MDH Minnesota Department of Health

Communicating Incidental Findings of SCT on the Newborn Screen

Maggie Dreon, MS, CGC

Jessica Tarnowski

MDH Minnesota Department *of* Health

JAMA The Journal of the American Medical Association

VIEWPOINT

Sickle Cell Trait—Neglected Opportunities in the Era of Genomic Medicine

Catherine Taylor, MB, The use of genomics to prevent and treat disease is tion represents a missed opportunit

CDC Centers for Disease Control and Prevention
CDC 24/7: Saving Lives, Protecting People™

Critical Gaps & Future Directions

This study shows that as many as 1.5% of babies born in the United States have SCT. Based on previous studies, there are no standardized methods or protocols for alerting families or healthcare providers to this information, educating them about the potential health outcomes that might be associated with the condition, or counseling them about the impact that this might have on the family's future reproductive choices. By including educational materials and providing genetic counseling at the same time that families are given positive SCT results, the occurrence and public health burden of SCD might be reduced.

ASHG THE AMERICAN SOCIETY OF HUMAN GENETICS

- The ASHG recommends additional research for assessing the utility of disclosing carrier results generated from NBS for reproductive decision making and cascade testing, as well as the impacts on systems of care and resources in the context of engagement with relevant stakeholders

MDH Minnesota Department of Health

Community Needs Assessment

Focus Groups and Semi-Structured Interviews

- 29 participants
- Ages 20-40
- Self-identified as African American or West African
- All parents

MDH Minnesota Department of Health

Focus Group Findings

Why is this important for parents to know?

- Knowledge is power
- Reproductive risk
- Health burden of SCD
- Prior awareness

MDH Minnesota Department of Health

Focus Group Findings

What qualities of the notification are valuable?

- Knowledge base
- Personal relationship
- Provision of support/resources
- Timeliness

Major Conclusions

- Parents in communities most affected by sickle cell trait want to be made aware of their newborn's trait result
- Carrier result notifications should be:
  - Multi-faceted
  - Facilitated by an individual knowledgeable on hemoglobinopathies

MDH Minnesota Department of Health

SCT Notification Changes

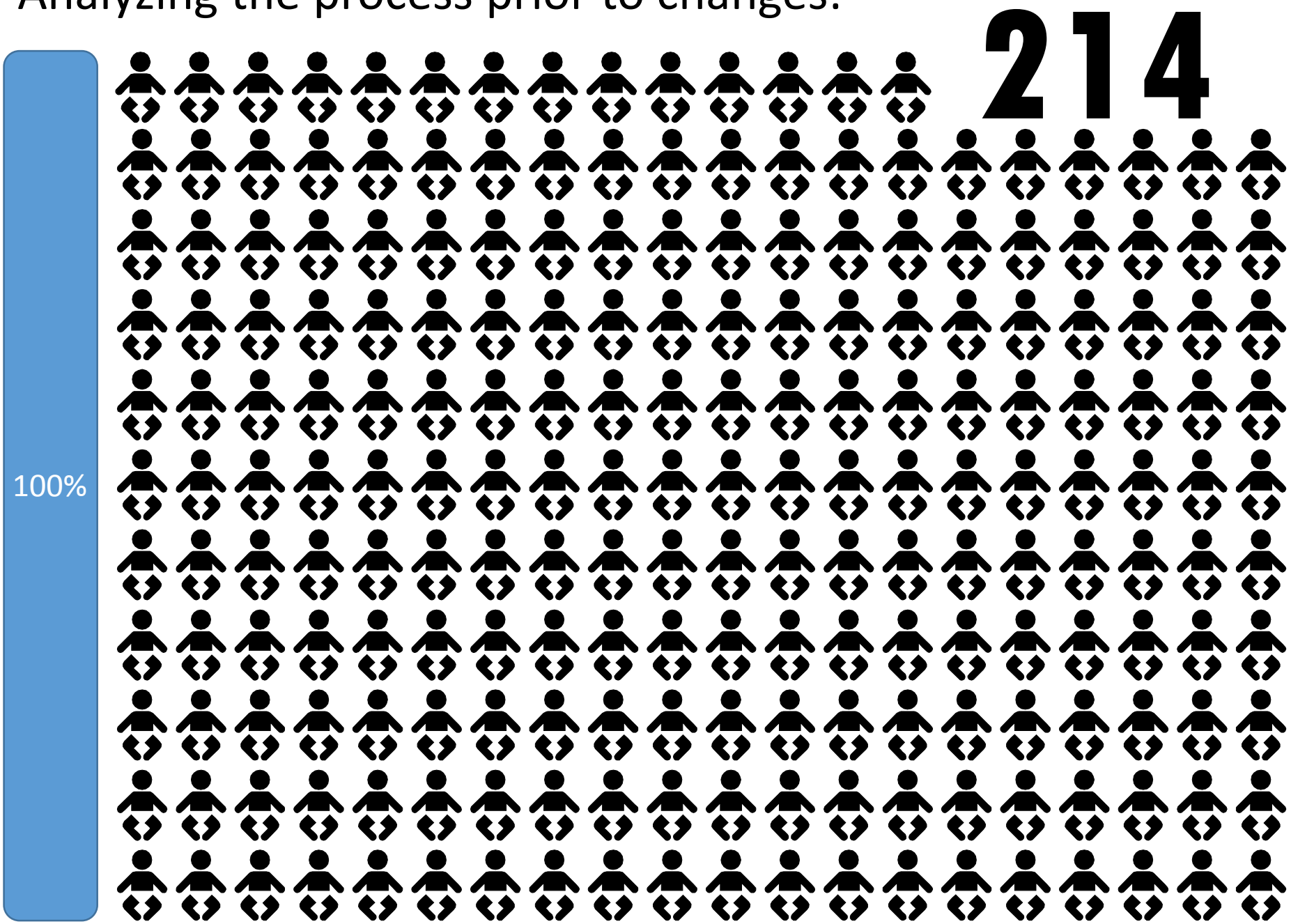
- MDH Newborn Screening has developed a multi-faceted notification process
  - Letter/mailing directly to parents when SCT is identified
  - Phone number of SCT educator will be provided to answer additional questions
  - PCP (listed on NBS cards) will be contacted and directly sent results with resources
  - Began June 2015
- Continue outreach to increase awareness of sickle cell trait and disease

MDH Minnesota Department of Health

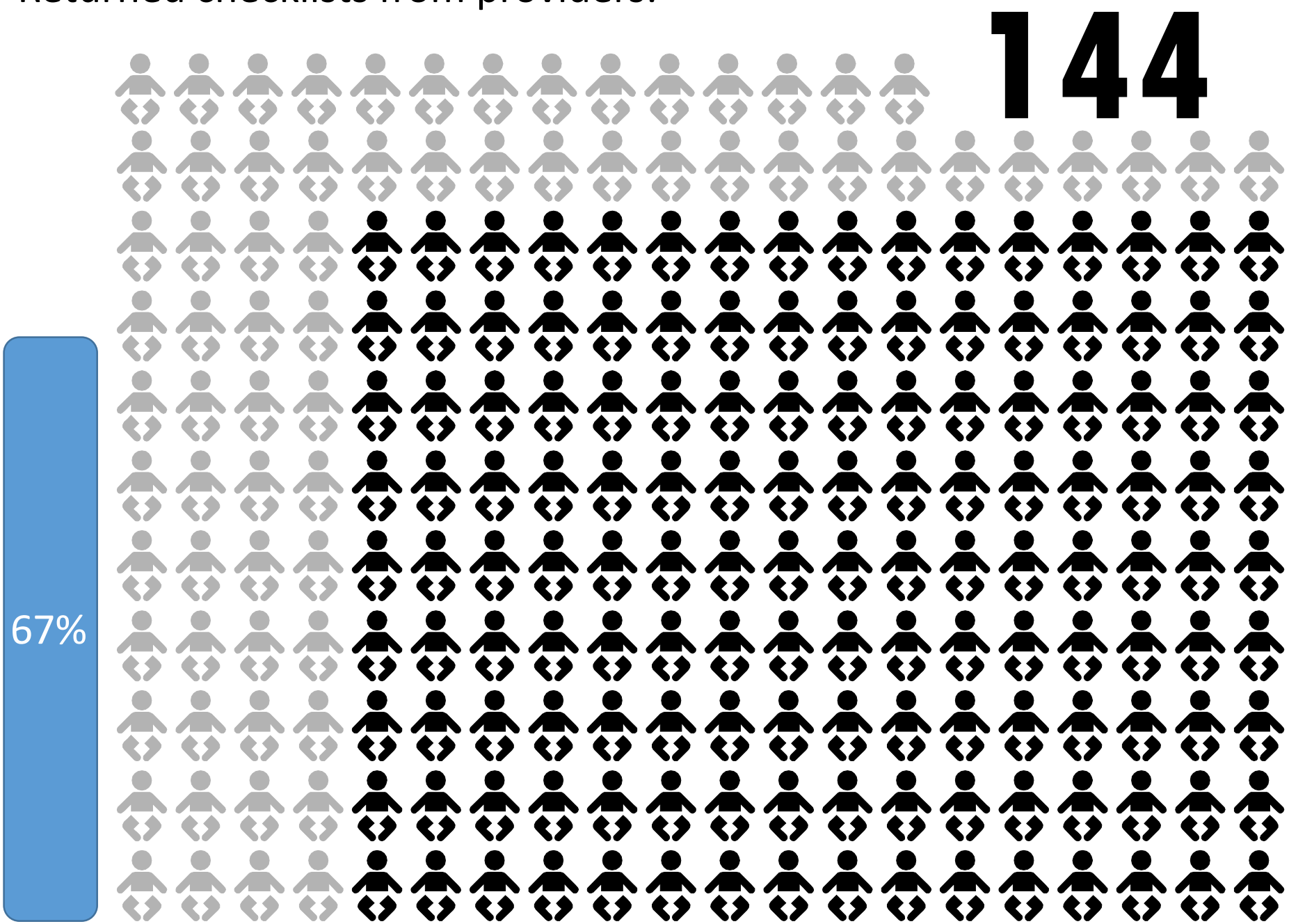
Notification Process

1. Report is received by clinic listed on the newborn screening specimen card
2. Infant is registered and seen at clinic
3. Provider discusses result with family
4. Provider confirms the result through hemoglobin electrophoresis

Analyzing the process prior to changes:

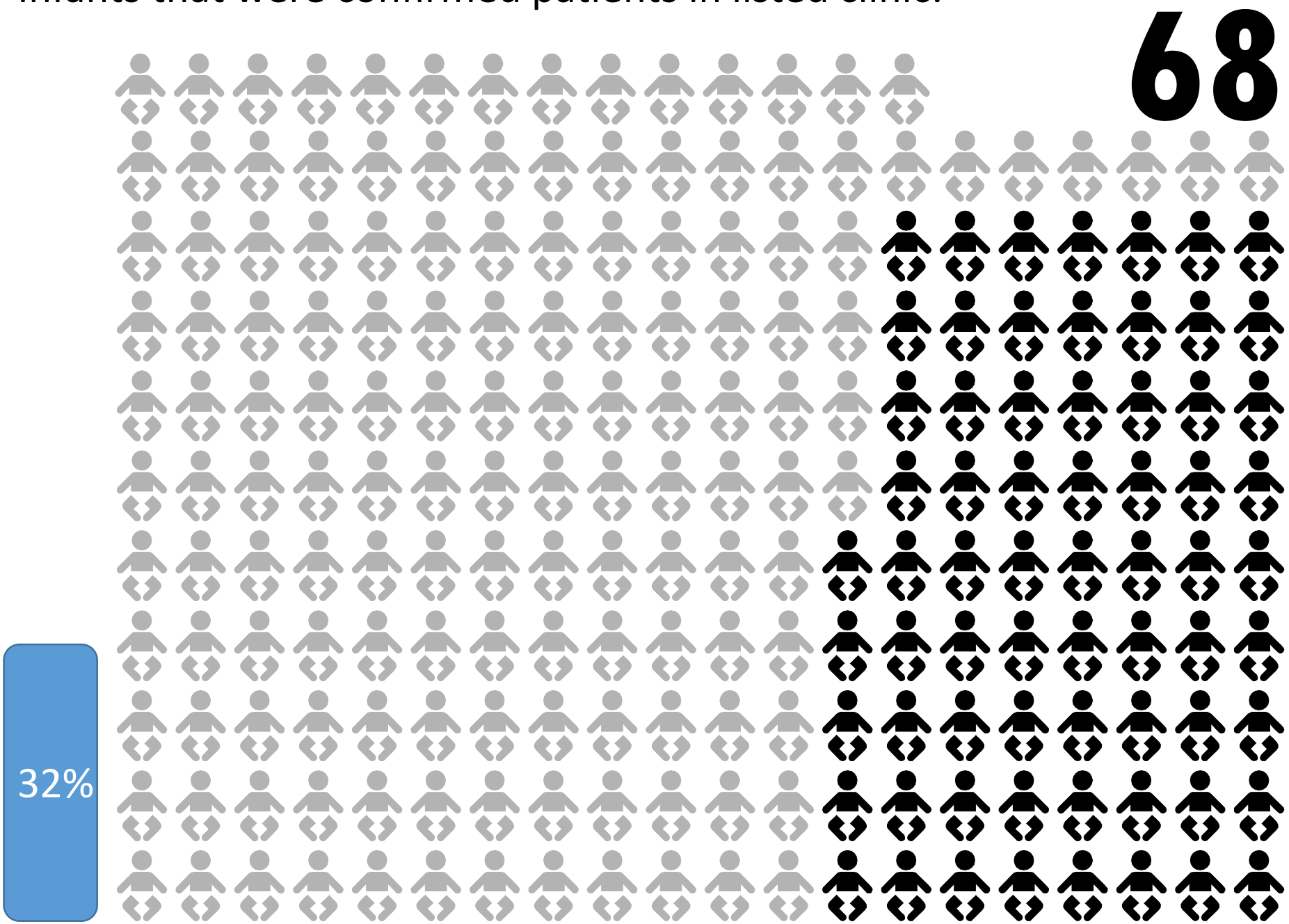


Returned checklists from providers:

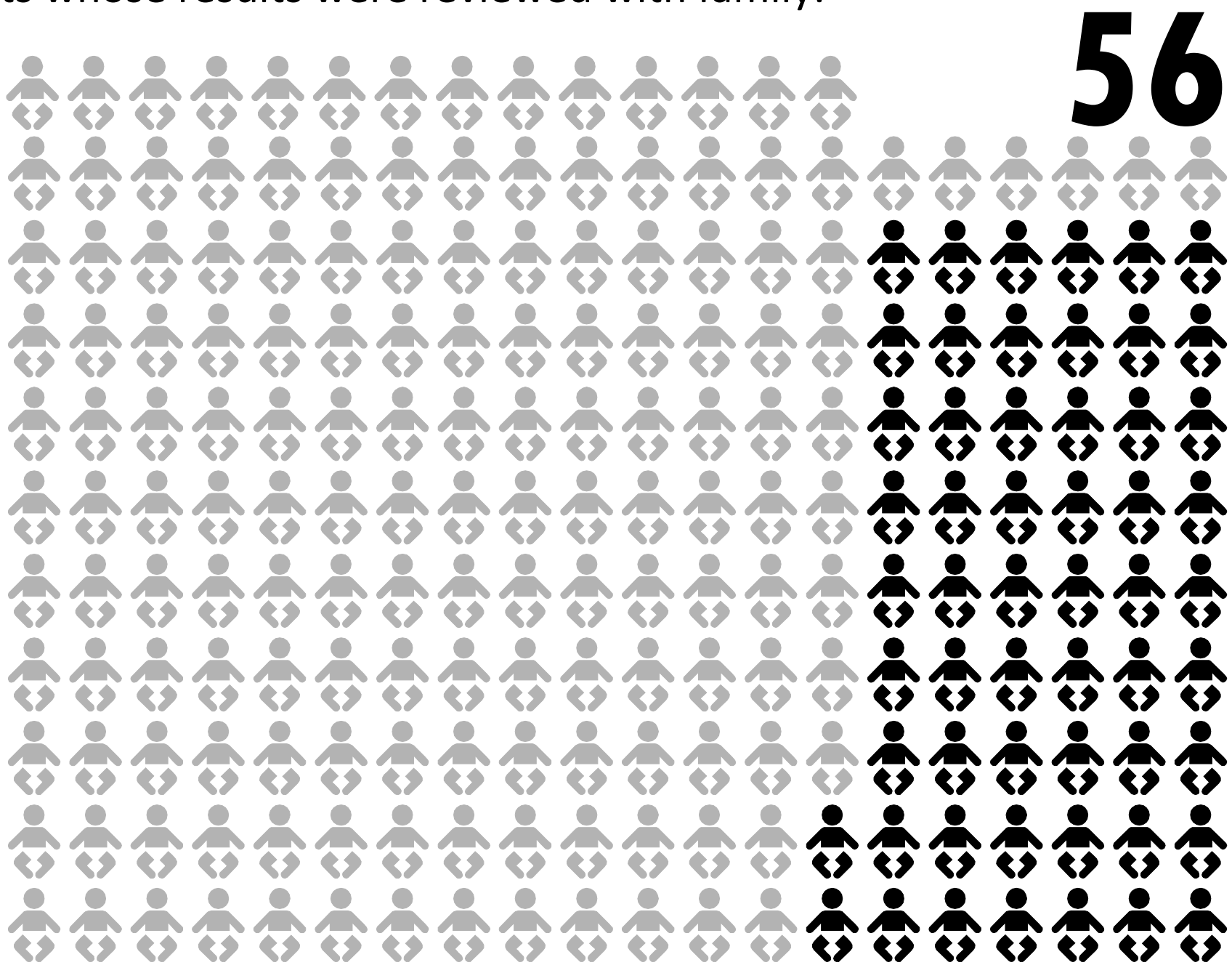


Infants whose providers received newborn screen report:

Infants that were confirmed patients in listed clinic:

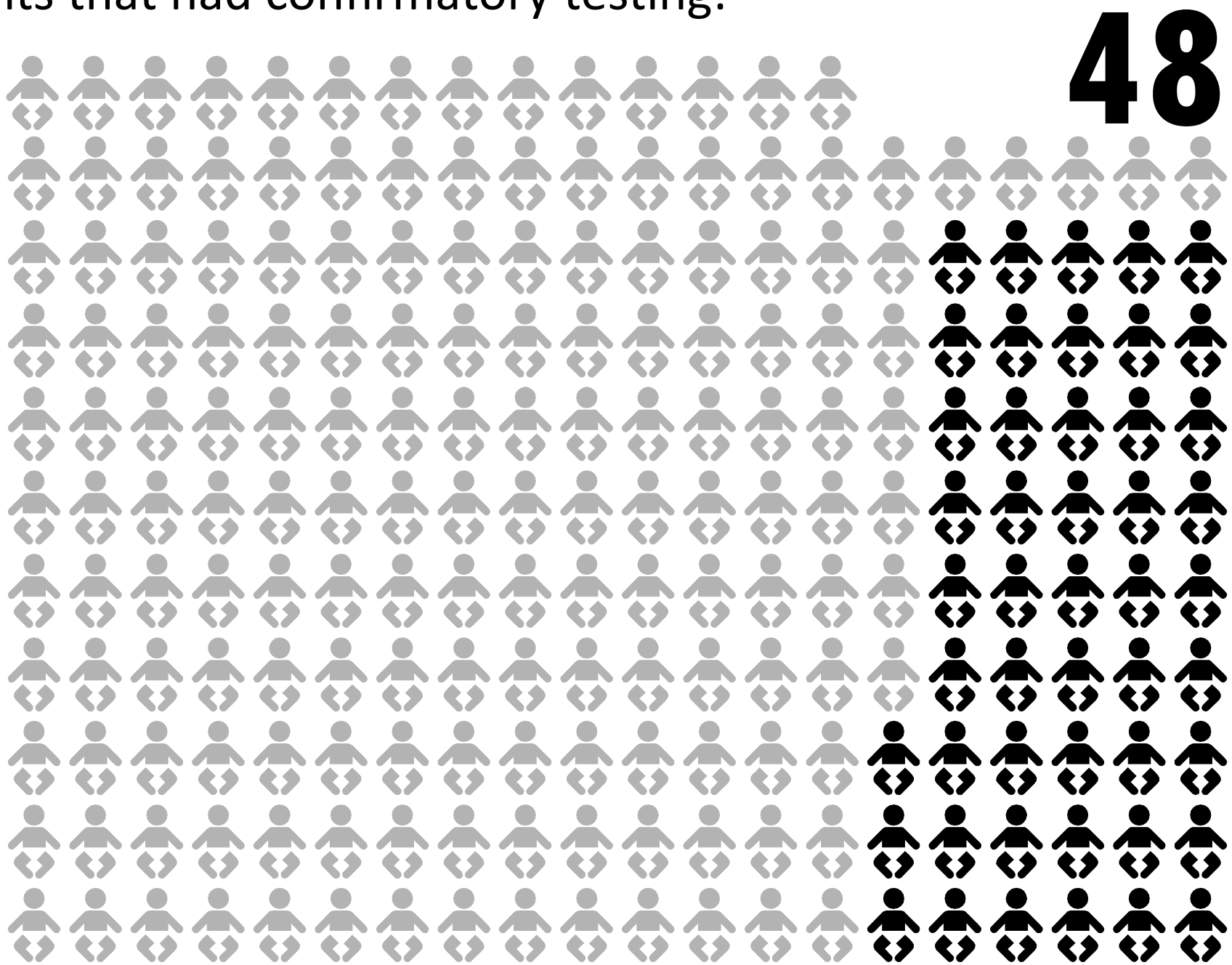


Infants whose results were reviewed with family:

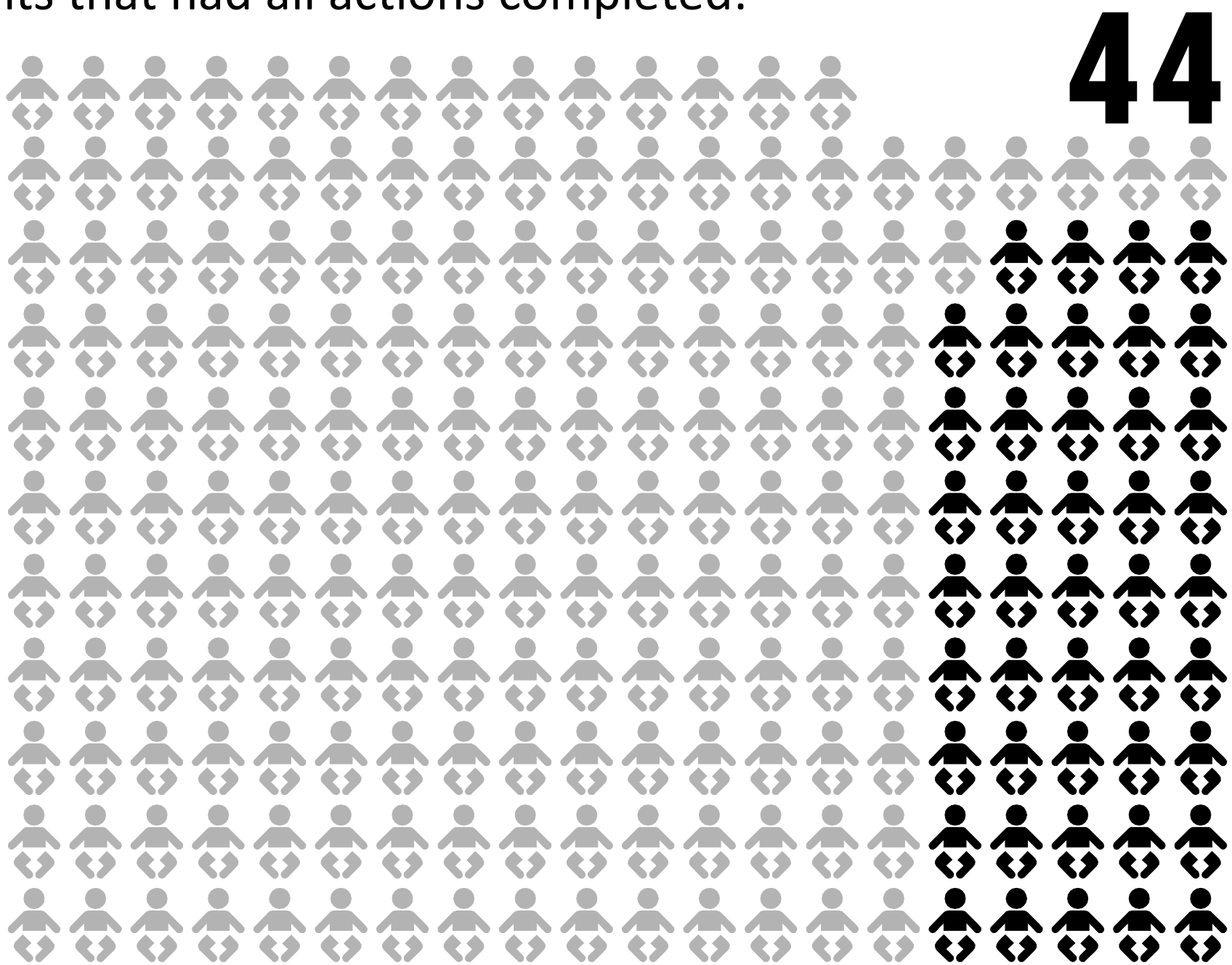


26%

Infants that had confirmatory testing:



Infants that had all actions completed:



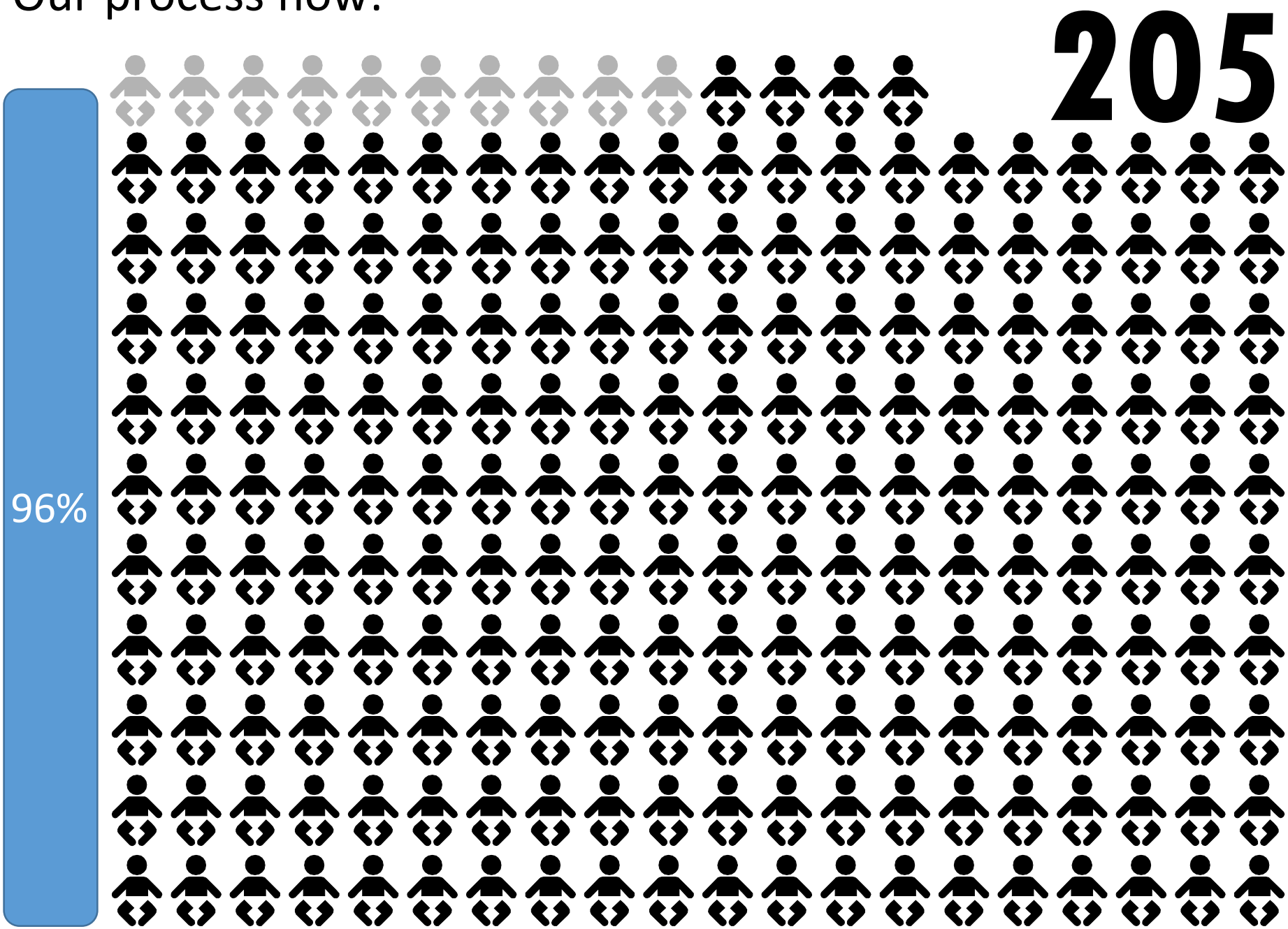
21%

MDH Minnesota Department of Health

Notification Process

1. Report is received by clinic listed on the newborn screening specimen card
2. Infant is registered and seen at clinic
3. Provider discusses result with family
4. Provider confirms the result through hemoglobin electrophoresis

Our process now:



Next Steps…

- Focus group of parents receiving notification
  - Reaffirmed current, active method to notification
  - Provided suggestions for increased parental engagement and understanding
- Expansion to other hemoglobin traits
- More outreach and increased awareness

MDH Minnesota Department of Health

Acknowledgements

Jessica Tarnowski, Nancy Silva,

Patti Constant, MPH, Amy Gaviglio, MS, CGC,
Sondra Rosendahl, MS, CGC, and Mark McCann

MDH Minnesota Department of Health

Questions???

Maggie Dreon
Newborn Screening Program
651-201-5670
Maggie.Dreon@state.mn.us