

# The NIH/NICHD Funded Newborn Screening Translational Research Network

An Project to Develop Infrastructure to  
Facilitate Research and Clinical Investigation  
to Improve Newborn Screening

# NBSTRN

## Patient Care Domain

### **Providers and Patients**

- Clinical provider networks
  - Patient demographics
  - Consent
  - Patient diagnosis and management
    - Documentation in medical record

# NBSTRN

## Public Health Domain

- Needs provider data for:
  - Long term follow-up for program evaluation
  - Clinical history of candidate diseases to improve public health decision-making
  - Epidemiology
  - Surveillance
  - Health services research
  - Population-based biospecimen repositories

# NBSTRN

## Research and Clinical Investigation Domain

- Clinical provider networks
  - Developing clinical histories of NBS conditions and candidate conditions including lab and clinical
  - Patient registries
  - Patient biospecimen repositories
- Clinical trials
- Clinical investigation
  - New treatments
  - New technologies

# NBSTRN

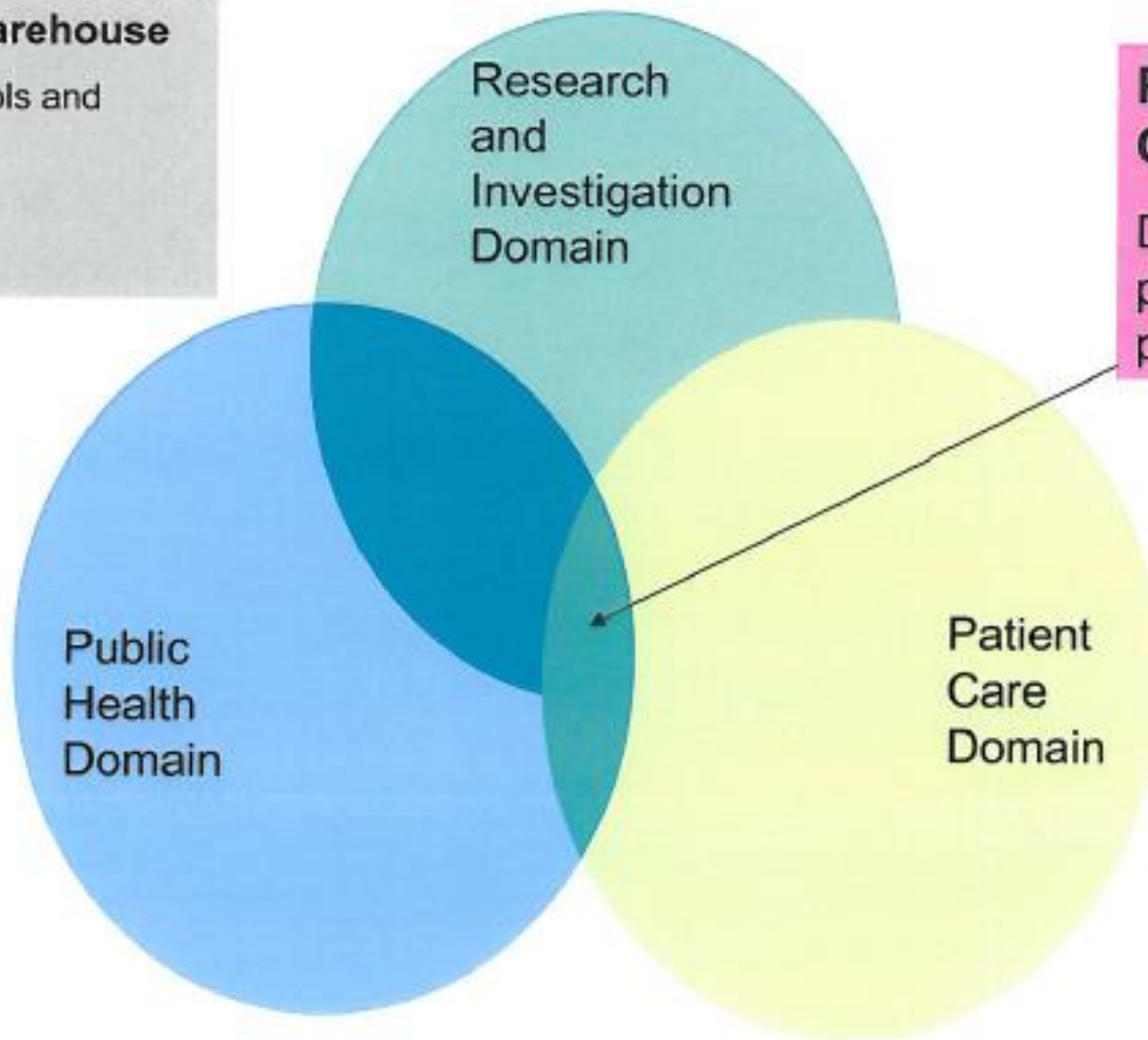
## Public Health Domain

### NBSTRN Data Warehouse

Standardized protocols and languages

Identifiable data

De-identified data



### Point of Overlap

Data from patients and providers

# NBSTRN

## Infrastructure to Meet Needs

- Informatics system to support
  - Patient registry development
  - Protocol development
    - Standardized protocols and data languages
  - Data warehousing
  - Minimal duplication of work and expense
- Patient data
  - Identifiable data available to provider
  - Deidentified data for public health
    - Appropriate to needs in LTFU as an evaluation tool
- Biospecimen repositories

# Additional NBSTRN-Related Activities

- Innovative Therapies in Newborn Screening
  - 17 projects funded
- New Technologies in Newborn Screening
  - New York State project to evaluate Luminex bead array technology for use in newborn screening
  - Dr. Ronald Scott at University of Washington for the development of MS/MS-based NBS for Lysosomal Storage Disorders