

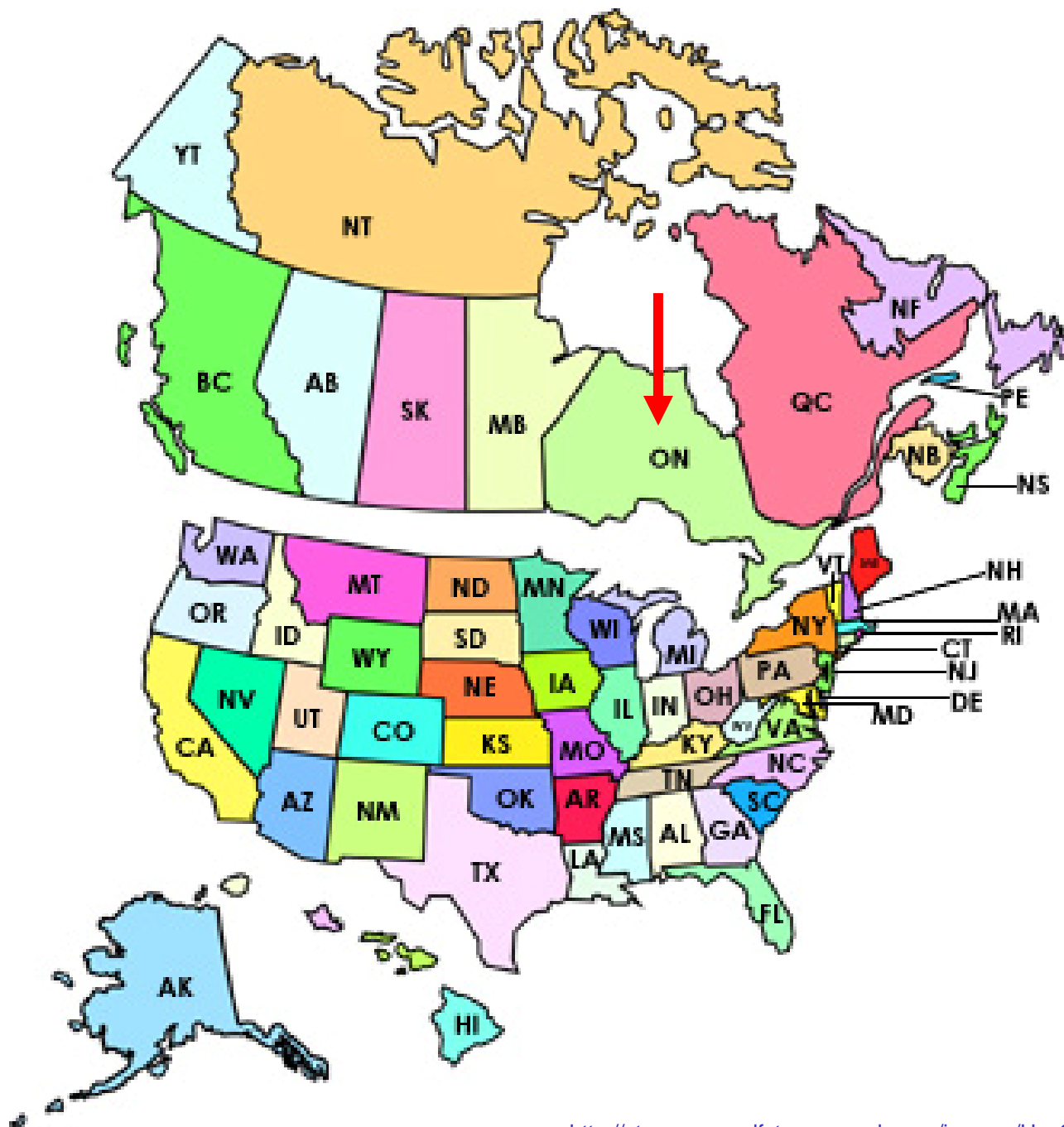
# Development of a Parent Education Strategy For Expanded Newborn Screening in Ontario: A Survey of Prenatal Educators' Practices and Perspectives

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M. Cloutier, C. Honeywell,  
N. Barrowman, and P. Chakraborty

Ontario Newborn Screening Program





# Objectives



- a) Learn what prenatal educators in Ontario are currently teaching expecting parents regarding NBS
- b) Learn about the NBS training needs of prenatal educators so that we can develop an education strategy
- c) Enhance parental awareness and knowledge

# Methods

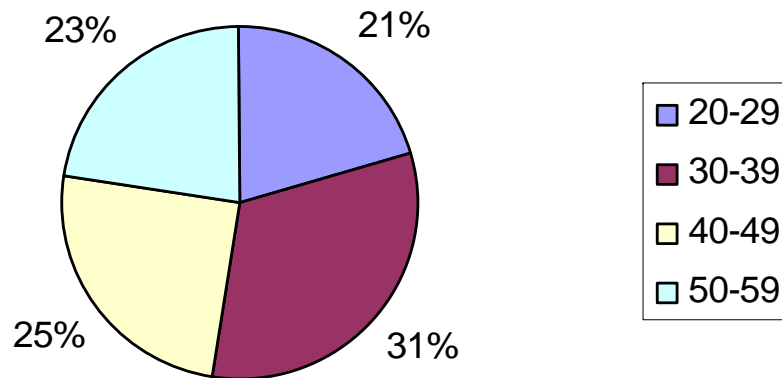


- 28-item online survey
- Sent through a provincial listserv of prenatal educators
- Descriptive statistics

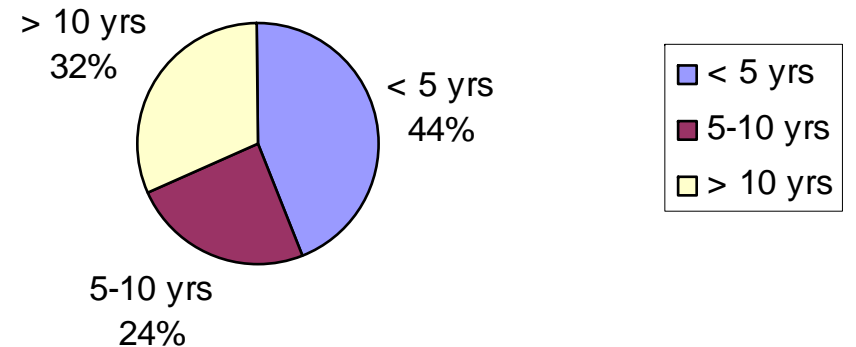
# Respondents' Characteristics



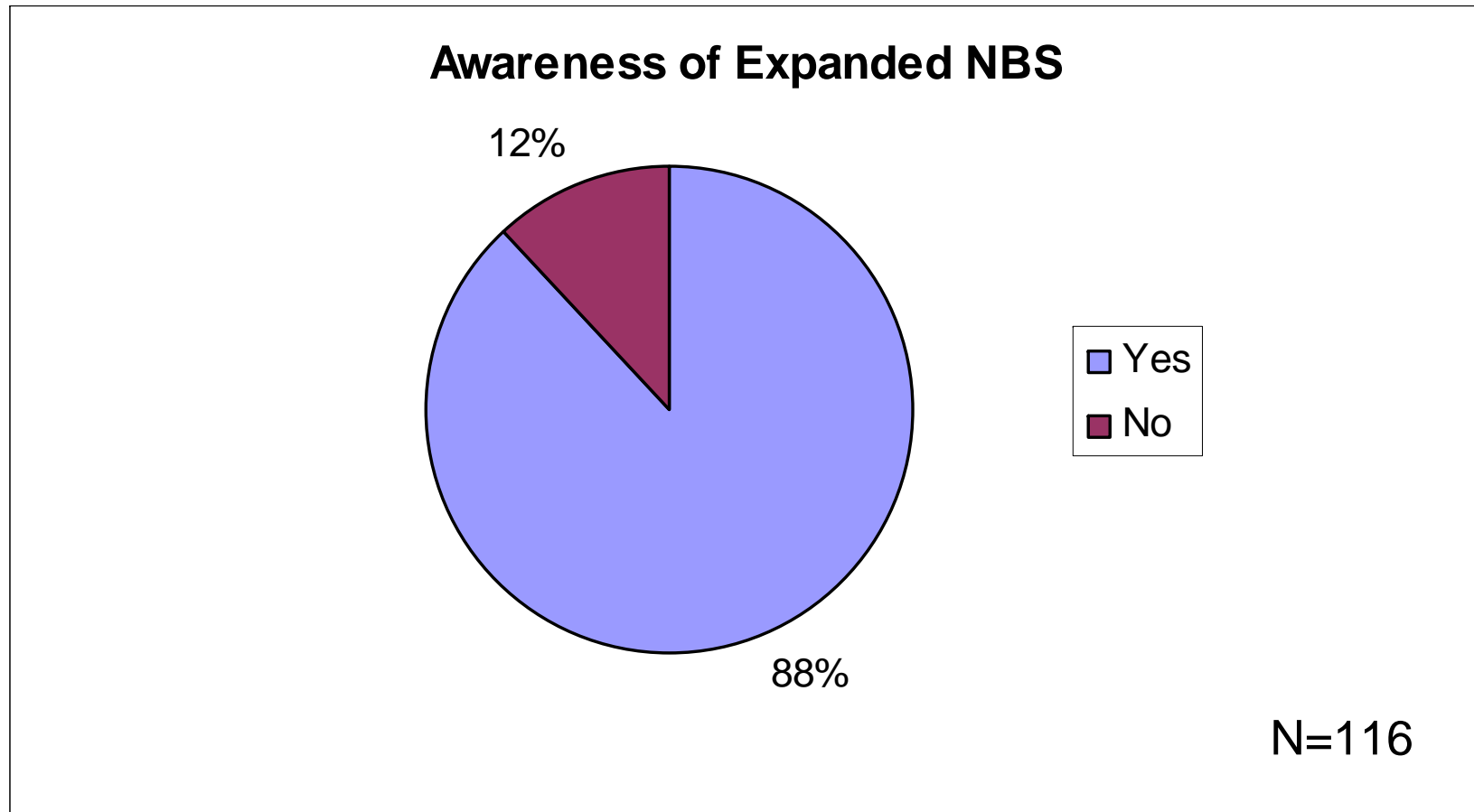
### Age of Respondents



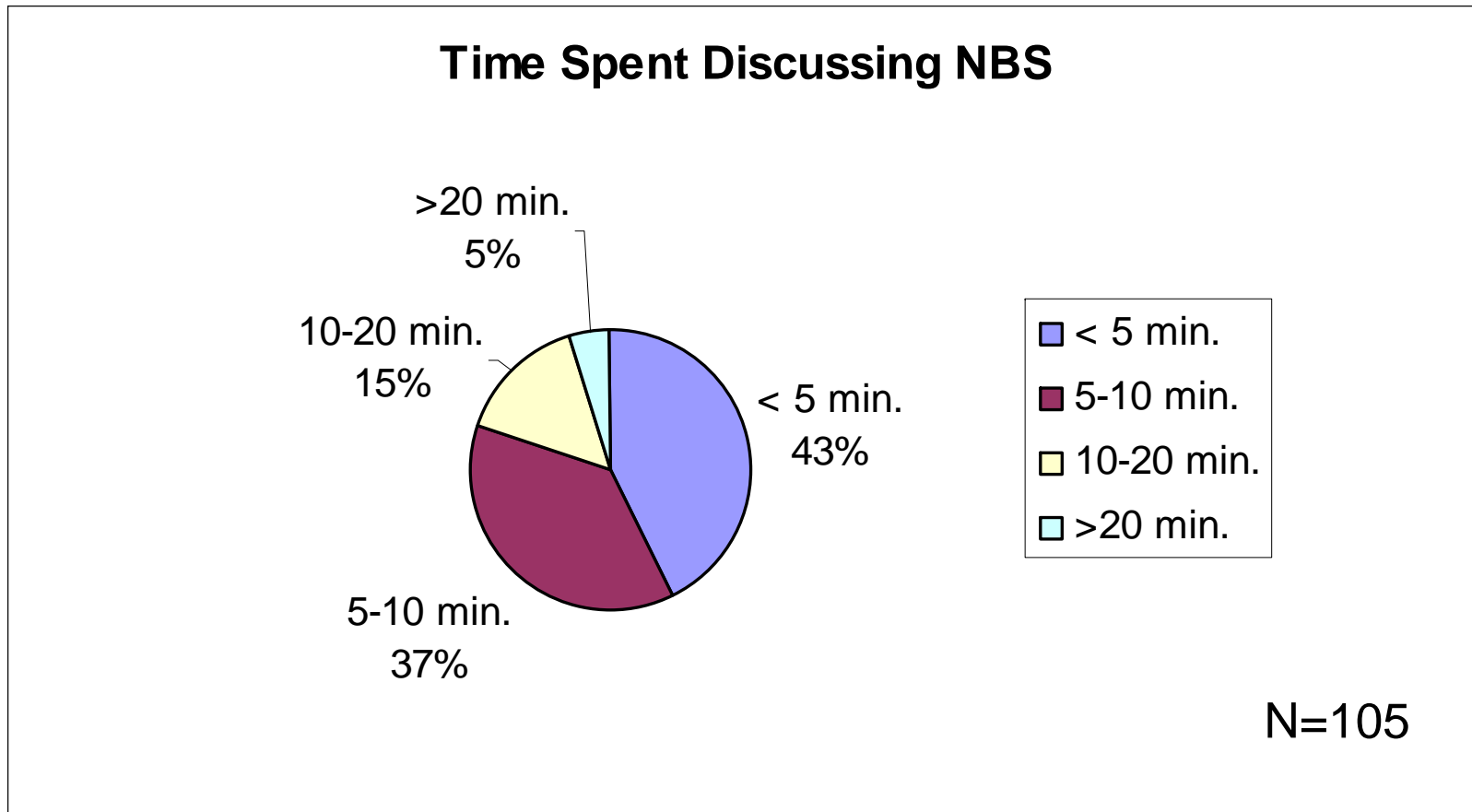
### Years of Experience



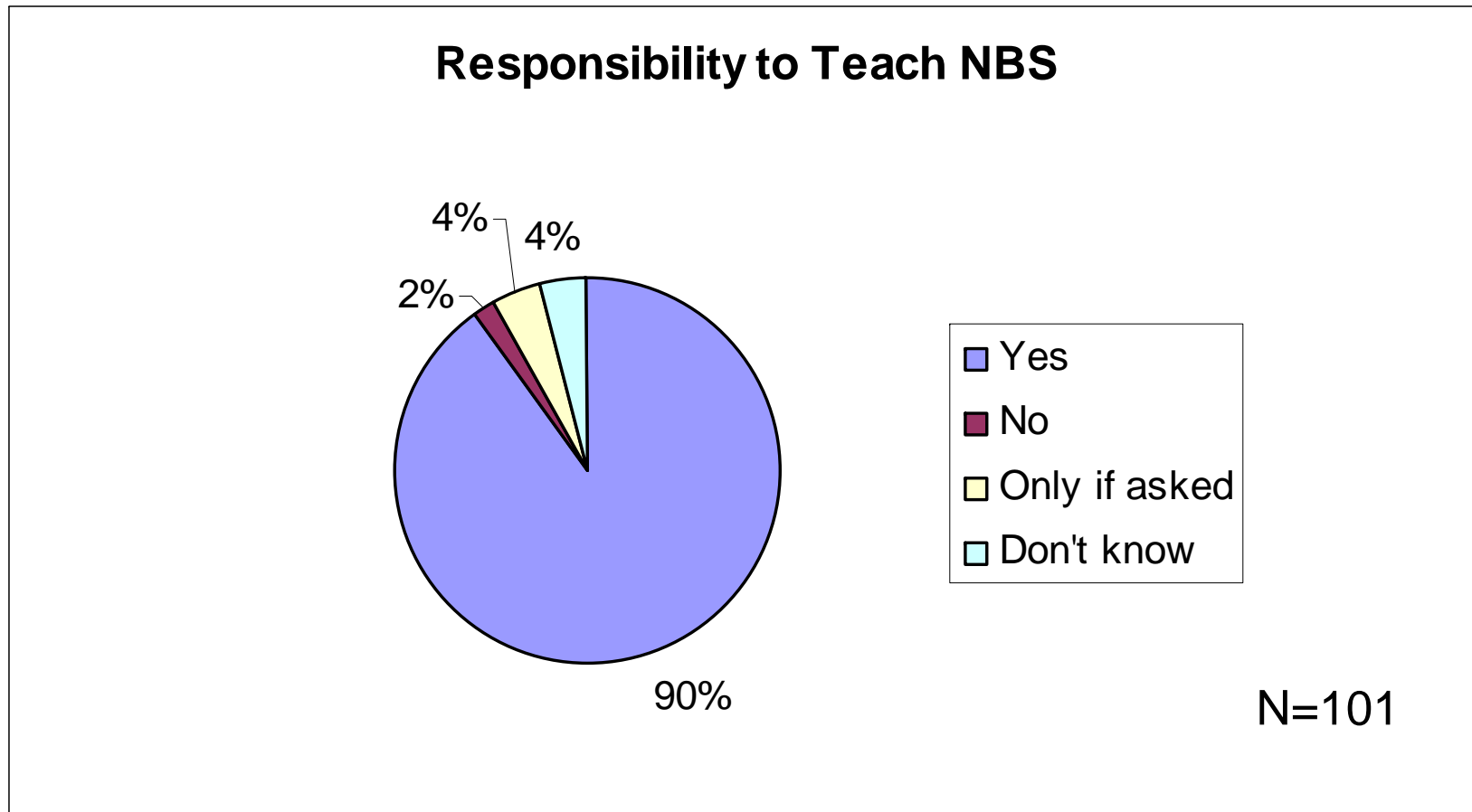
# Are you aware that the ONSP has greatly expanded since April 2006?



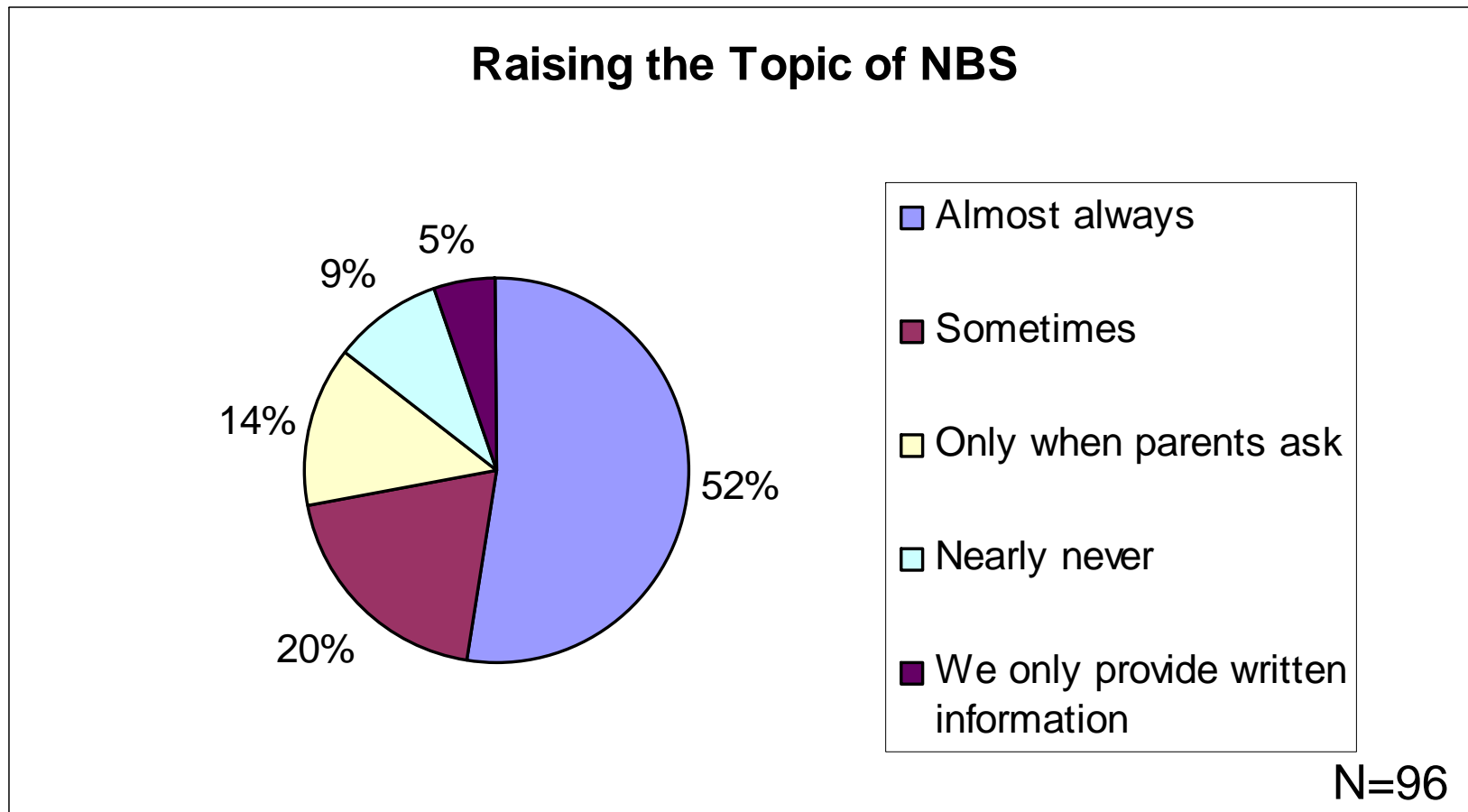
# How much time, on average, would you say your program spends on the topic of expanded newborn screening?



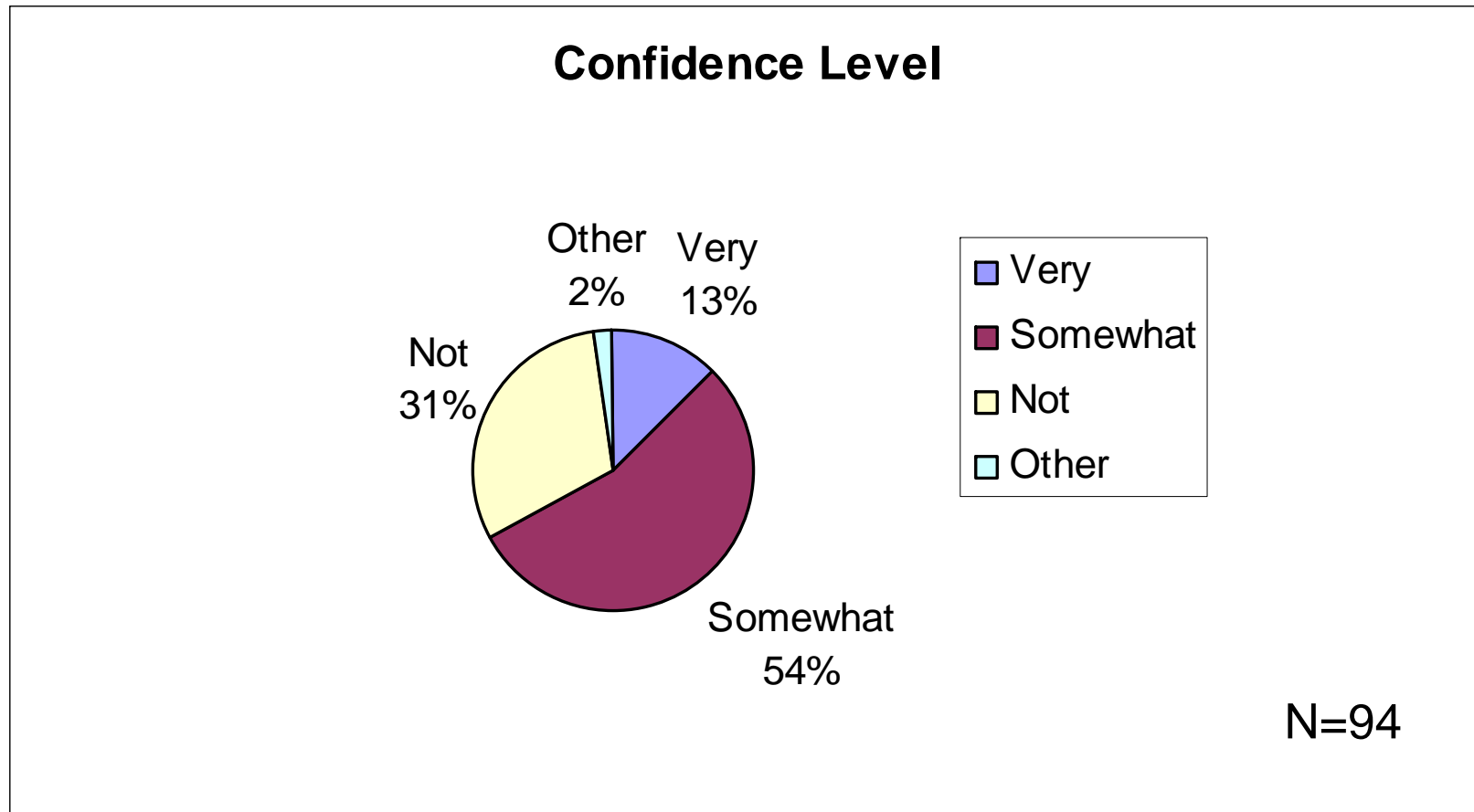
# Do you think that prenatal education programs have a responsibility to cover the topic of newborn screening?



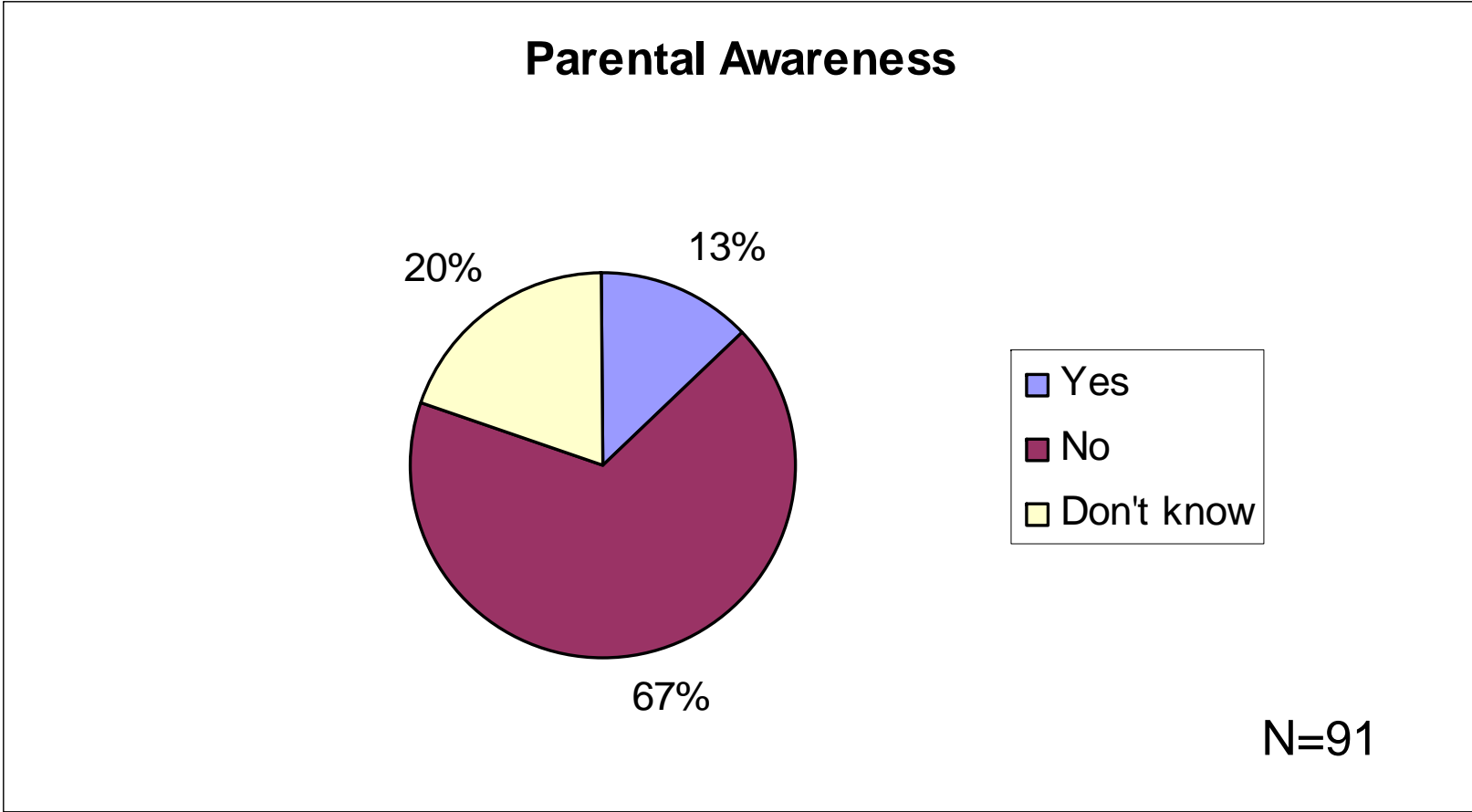
# How often, on average, would you say you raise the topic of expanded newborn screening with expecting parents?



# Do you feel confident in your ability to educate about expanded newborn screening?



Based on your experience, are parents generally already aware of expanded newborn screening when they attend your classes?



# Theme: Sharing Responsibility



- “I am responsible in telling the expectant parents what the screen is and what it covers. Those individuals who want detailed information should be directed to their Primary Provider.”
- “It should not be the sole responsibility of the prenatal educator to inform the client of newborn screening.”
- Challenge: not all expecting parents will attend prenatal classes

# Key Messages For Parents



- The topic of NBS is vast and can be overwhelming.
- We have developed a **teaching guide** for prenatal educators.

# Key Messages For Parents



- 1) **Newborn Screening is important for every baby because every baby is at risk**
- 2) **The diseases are serious and could be life-threatening if untreated**
- 3) **You can't tell by *looking* at a baby if he or she has one of the diseases**
- 4) **A common misconception for parents is: “these diseases don't run in my family so my baby is not at risk”**
- 5) **After the screen, parents will receive a phone call if the baby needs more tests**

# [www.newbornscreening.on.ca](http://www.newbornscreening.on.ca)



## Ontario Newborn Screening Program



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An area of this website especially for parents.

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### Parents



### Health Care Providers



### Public





**Contact Us:**  
**GeneticsEducator@cheo.on.ca**

Mireille Cloutier: (613) 737-7600 x 2354

Christina Honeywell: (613) 737-7600 x 3474