

NewSTEPs

Long Term Follow-up Taskforce

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Co-Chair APHL NewSTEPs Short Term Follow-Up Workgroup
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LTFU Taskforce Creation

NewSTEPS Short Term Follow-up National Meeting May 2018

Addressing LTFU Needs:

- Role and scope of NBS
- Assessing LTFU effectiveness
- Justification for LTFU



LTFU TASKFORCE DELIVERABLES



Analysis. Answers. Action.

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Taskforce Deliverables

- Working definition for LTFU
 - Elements of LTFU
 - Clinical Goals
 - Public Health Goals
- LTFU Landscape Survey
 - LTFU Activities
 - Program Needs
 - Barriers to LTFU

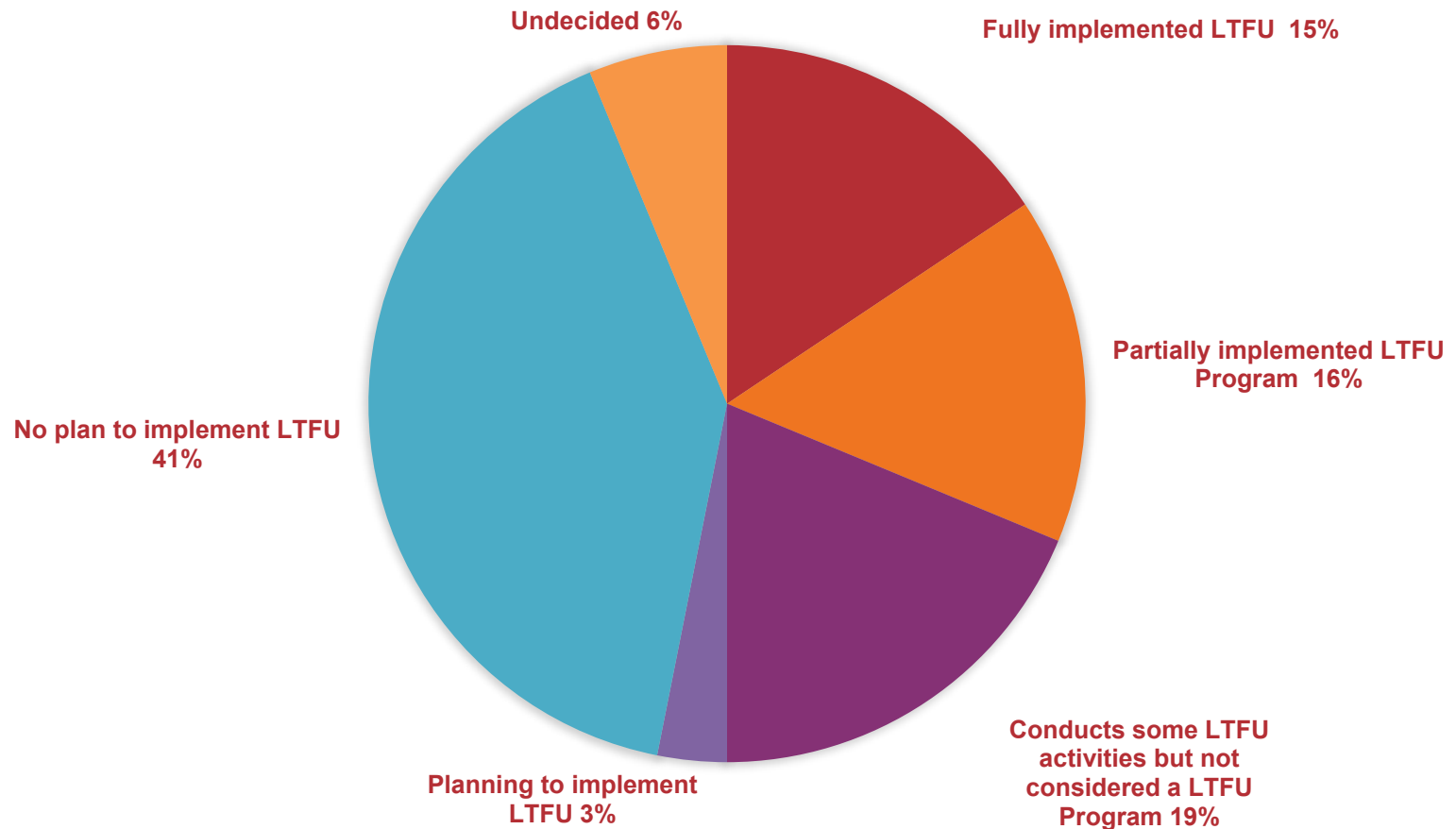
LTFU Landscape Survey

- Twenty questions
- Welcomed responses from multiple entities per state
- Distributed to 76 distinct contacts, 54 distinct states
- Survey included hearing, heart and dried blood spot screening
- Received 42 responses (survey completion: 55%); Of these, 32 responses complete; 10 partial responses (excluded from analysis)



LTFU Landscape Survey: RESULTS

WHAT IS THE CURRENT STATUS OF NBS LTFU WITHIN YOUR STATE?

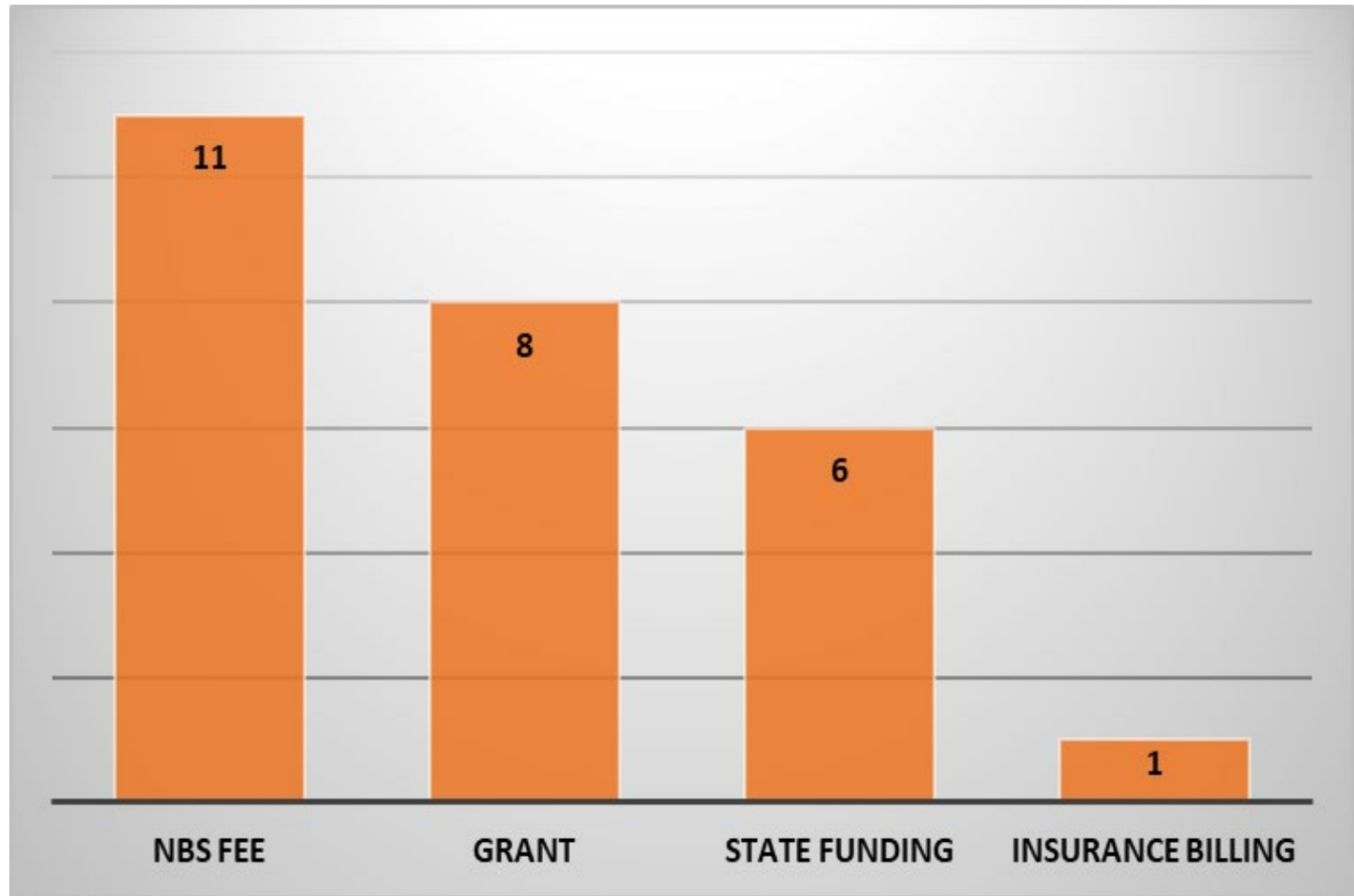


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LTFU Landscape Survey: RESULTS

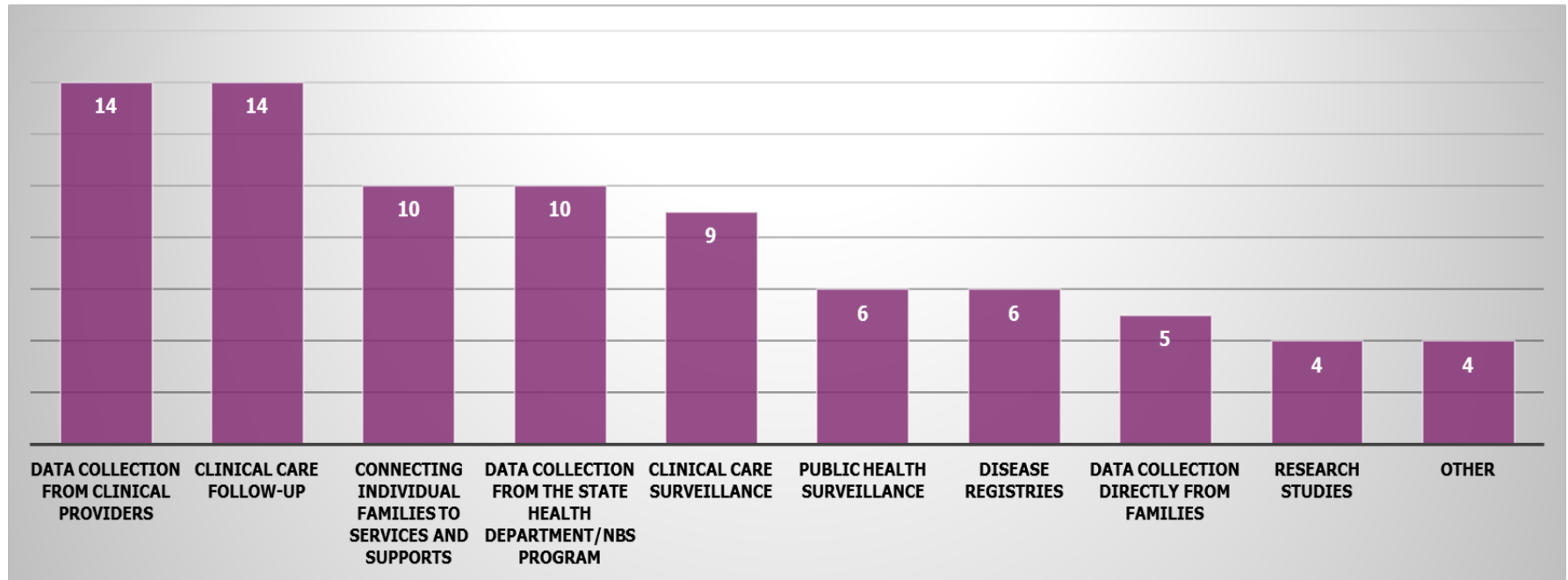
LTFU FUNDING SOURCES



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LTFU Landscape Survey: RESULTS

LTFU ACTIVITIES PERFORMED

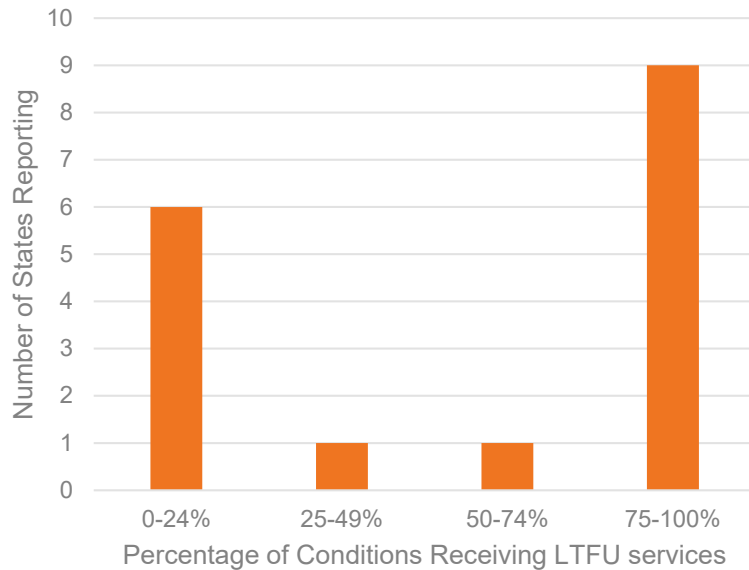


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LTFU Landscape Survey: RESULTS

What percentage of conditions on your NBS panel receive LTFU services or activities?



What percentage of individuals identified through newborn screening receive LTFU services or activities?

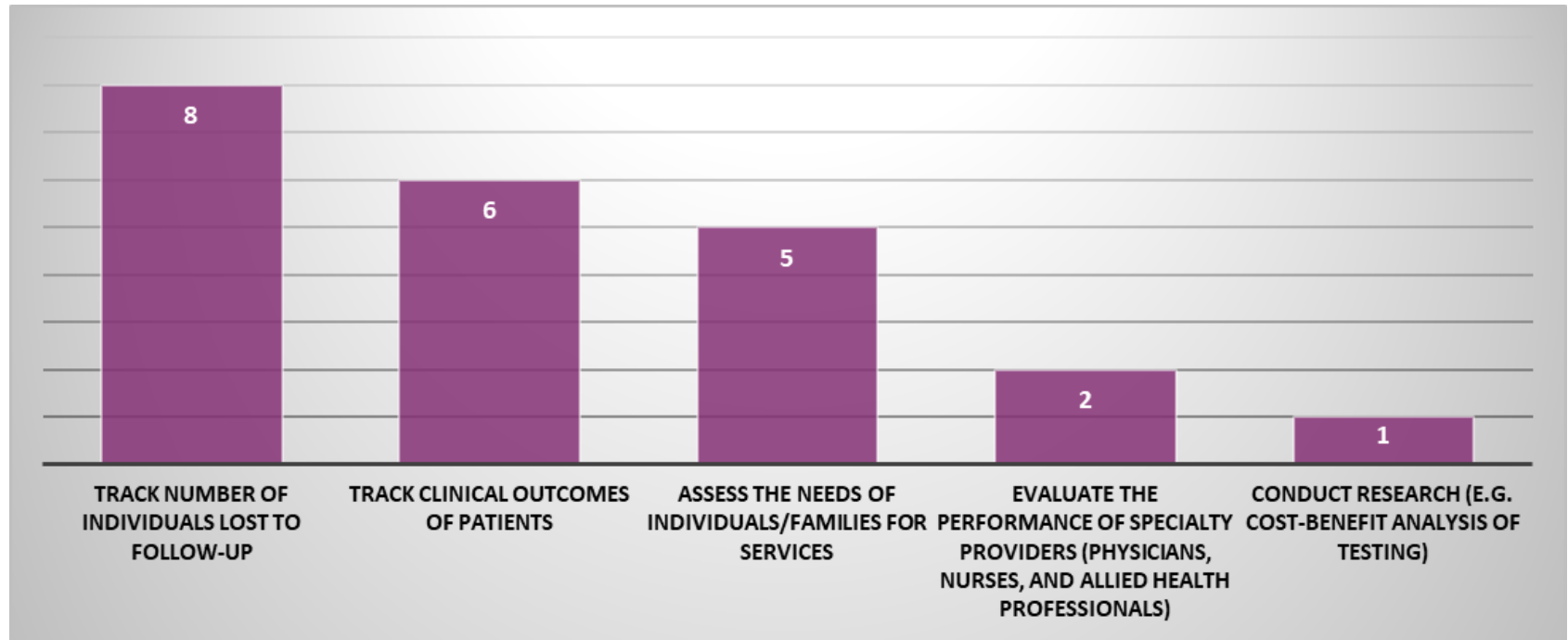


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LTFU Landscape Survey: RESULTS

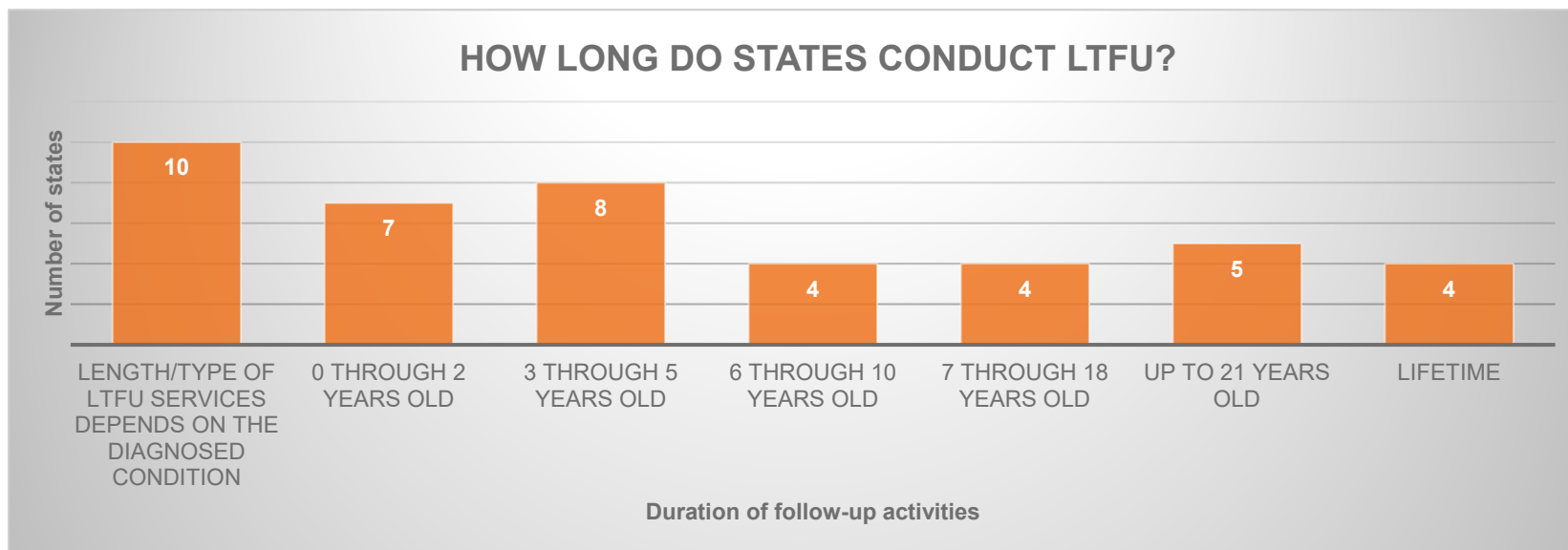
HOW IS DATA COLLECTED BEING USED?



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LTFU Landscape Survey: RESULTS



Variations:

State 1: ALD age 0-21

State 2: All bloodspot conditions lifetime, CCHD age 0-2, Hearing age 0-3

State 3: All metabolic conditions lifetime, Sickle cell lifetime

State 4: CH age 0-5, CAH age 0-21

State 5: CCHD age 0-4

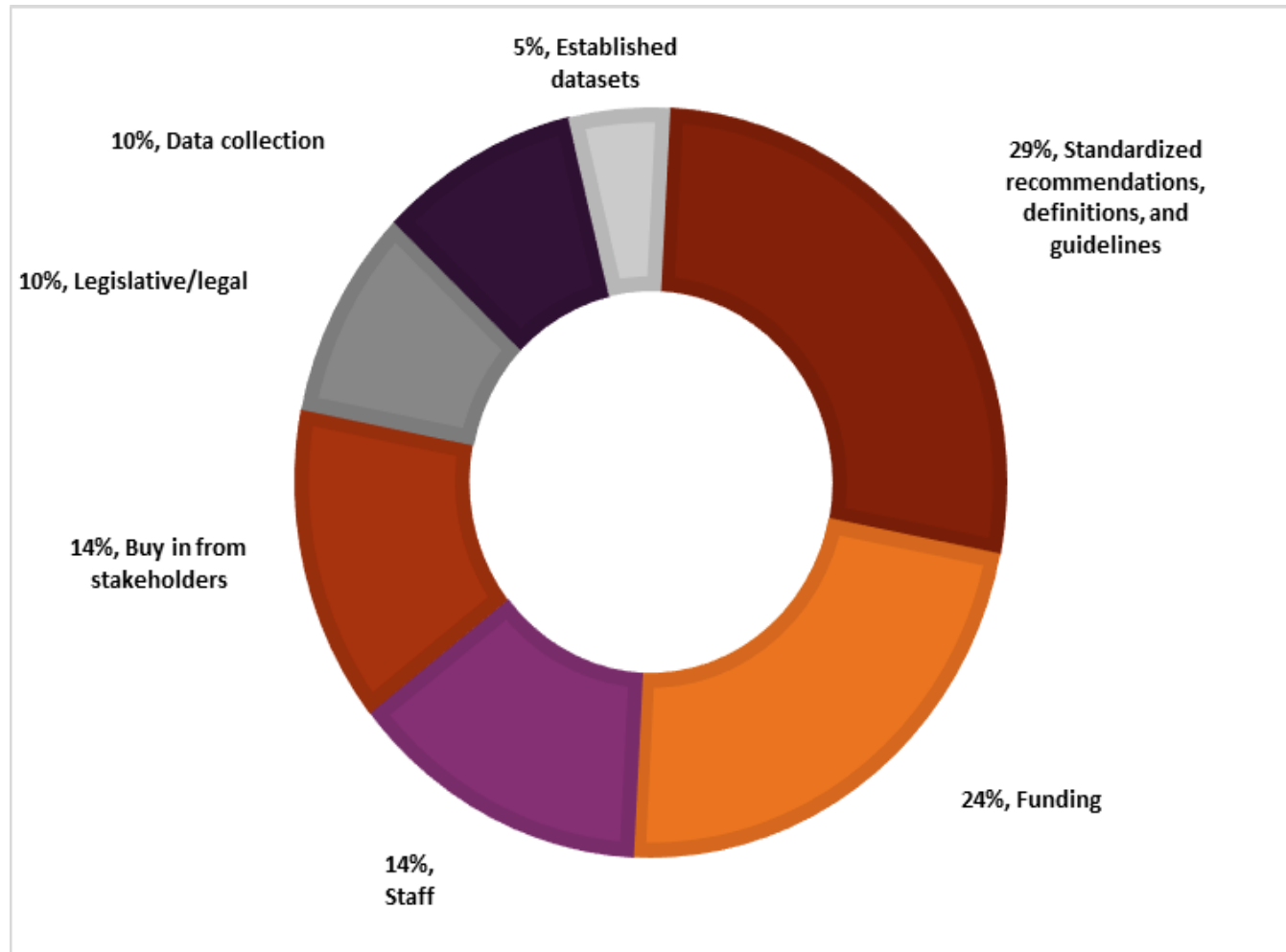
State 6: CF age 0-2, medical foods lifetime

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LTFU Landscape Survey: RESULTS

WHAT DO STATES NEED TO IMPLEMENT LTFU?



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What States are Saying

“We aren’t doing LTFU, but what we call “ongoing clinical care” due to a lack of sustainable funding and staff to provide a quality LTFU program.”

“With implementation of X-ALD and LSDs, LTFU became a necessity but lack of adequate resources has stalled progress.”

“It is hard to argue the case for LTFU without guidelines of minimum requirements.”

“If state testing labs are not willing/able (or pressured by APHL) to help organize a NBS system, I am not hopeful for change.”

“I do not foresee the DOH would consider LTFU NBS program as a priority public health initiative/activity for the Department.”



APHL'S ROLE IN LTFU



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Role for APHL

LTFU is a critical component of the NBS system

- Position Paper
- White Paper
- Program Guidance
- Technical Assistance

“The newborn screening system is intended to be comprehensive, including not only screening and diagnosis, but also long-term follow-up care through the medical home.”

Kemper et al., 2008



ACHDNC'S ROLE IN LTFU



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Acknowledgments

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