

Assessing the Experience of Parents of Newborns Diagnosed with a Condition through Michigan's Newborn Screening Program

2019 Newborn Screening and Genetic Testing Symposium
April 9, 2019

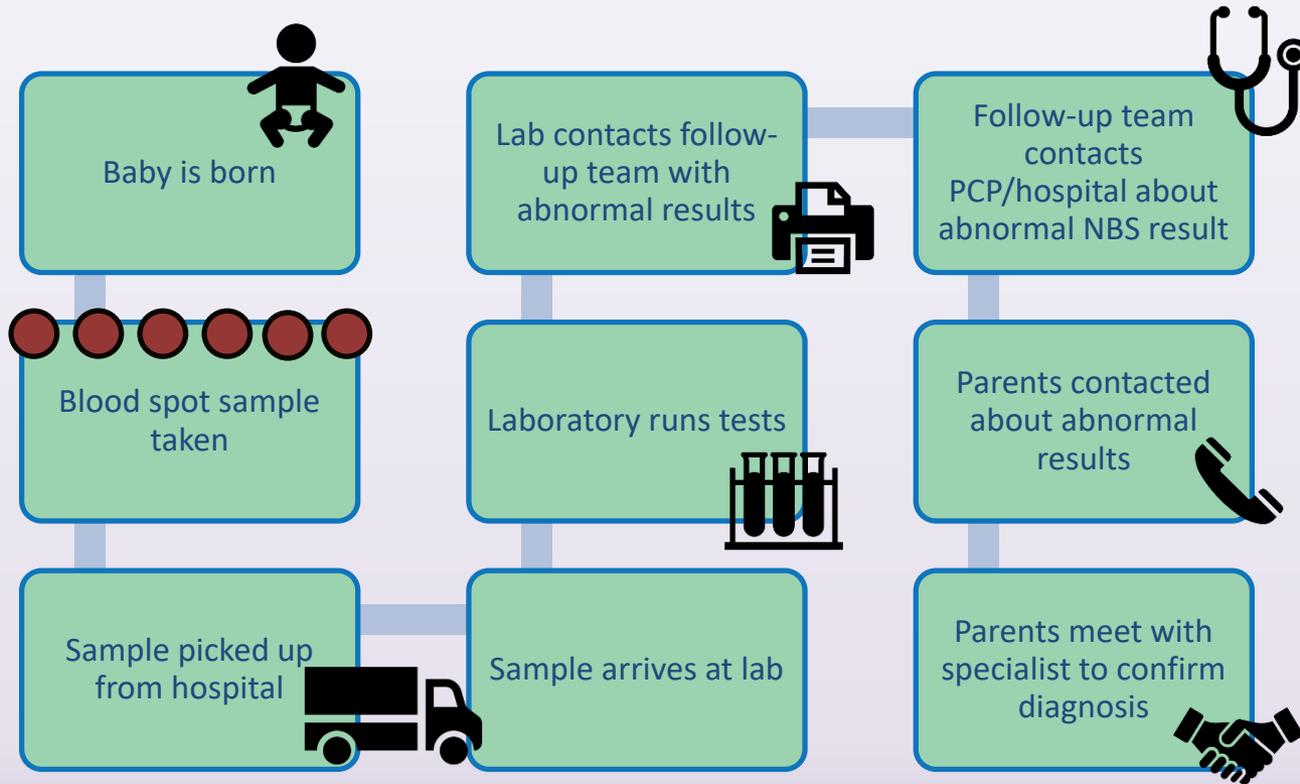
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Michigan Newborn Screening Follow-Up Program

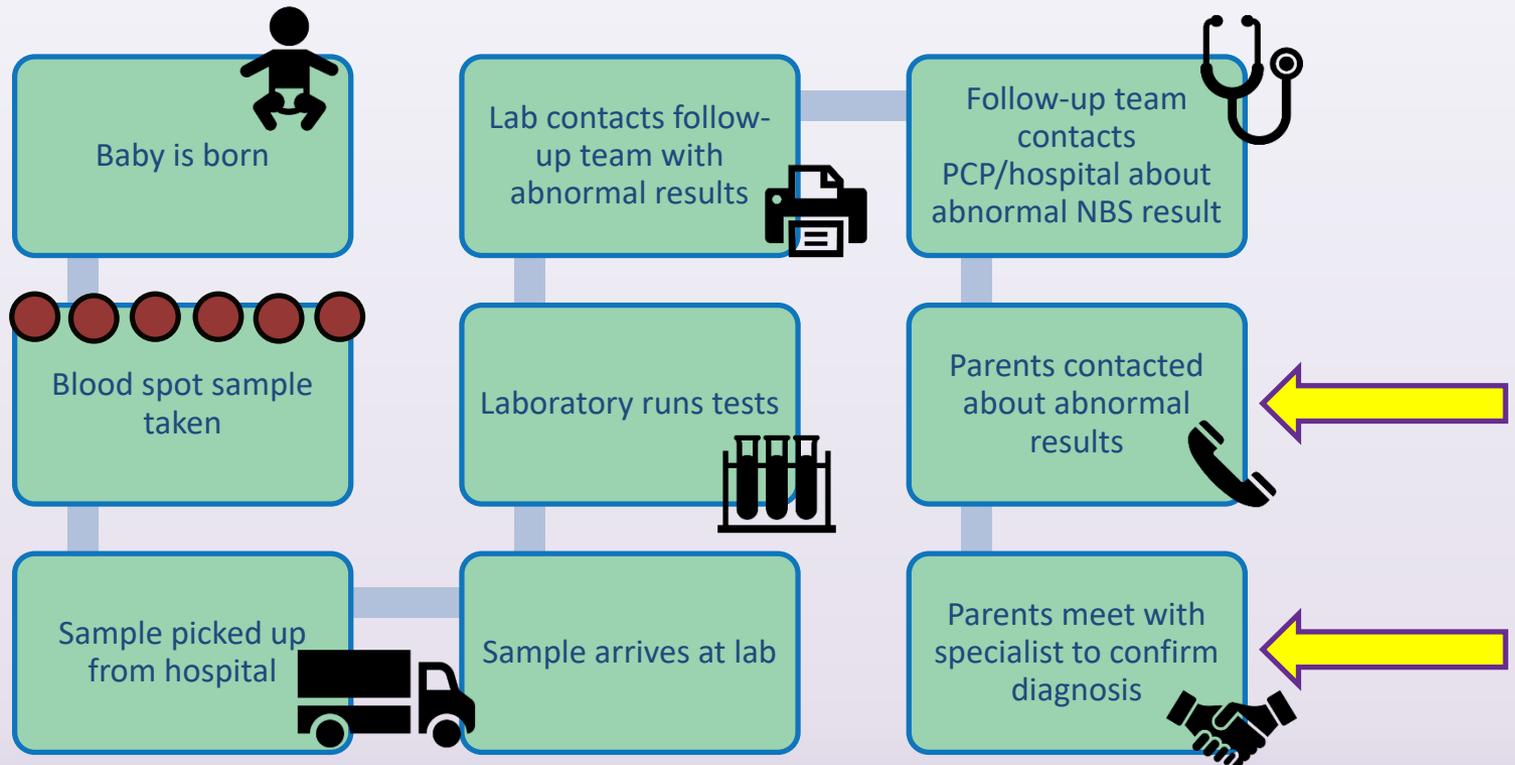
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Newborn Screening Process: Blood spot to diagnosis



Assess parent experiences



Parents learning NBS results and receiving confirmatory diagnosis

Parents contacted about abnormal results



- Parent contacted
 - In-person, over the phone, letter
 - By PCP, PCP office staff, specialist
- Specialist appointment scheduled
 - By PCP office or parent
- Specialist visit for confirmatory testing
 - Extra tests completed
 - Infant diagnosed or ruled-out

Parents meet with specialist to confirm diagnosis



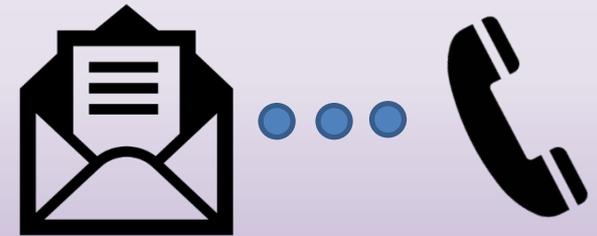
Assessing parent experiences with NBS process

- Survey parents of infants diagnosed with a condition identified through NBS
- Goals:
 - Receive feedback from parents about their experience with NBS
 - Identify areas of success and areas that need improvement within the NBS process
 - Develop resources and educational materials
 - Improve overall NBS experience for future families
- This study was approved by the MDHHS Institutional Review Board



Methods

- Follow-up team inputs limited contact info into Access database
 - Births from Jan 2017, June 2017, January 2018 – November 2018
- Introductory letter mailed
 - Parents contacted up to three times by phone
 - Phone survey completed or message left if no answer
 - Called during different days and times
- Closing letter and hard-copy survey sent if no contact after three attempts
- Results recorded in Access database



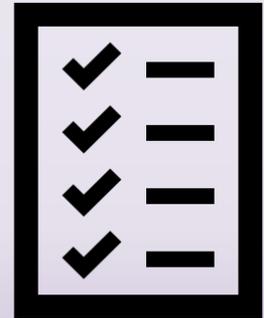
Survey Content

- 3 sections
 - Introduction
 - Confirms parent contact, asks if willing to participate
 - Learning the NBS results
 - How they were told, who told them, did they get enough info, satisfaction, feedback for improvement
 - Follow-up testing and visit with specialist
 - Scheduling appointment, information received, address any barriers, feedback for improvement

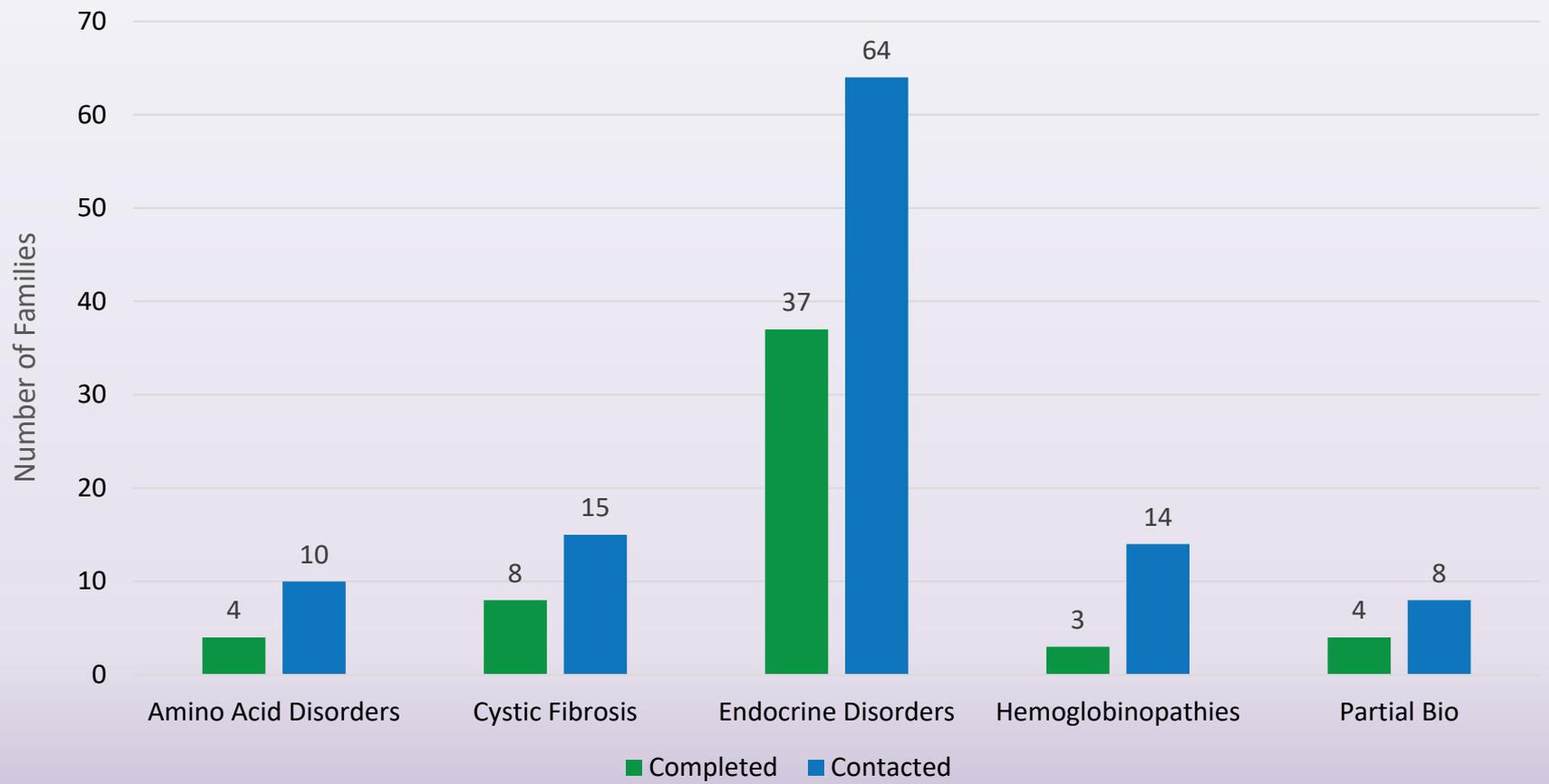


Survey Results

- Response rate
 - 111 parents contacted
 - 56 completed the survey (50%)
 - 68% over the phone
 - 32% returned hard copy survey
 - 6 refused (5%)



Conditions represented in survey respondents





Key results – Learning NBS Results

- NBS awareness

-  – 84% of parents aware of NBS before receiving their child's result

- 86% of respondents received NBS results by phone or in-person

- If received specific information on condition

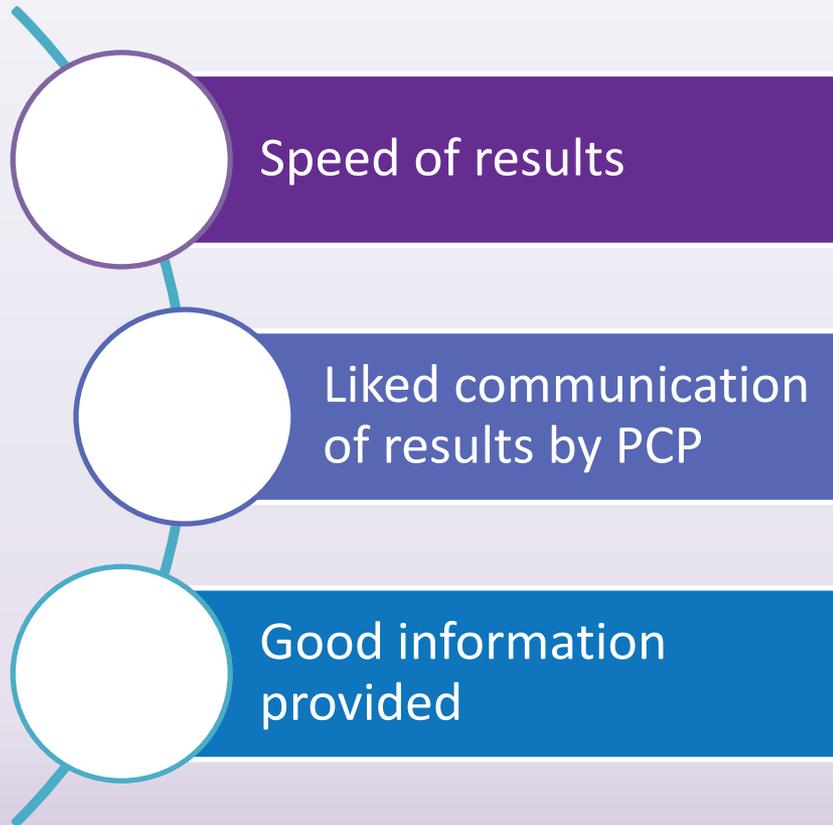
- More than half of respondents felt it was just the right amount
- More than one-third felt they didn't receive enough

- More than half satisfied with how NBS results were delivered

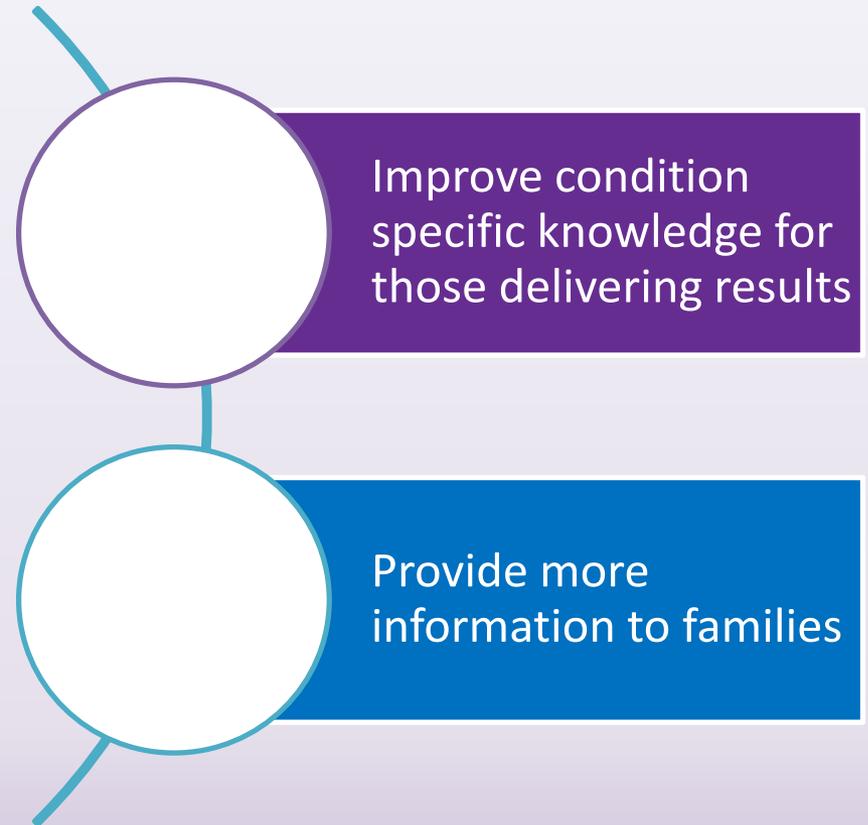


Parent feedback: Learning NBS Results

Positive feedback

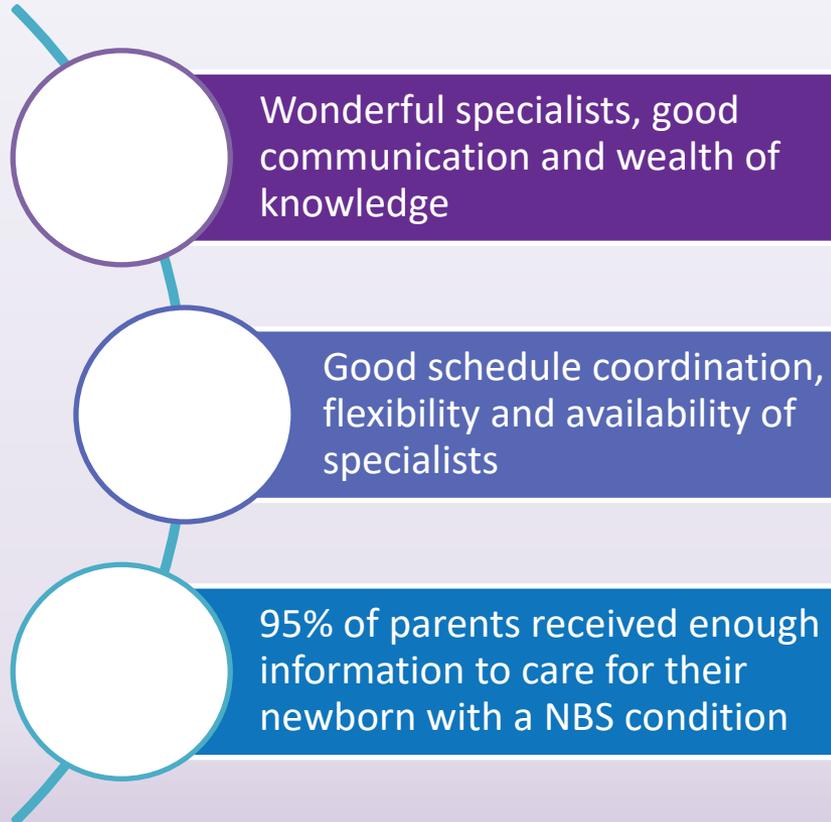


Areas for Improvement

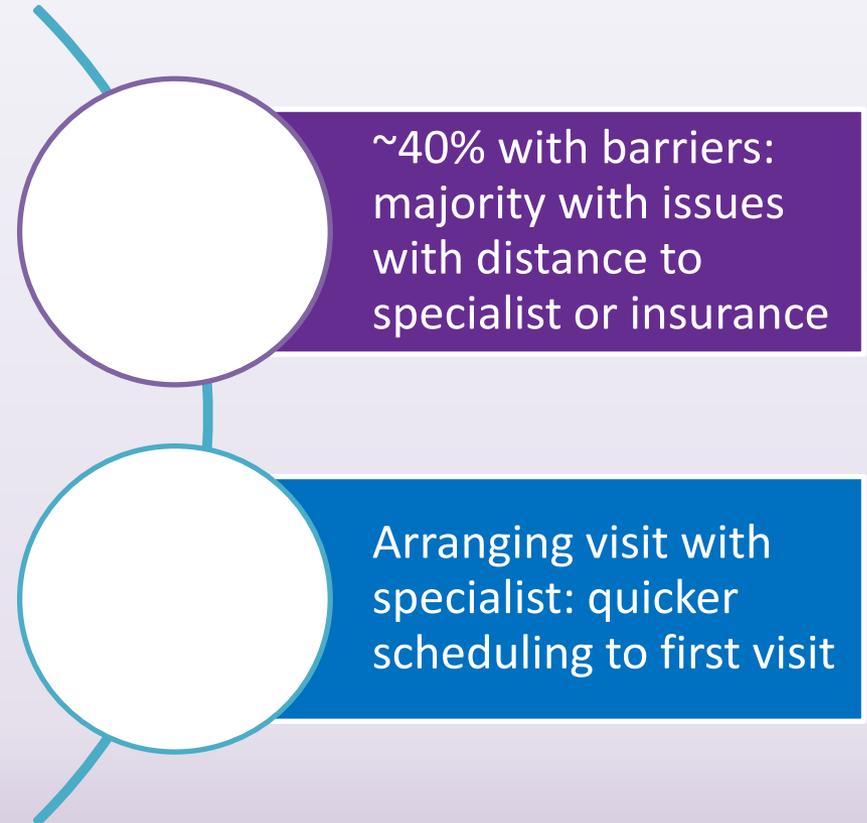


Parent feedback: Diagnosis with Specialist

Positive feedback

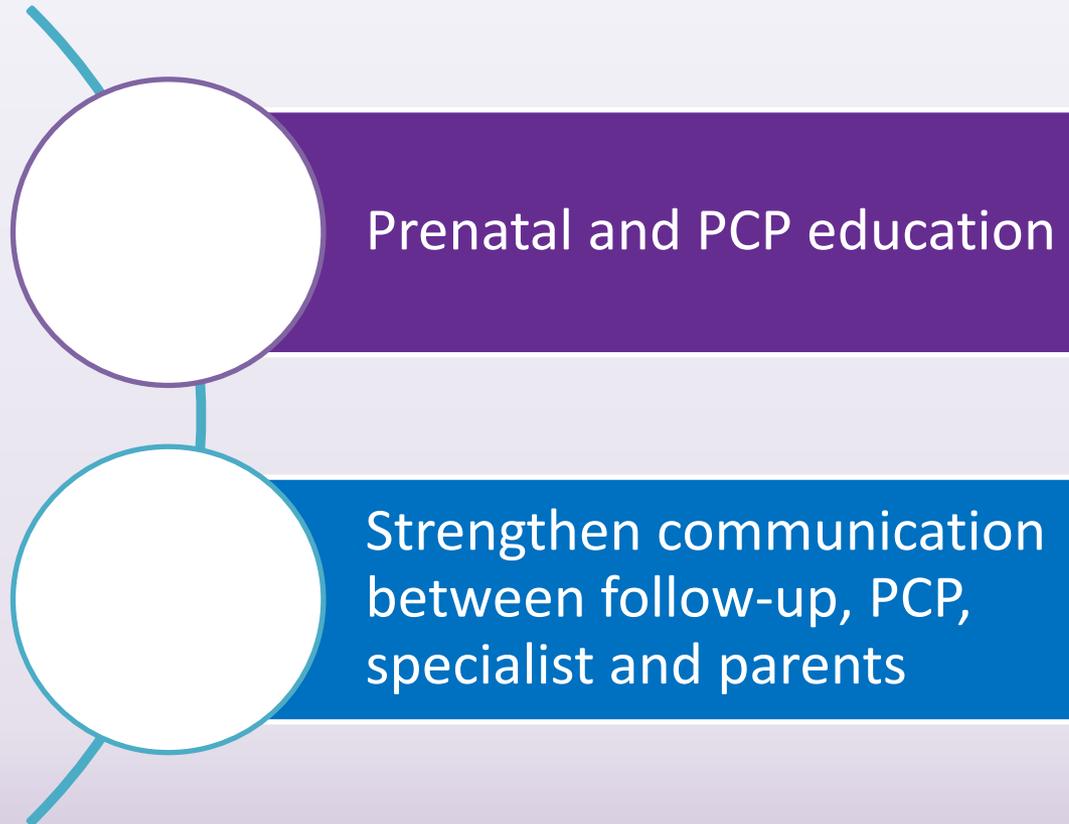


Areas for Improvement



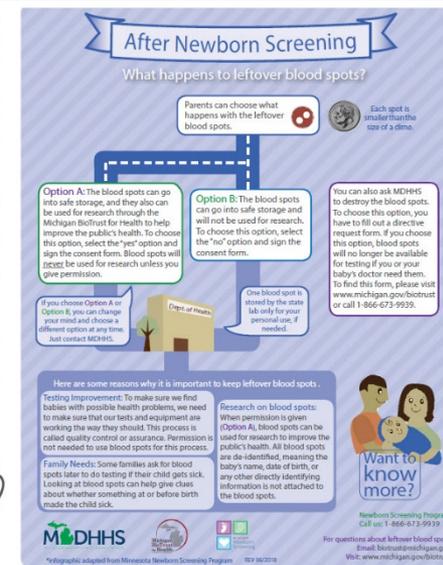
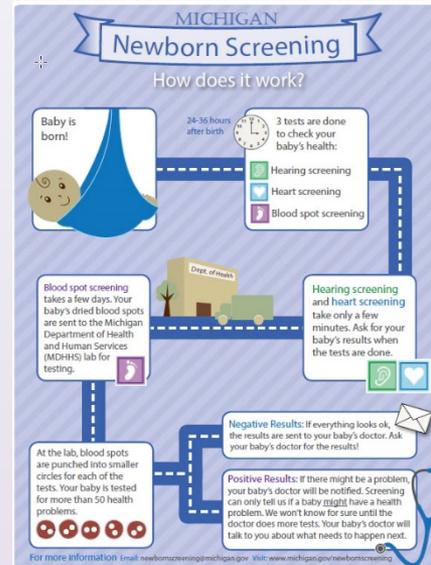
Overall NBS Experience

Areas for Improvement



Next Steps

- Internal NBS education workgroup
- Developing educational products
 - Roadmap
 - Positive NBS fact sheet
- Expand prenatal education
- Summer health education intern
- Continue administering survey
- Examine results by condition to identify specific issues by disorder



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