

# Alberta's NMS Program

## Engaging with Parents to Improve Resources

September 2022

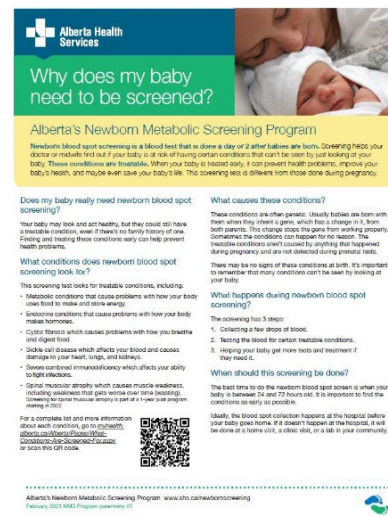
The Newborn Metabolic Screening (NMS) Program is a population-based screening program that provides newborn blood spot screening to all infants born in Alberta. It works toward minimizing morbidity and mortality of Alberta infants through early diagnosis and treatment of screened conditions. The program engaged parents in 2020-2022 to help inform improvements to a key program resource (see figure 1) and how information is shared with parents about newborn screening in Alberta.

A total of 35 parents completed an online survey in 2020 and another 16 parents participated in phone interviews to gain feedback on the content, clarity, and appearance of the resource *Why does my baby need to be screened?*. Based on the parents' recommendations, the resource was reformatted to have more white space, condition specific details were removed and information added to improve the resource for better understanding. See figure 1 for a visual comparison of the updated version of this resource with the original.

**Figure 1: NMS Parent Resource "Why does my baby need to be screened?"**

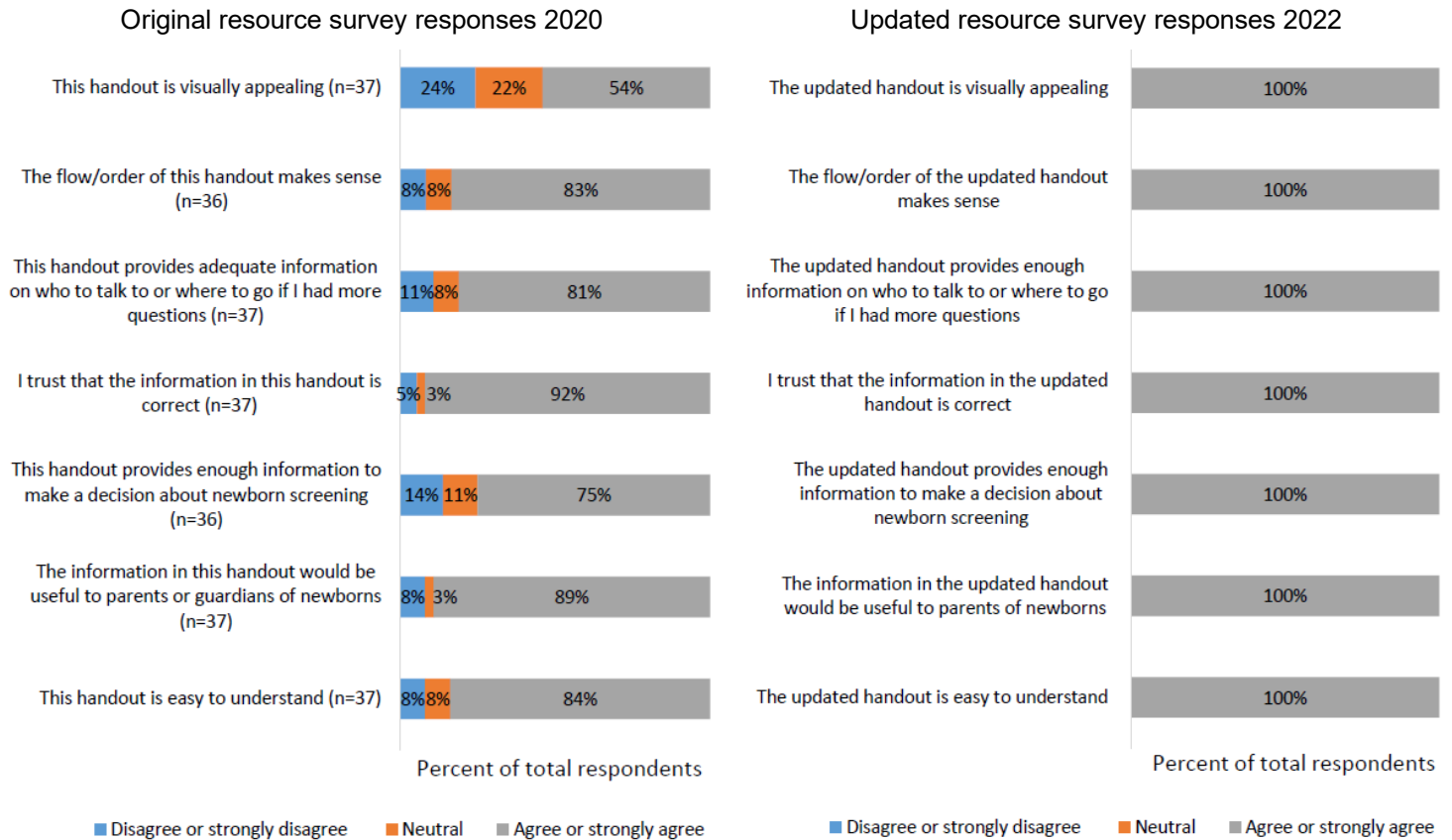
Original version

Updated version



A follow-up online survey was conducted with 16 parents who participated in the 2020 telephone interviews. Of these, six parents completed the updated resource online survey in 2022. The purpose was to verify whether the updated resource adequately reflected the feedback previously provided. Overall parents responded positively to the changes in the updated resource. See figure 2 for comparison between 2020 and 2022 surveys' Likert scale questions.

**Figure 2:** Comparison between Likert scale questions from original resource and updated resource



The follow-up survey results clearly reflect an improvement in the content and design of the updated resource. By engaging parents to get their perspectives, we were able to improve this key program resource in a way that facilitates their understanding of newborn blood spot screening, thus enhancing our patient & family centered care approach to early detection and treatment of screened conditions for infants in Alberta.