

Oklahoma Program: Long Term Follow-Up

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Definition

LTFU is a mechanism for determining if the newborn screening system is accomplishing its intended **goal of improving health outcomes**.

LTFU includes an **infrastructure** with the capacity for periodic monitoring of selected health outcome indicators appropriate for evaluating the efficacy of newborn screening.

LTFU may include **facilitation of services** to ensure coordinated, comprehensive care for the affected individual and family.

Clinical Laboratory and Standards Institute 2006.



Centers – Metabolic, Genetic, Endocrine

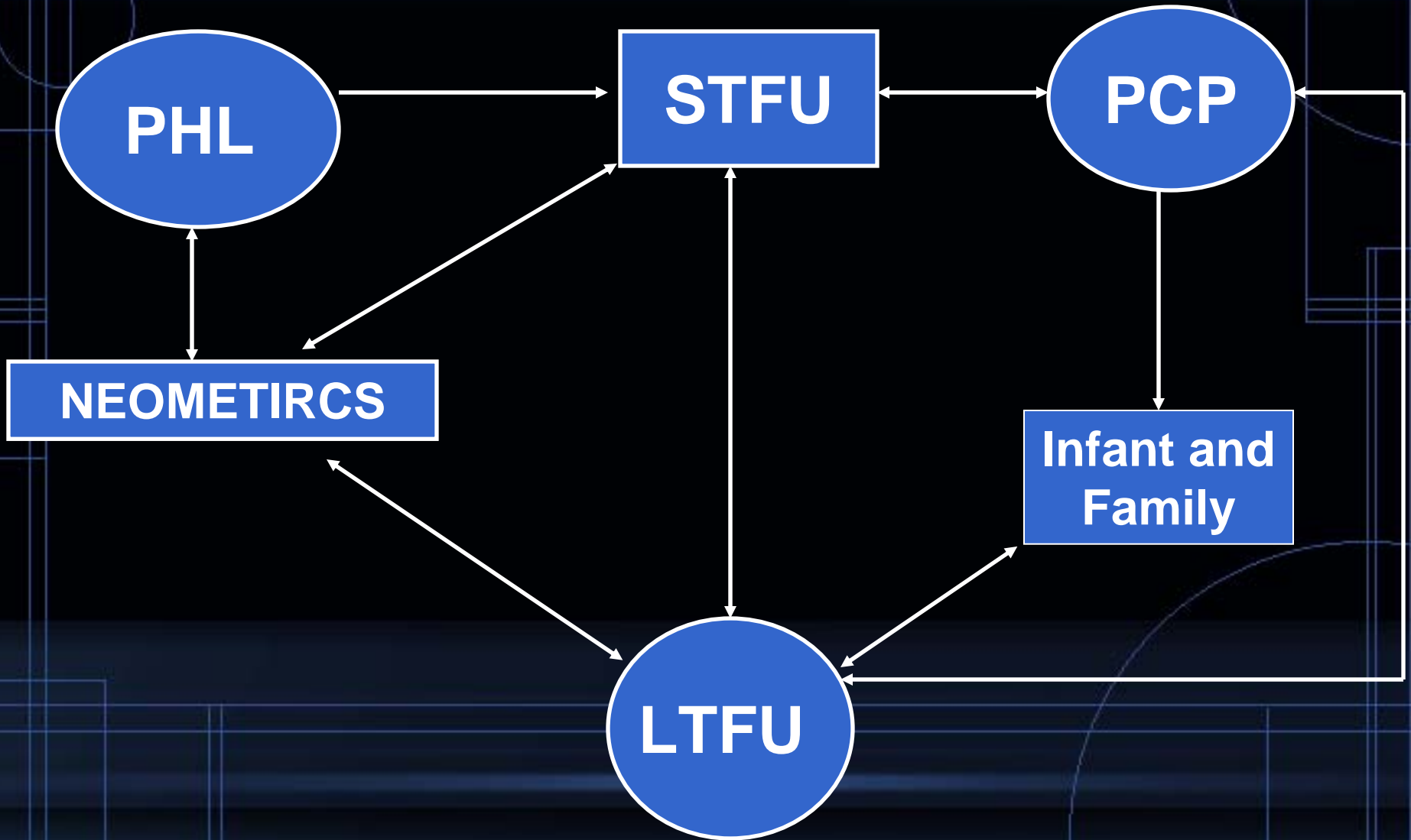


How is LTFU supported?

- Contractual collaborative agreement with CSHCN's, Oklahoma State Department of Health, Department of Pediatrics (OUHSC)
- Funded through the NBS fee and Title V, Part C
- Funding supports staff salaries, patient supplies, educational material, and travel for staff education



PROCESS OF REFERRAL



LFTU Hemaglobinopathies

- Established in 1992
- Supports one full time RN located in OKC and a part time RN Sickle Cell Clinic Coordinator in Tulsa
- Healthy and Ready to Work Coordinator
 - Focuses on transitional care for young adults with sickle cell disease



LFTU Metabolic

- Established in 2003
- Metabolic Dietician
- Metabolic Nurse Specialist
- Low Protein food program
- Adult Program for patients with PKU



LTFU Endocrine

- Established in 2004
- Coordinates care for infants with CAH and CH

Cystic Fibrosis

- Cystic Fibrosis LTFU nurse coordinates services thorough the Cystic Fibrosis Centers.



LTFU Activities

- Interdisciplinary team coordination
- Clinical services
- Tracking system
- Promote wellness
- Assist family with financial concerns
- Coordinate community resource planning
- Develop and disseminate educational materials



Activities Continued

- Provide educational seminars
- Develop standard care plans for families and providers
- Develop organizational resource booklet for families
- Data collection
- Participate in policy development
- Network with other state speciality clinics
- Attend national meetings



Communication

- LTFU communicates outcomes directly with OSDH NBS through annual and quarterly written reports
- Outcomes tracked through Neometrics
- Outcomes
 - Progression through school
 - Developmental milestones
 - Enrollment in the LTFU program



NBS Statistics for 2007

# of Newborns screened	App 54,000
Out-of-range Screens (STFU)	1680
Diagnosed cases	58
PKU	3
Galactosemia	2
Congenital Hypothyroidism	15
Congenital Adrenal Hyperplasia	4
Hemoglobinopathies	12
Cystic Fibrosis	16
MCAD	6



Disorder Presumptive Diagnosed

PKU	32	3
Galactosemia	7	2
CH	19	15
CAH	97	4
Hemoglobinopathies	21	12
Cystic Fibrosis	22	16
MCAD	9	6
Total	207	58



Tools for Success

- Clear guidance of expectations
- Ongoing communication with STFU, Metabolic Specialists, PCP's, Families
- Commitment for ongoing collaboration
- Shared database (Neometrics)

Future Plans (*Wishes*)

- LTFU staff dedicated to the Northeast quadrant of the state
- Utilization of telemedicine to coordinate activities and care in rural Oklahoma
- HRTW coordinator for metabolic, cystic fibrosis and endocrine to ease clients into an adult medical home

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