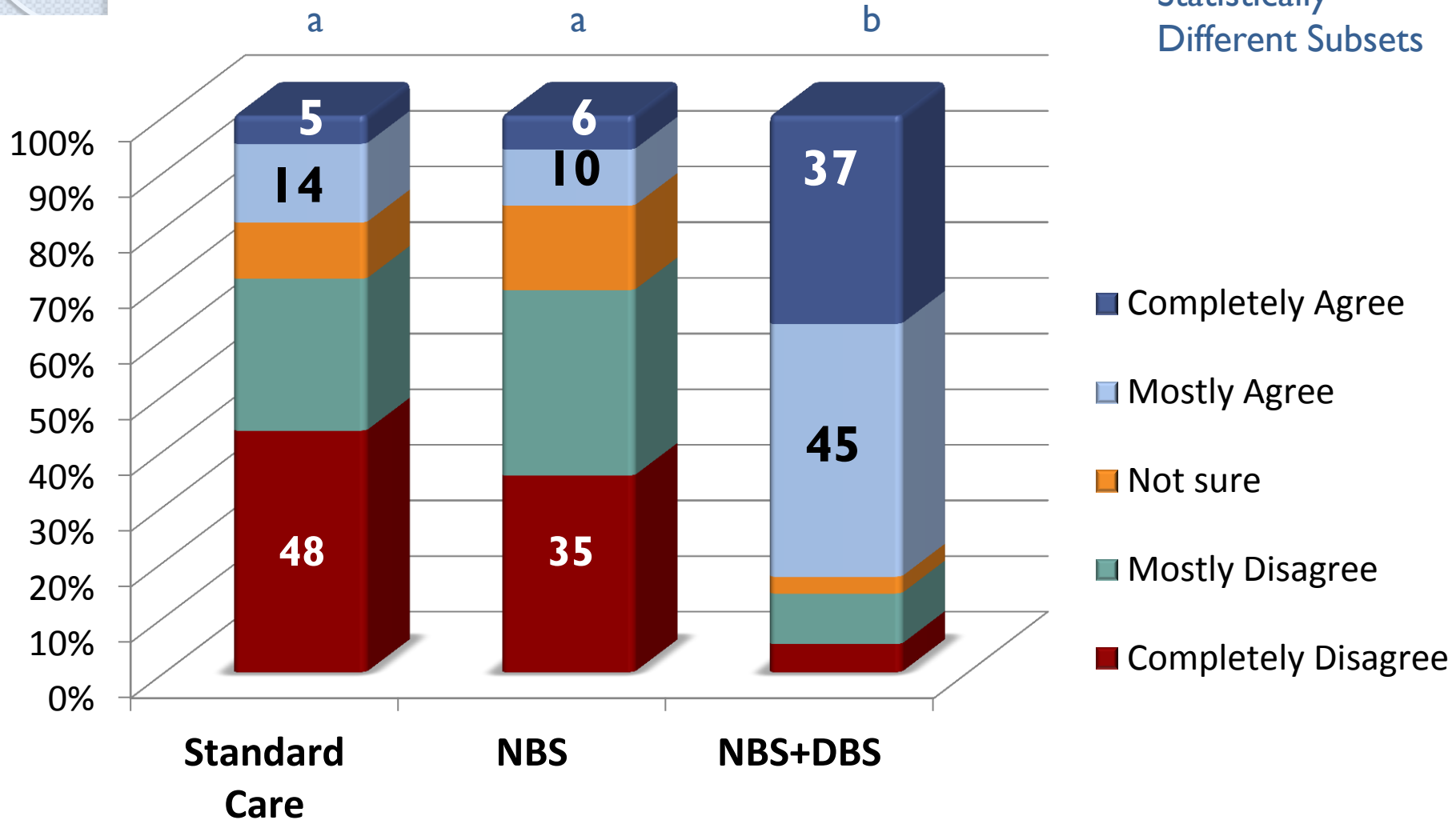
From your experience, and what you understand about newborn screening, how supportive are you of this program?



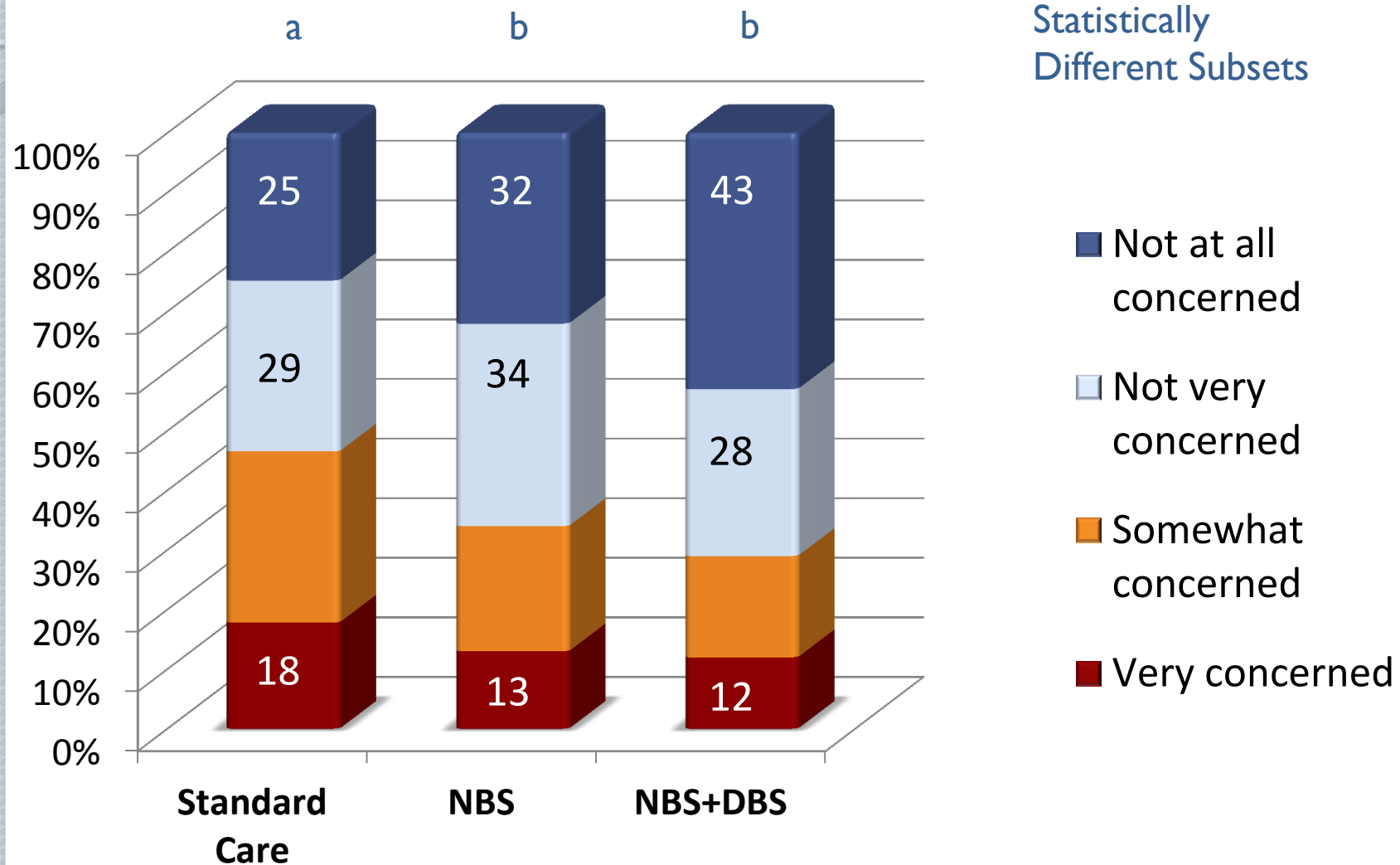
I am satisfied with the information I have received about newborn screening



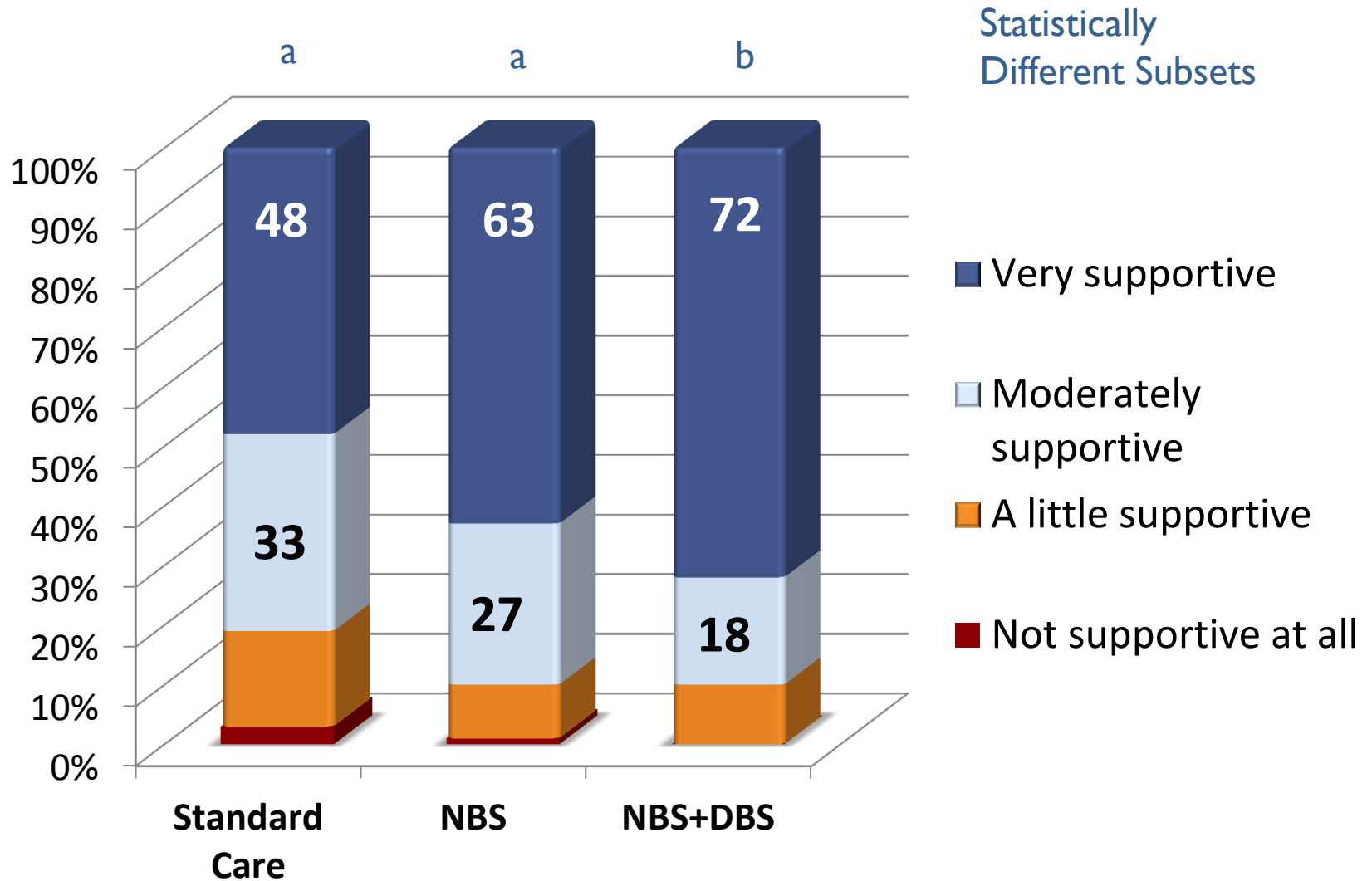
I am satisfied with the information I have received about the use of dried blood spots after newborn screening...



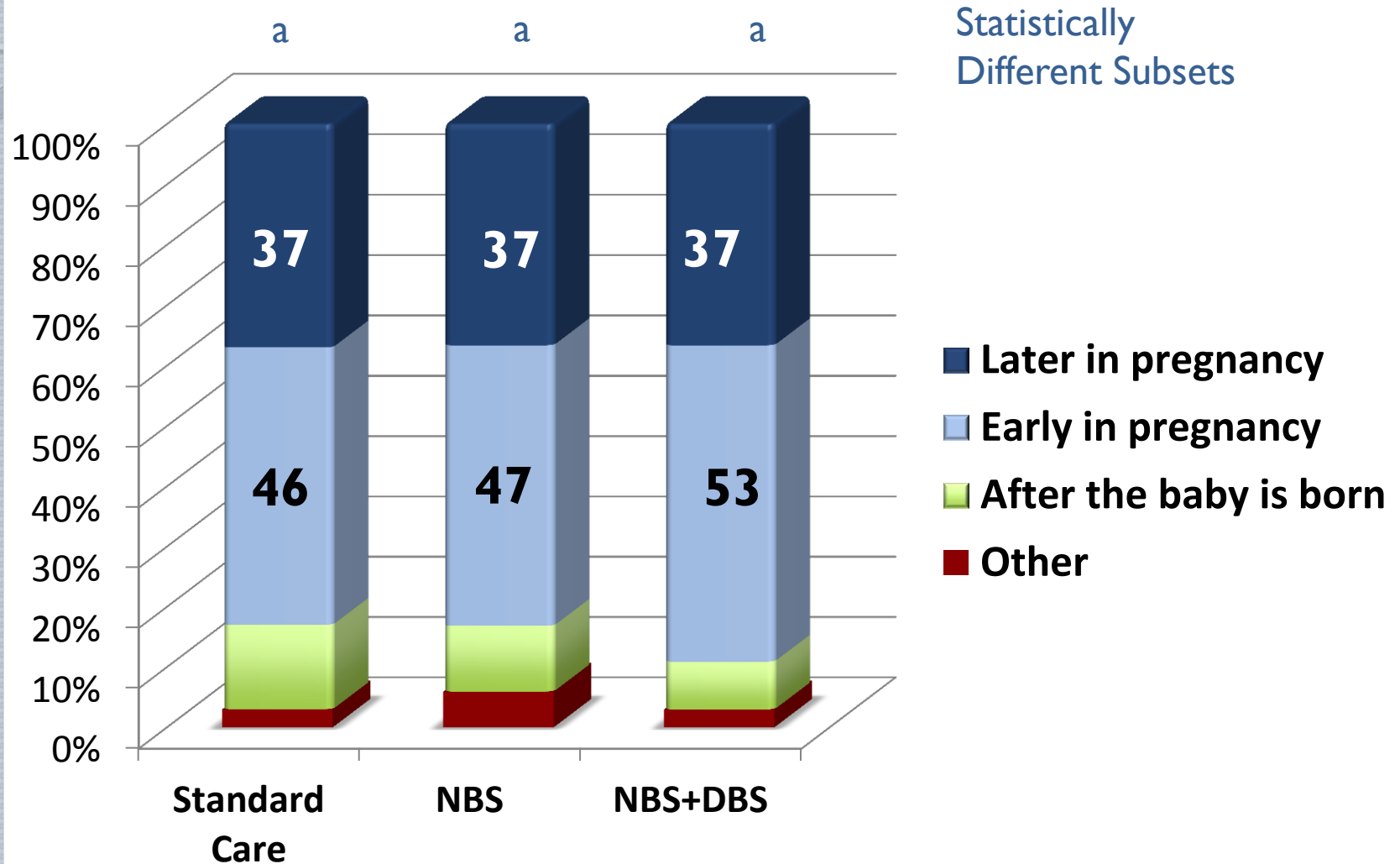
How concerned are you that your state saves the leftover blood spots from babies after testing is done?



How supportive are you of using these blood spots for research?



In your opinion, when would be the best time to educate parents about newborn screening?



Conclusions

- The dynamics of population screening for rare disorders makes adequate education a challenge
- Parents want information about NBS and DBS during the prenatal period
- Concise, high-quality multimedia education tools can increase knowledge and enhance support for these programs

Challenges...

- How to effectively incorporate multimedia educational tools into prenatal care?
- How to effectively promote choice about DBS in the prenatal environment for postnatal retention and use?

Thank You!

- Questions?

