

To screen or not to screen: why do parents accept or decline newborn bloodspot screening?

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INTRODUCTION

Despite the longstanding availability of newborn bloodspot screening (NBS), very few studies have explored what leads parents to accept or decline NBS for their child. As part of a larger study, we collected and explored this information to allow better understanding of the parents' decision-making process and reasoning related to refusal of newborn screening, which in turn could inform program development. We also explored the reasoning behind parental decline of NBS as reported by healthcare professionals (HCPs).

METHODS

Semi-structured interviews were conducted with parents (n=29) and HCPs (n=19) in Ontario and Newfoundland and Labrador. Interviews were audio-recorded and transcribed verbatim prior to analysis. The transcripts were analyzed using a thematic approach. The protocol has been published in full.¹

RESULTS

Although NBS was not always presented as a choice to parents, almost all respondents reported reasons why they accepted or would have accepted the test. Parents most commonly reported accepting NBS because it was in the best interest of the child: it's important and good information to have, it's important to know early if the child has a serious disease, and it's important to provide treatment quickly if needed.

"I would 110% recommend doing the newborn screening and [spouse] and I are the type of people that would have went along with it anyway because we would want the best for our child and if finding out what those you know any medical issues that our child would have in order for us to be prepared we would want to know the information." – true positive, Newfoundland and Labrador

Some parents also expressed a sense of trust in the healthcare system and healthcare authorities.

"I guess maybe, I don't know to say, but I sort of trust that the, you know, the clinicians and the policy makers and whoever it is that guides the newborns or puts together the newborn screening program and did, you know, select the conditions that you're testing for, and the process it involves, like I sort of...you know there's a lot of babies born in Ontario, so I guess I also trusted the process as well, like... Yeah. I mean, if the fact that it's Ontario-wide, I just...I guess I felt it was...like I felt confident in it too." – screen negative, Ontario

"This is how it goes especially as a first time mom too you don't really question what they're doing you assume this is the protocol and how everything is supposed to go so you're kind of trusting really in the people around you the physicians and the nurses and stuff to kind of do what they do best because you're new at it." – false positive, Newfoundland and Labrador

Only two parents in this study, both from Ontario, declined NBS. In both cases decisions were taken in line with parental beliefs of what was in the best interest for their child. In one instance, a parent reported declining NBS because they did not want to cause any pain in the baby, and because the test was unnecessary due to the fact that the older siblings were healthy. The second parent reported declining because faith in God ensure the health of the child. In both cases, past experiences related to healthcare influenced their decision.

"We had a terrible experience. I think this was just torturing the baby... the way we were handled there, like, the baby was handled with... (...) Now, this time, I found out... the midwife told me that actually is not mandatory, so then I said – well, then I won't even have it. So actually the third baby doesn't have it done, because I said I... I feel I don't need to because ah, there's no point. Um...we no... none of us... not the first two kids have any of those um, like, illnesses, (...) so I just don't believe my baby, the third one now, the two-month old has anything to do with that, you know." – decline, Ontario

"I had a life experience myself where I had uterine cancer that um, was healed sort of miraculously: the doctors can't explain how it went away. (...) And, um, now I trust Him [God] completely for...everything that happens to my life and my health. And...same with my kids. So that was my deciding factor." – decline, Ontario

Almost half of HCPs in our sample experienced at least one NBS decline in their career. Consistent with parental comments they reported that parents had declined NBS for several reasons: not wanting the baby to be poked/hurt, not wanting to government to have the baby's DNA, the perception that the test was not beneficial or that their baby was not at risk, and trusting God when it comes to their child's health.

CONCLUSION

The child's 'best interests' was a common standard against which parents held screening. These results are in line with a recent review's findings.² The role of parents' prior experiences also appears key, as reported by a previous study.³ This study explores individual parental decisions, an aspect currently lacking in the literature.² Addressing concerns regarding pain – for example through pain management best practices – could alieve some burden. Further exploration regarding appropriate accommodation of faith requires further study. Further research could also explore whether parents decline NBS for reasons extrinsic to the healthcare system (non-health related personal experience or knowledge), or intrinsic to the system, such as negative previous experience with HCPs. As for reasons to accept NBS, our study suggests that they are in line with the existing goals of NBS programs.

References

1. Nicholls SG, et al. Stakeholder attitudes towards the role and application of informed consent for newborn screening: Study protocol. *BMJ Open* 2014;4:e006782
2. Nicholls, SG, et al. Benefits and burdens of newborn screening: public understanding and decision-making. *Personalized Medicine* 2014; 11(6) 593-607
3. Nicholls, SG and Southern, KW. Parental Decision-Making and Acceptance of Newborn Bloodspot Screening: An Exploratory Study. *PLoS One*; 8(11): e79441

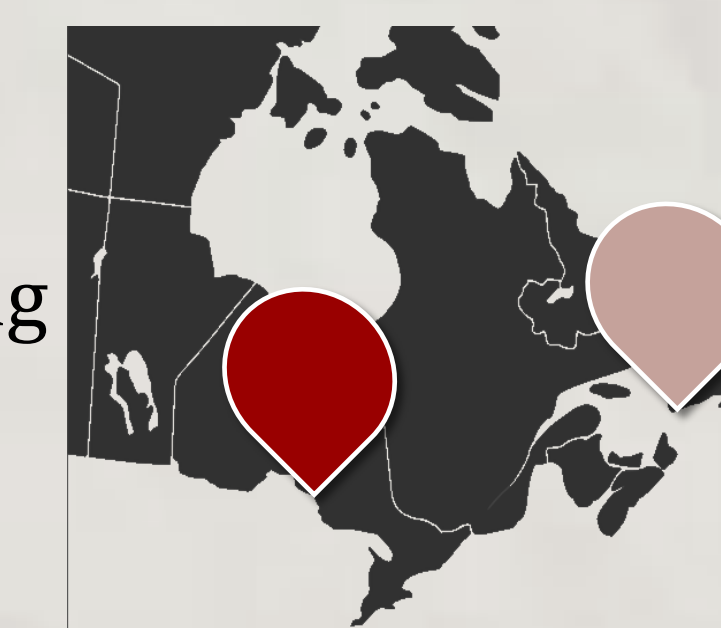


Figure 1. Participants were recruited from Ontario and Newfoundland and Labrador

Use the QR code to access the full Study Protocol
Nicholls et al. *BMJ Open* 2014;4:e006782
doi:10.1136/bmjopen-2014-006782

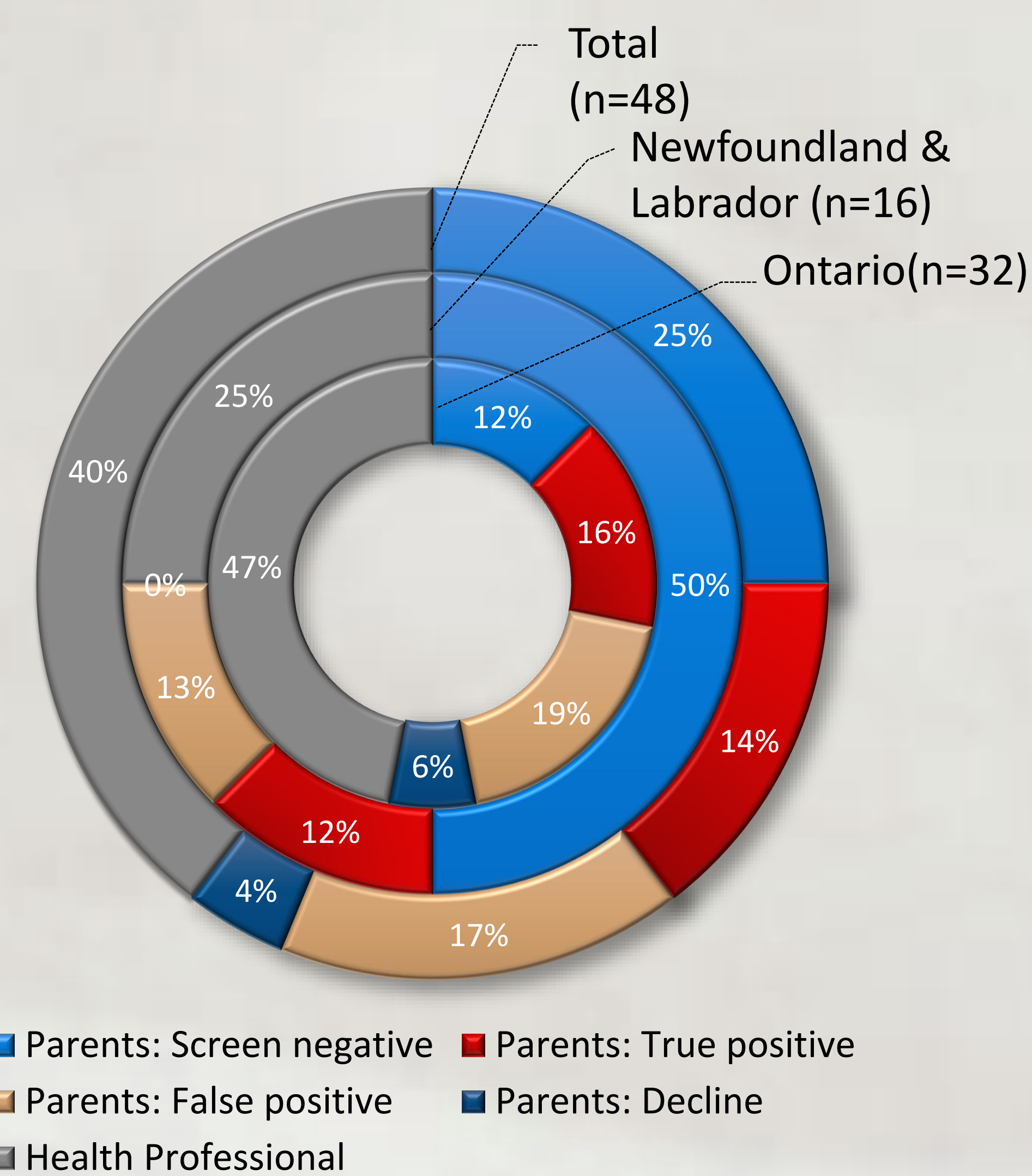


Figure 2. Percentage of participants by stakeholder type and location