

# Assessing Consumer Exposure to Newborn Screening

Environmental Scan

September 2011



# Awareness Campaign: Phase 1

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- Porter Novelli was engaged by Altarum and HRSA to assess field readiness for a newborn screening awareness campaign
  - Assess types of information consumers can access
  - Convene stakeholders for strategic planning and consensus building
  - Recommend next steps to build consumer awareness



# Environmental Scan Process

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- Consumer-facing
  - Parents
  - Parents-to-be
  - General population
- Guided, yet exploratory
  - Search terms
  - Selected sites
  - “See where it leads”
- Comprehensive
  - Campaign inventory
  - Literature review
  - Media audit
  - Stakeholder organization identification
  - Web scan



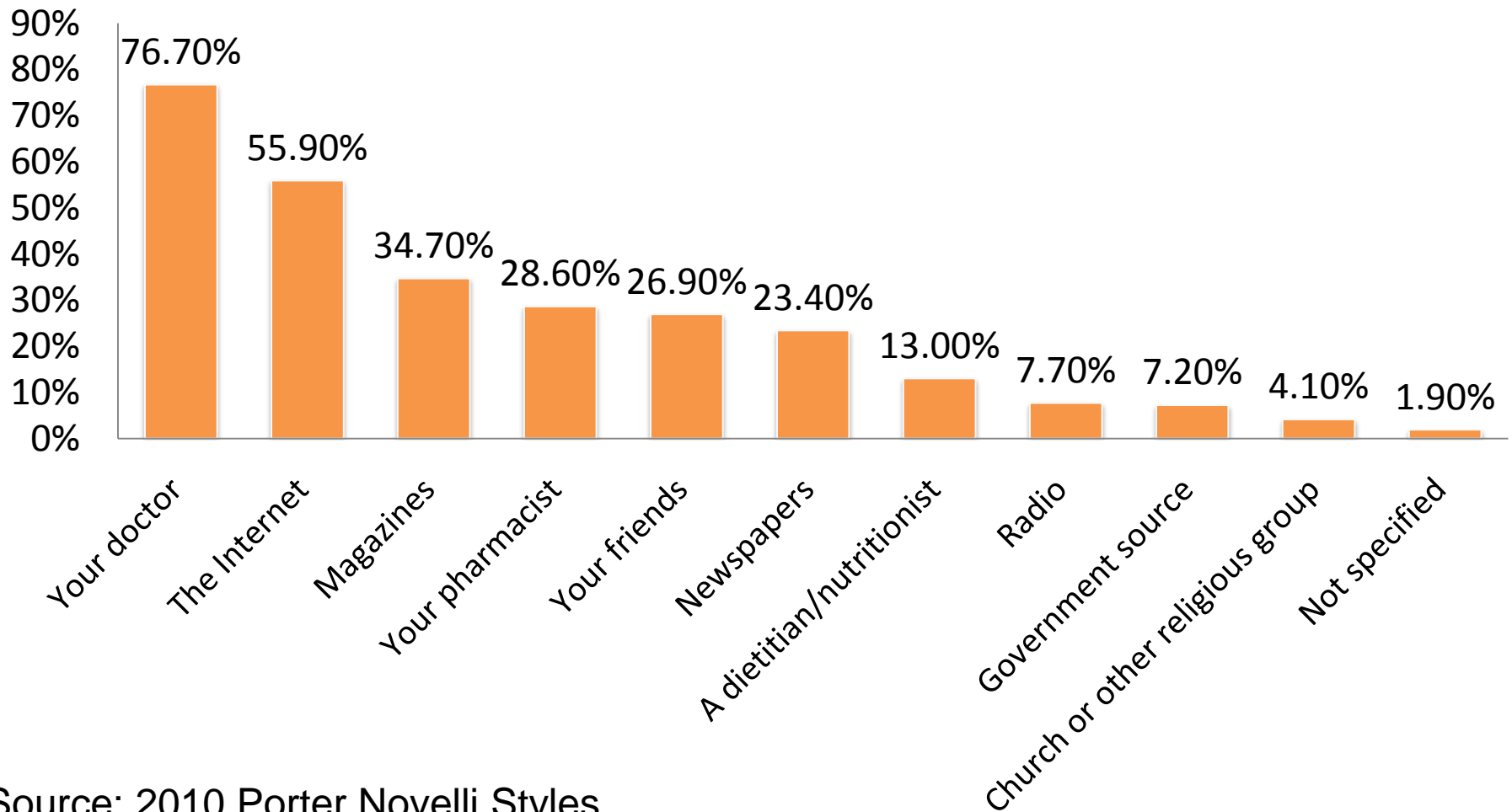
# Through consumers' eyes

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- Guiding question
  - “What is available for consumers about newborn screening?”
- Key questions
  - What messages are directed towards consumers?
  - What channels target consumers with newborn screening messages?
  - What is the depth and range of information that is directed towards consumers?



# Sources respondents turn to most often for health and nutrition information



Source: 2010 Porter Novelli Styles

# CHANNELS & MESSAGES

Internet

Health Care Providers (HCPs)

Media

Community Organizations & Campaigns

Academic Literature\*



# Who is on the internet?

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- Most frequently referenced sites
  - CDC
  - AAP
  - March of Dimes
- Other sites in web search
  - [www.nlm.nih.gov/medlineplus/newbornscreening.html](http://www.nlm.nih.gov/medlineplus/newbornscreening.html)
  - [www.kidshealth.org](http://www.kidshealth.org)
  - [http://en.wikipedia.org/wiki/Newborn\\_screening](http://en.wikipedia.org/wiki/Newborn_screening)
  - [www.wadsworth.org/newborn](http://www.wadsworth.org/newborn)
  - [www.cff.org](http://www.cff.org)
  - [www.americanpregnancy.org/](http://www.americanpregnancy.org/)
  - [www.webmd.com](http://www.webmd.com)



# What is on the internet?

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- CDC, AAP, and March of Dimes websites include
  - Definition of newborn screening
  - Impact on child health: individual and societal
  - Early diagnosis and treatment
  - State-specific screening
  - Explanation of the screening procedure, timing





# What do HCPs provide?

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- Sampling of hospital websites
  - Explanation of newborn screening
  - Condition descriptions
  - State-specific information
  - Links to AAP and ACMG
- Sampling of pediatrician websites
  - Links to AAP and ACMG



# What's in the media?

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- Scanned 299, reviewed 88 articles (29%)
  - From web, newswires, newspapers, medical journals
  - National and local
  - Primary topics of focus: education, policy, disease-specific issues
  - Mostly positive in tone, with some neutral, less than 5% negative
- Newborn Screening Awareness Month



# What do other sources provide?

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## Organizations

- Resources for consumers
  - American Academy of Pediatrics
  - Genetic Alliance
  - March of Dimes
  - National Newborn Screening & Genetics Resource Center of the US
  - Save Babies through Screening Foundation
  - National Healthy Mothers, Healthy Babies Coalition

## Campaigns

- General
  - Saving Babies Through Screening
- Disease-specific
  - SCID Newborn Screening Campaign
  - CARES Foundation



# Consumer Perspective

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- Brief review of academic literature to understand parent attitudes
- Parent perceptions of newborn screening
  - Generally positive
  - Part of newborn process in hospital
  - Some anxiety about false negatives/positives
  - Some conditions sound familiar (i.e. sickle cell), other conditions are not familiar
  - Limited understanding over residual storage and research



# Summary

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- Basic information about NBS is available on sites accessed easily through Google (including stakeholder websites)
  - More information is available on sites that are less accessible for consumers.
- Media coverage is limited, though generally positive
- Absence of ongoing comprehensive campaign
- Additional research is needed to assess what pediatricians and hospitals provide parents-to-be

