

Strategic Partnerships to Ensure a Comprehensive Public Health Surveillance System to Monitor Birth Defects

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Background

- History
 - Monitored birth defects since 1998.
 - Funded through the CDC from 1999-2005 and 2010 to present.
 - KRS 211.655, KRS 211.660, KRS 211.665, KRS 611.670, and 902 KAR 19:010
- Methods
 - Passive surveillance with confirmation
 - Children ages 0 – 5 years seen at a Kentucky facility
 - Mandatory inpatient reporting, voluntary outpatient reporting
 - 8 reporting sources
 - Prior to October 2015, database maintenance was so substantial that it hindered other programmatic activities

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Phase 1- Investigation

- **Steps:**
 1. Identify others who have built databases
 2. Seek advice and input
 3. Build a wish list
- **Collaborations:**
 - NBDPN Guidelines for Conducting Birth Defects Surveillance
 - Illinois Adverse Pregnancy Outcomes Reporting System
 - Kentucky childhood lead prevention program
 - Kentucky newborn screening case management program
- **Results:**
 - List of essential attributes

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Phase 2- Design

- **Steps:**
 - Too many to list here!
- **Collaborations:**
 - Kentucky Office of Application Technology Services
 - University of Kentucky and University of Louisville genetics clinics
 - Genetics labs
 - Kentucky Hospital Association
 - Kentucky Newborn Screening Case Management Program
 - Public Health Neonatal Abstinence Syndrome Reporting Registry
 - Kentucky Office of Vital Statistics
- **Results:**
 - Fully functional database

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Phase 3- Refinements

- **Steps:**
 1. Sign formal agreements with partners
 2. Outline referral process and design tracking mechanism
 3. Create reports based on data-sharing needs
 4. Enhance case database features for case confirmation
- **Collaborations:**
 - First Steps- Kentucky Early Intervention System
 - Office of Children with Special Health Care Needs
 - Environmental Public Health Tracking Network
 - Kentucky Health Information Exchange
- **Results:**
 - Enhanced database with case management and reports

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Other Benefits

- **System improvements:**
 - More complete, accurate, and timely data
 - System is tailored to the needs of program staff
 - More automation has reduced manual effort
- **Allowing KBSR to:**
 - Produce reports, fact sheets, and data briefs
 - Facilitate academic collaborations and publications
 - Participate in national birth defects epidemiology studies
 - Identify gaps in services for partner service agencies
 - Inform data-driven prevention efforts

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Conclusion

- **Partnerships are essential in:**
 - Learning from peers
 - Establishing needs, barriers, and assets
 - Serving families
- **However,**
 - Formal agreements move slowly
 - Partnerships can be expensive

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Thank you!

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