Family Contact Calls

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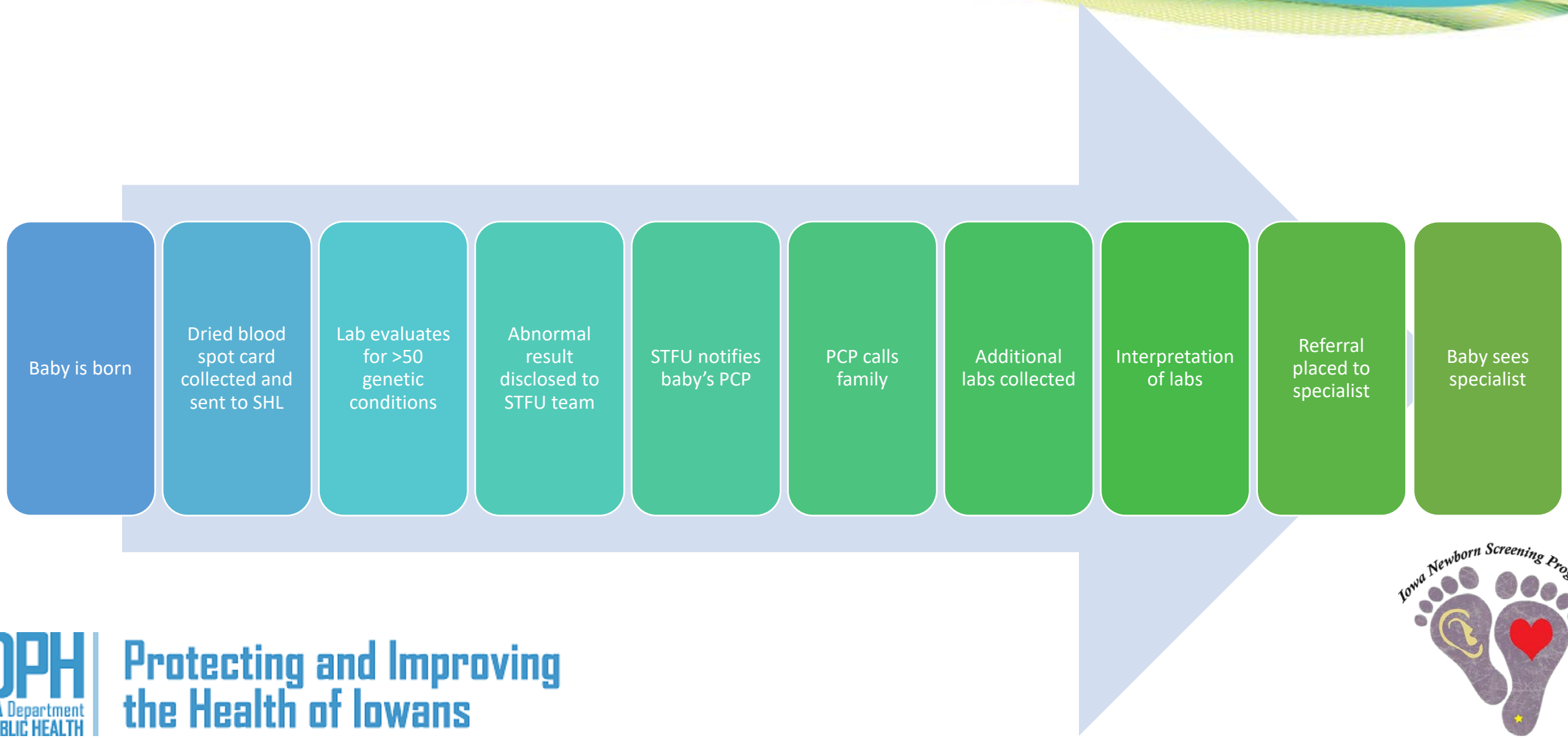
Background



IDPH IOWA Department of PUBLIC HEALTH

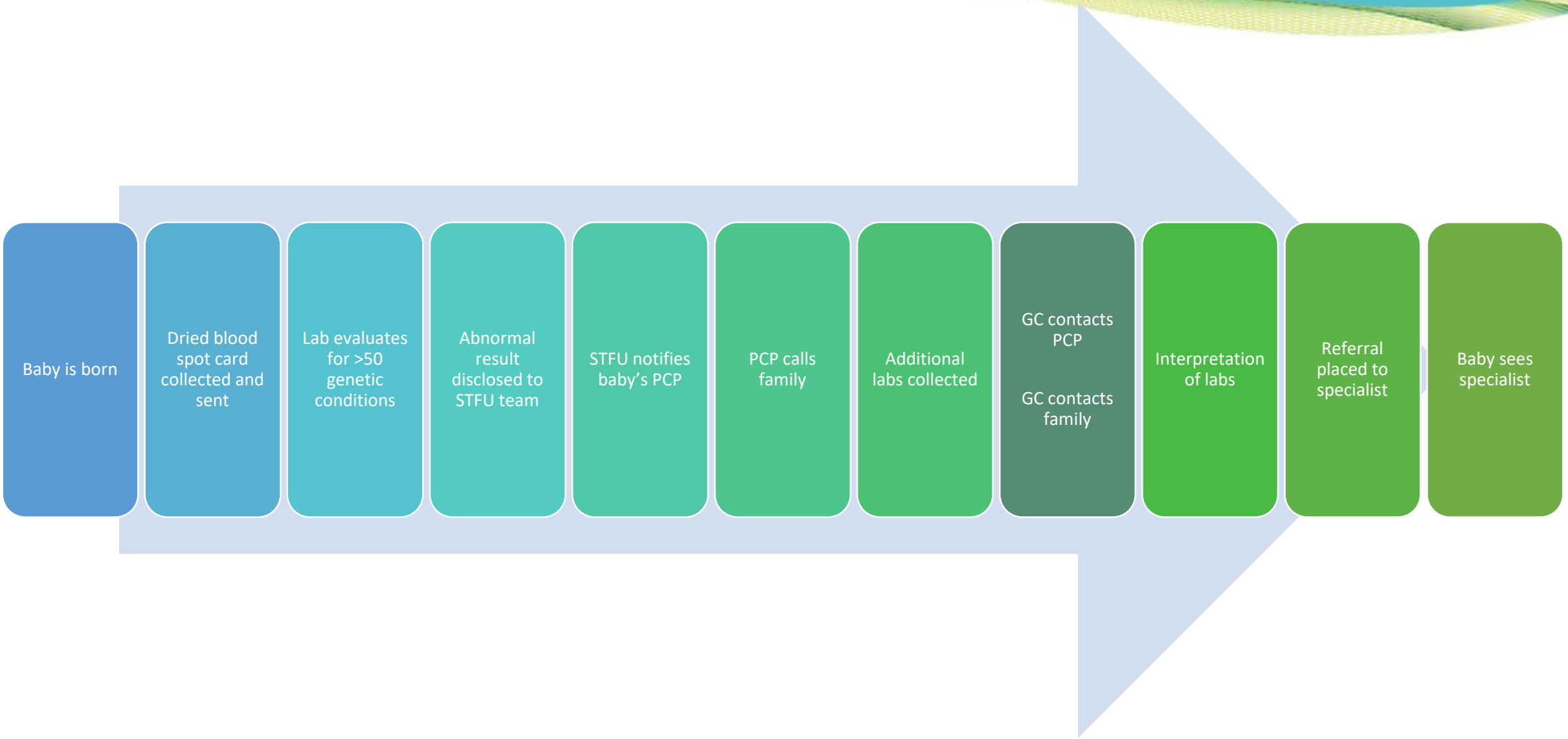
Protecting and Improving the Health of Iowans

Iowa Newborn Screening Programs

GOAL:

To relieve parent anxiety

New Initiative



Family Contact Call

1

Review newborn screening

2

Review patient's abnormal result (briefly)

3

Answer parent questions

4

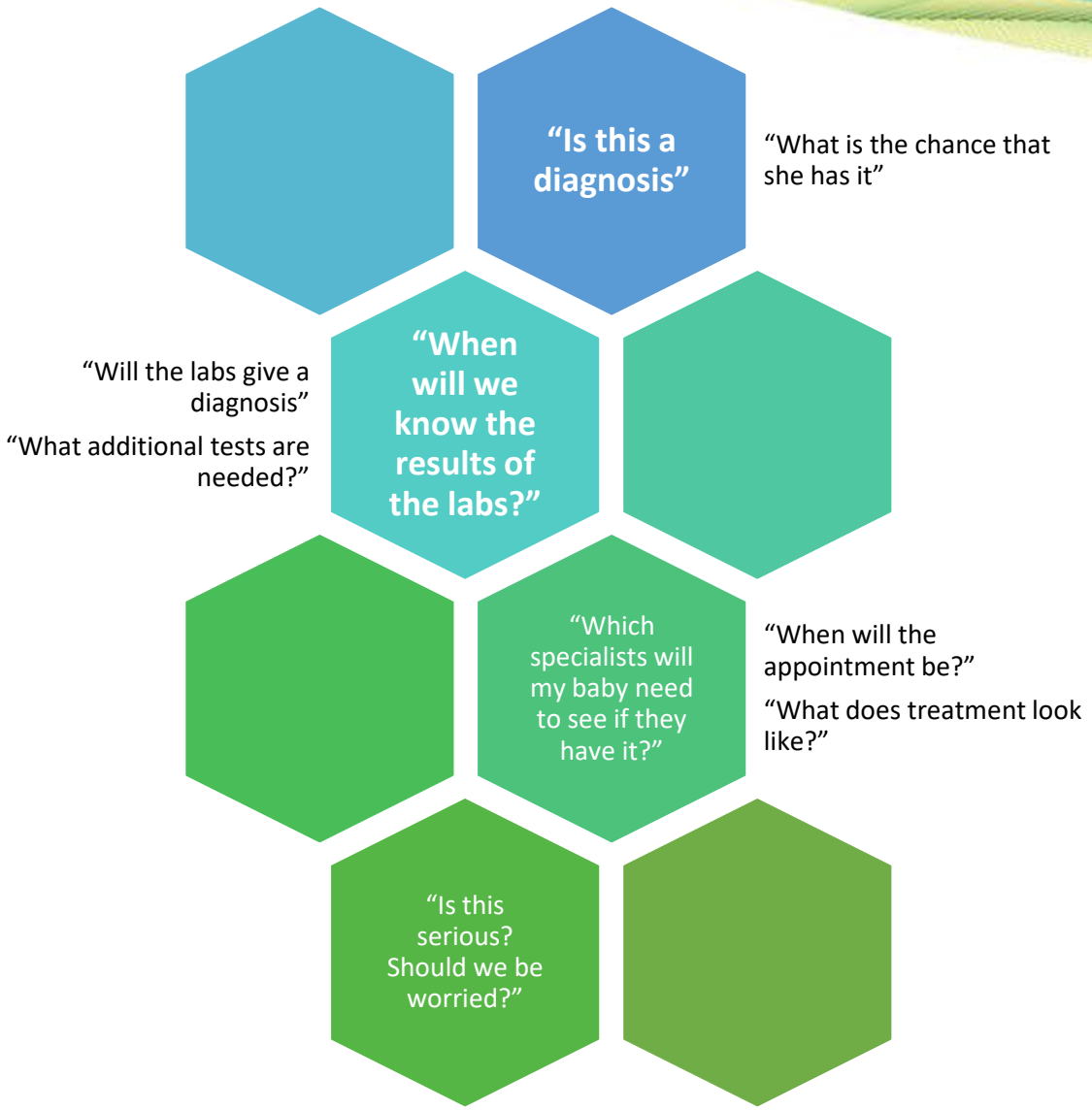
Review next steps

First 4 Months

Condition Category	2020	2021
Hemoglobinopathy	5	3
Biotinidase	0	0
SCID	1	0
Cystic fibrosis	11	0
Galactosemia	0	0
Organic acidemia	5	0
Fatty acid oxidation	16	4
Amino acidemia	9	1
TOTAL	47	8

- In the process of adding endocrine disorders to our work-flow

Parent Questions



Patient Case

10/5 – Baby flagged “possible cystic fibrosis.” PCP notified
10/6 –Baby referred to Blank Children’s Hospital. GC called PCP.
10/6 – GC called family
10/6 – Parents called back with questions
10/7 – Parents called back with questions
10/8 – Parents called back with questions
10/15 – Sweat test. QNS
10/27 – Sweat test. QNS
11/12 – Sweat test. Carrier status
11/13 – Genetic counseling by phone

Challenges:

- Babies in the NICU
- Miscommunication

Take-Away Points:

- Call addresses the gap between result disclosure and follow-up with specialists
- Families are appreciative of the phone call
- Parental anxiety varies
- Level of understanding varies

Thank you!

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