Kentucky Birth Surveillance Registry

Counting Every Baby because Every Baby Counts

National Birth Defect Prevention Annual Meeting February 27, 2012 Sandy Fawbush RN, BSN

Mission

To develop and implement a birth surveillance registry that promotes early and accurate identification of children with birth anomalies and other disabling conditions and facilitates prevention, planning and service delivery in the Commonwealth of Kentucky.



Legislation

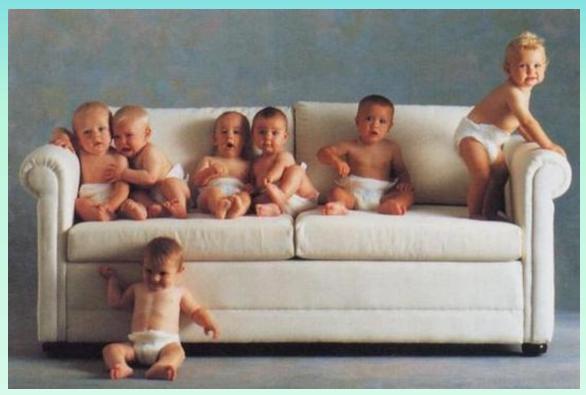
- KRS 211.655-670 passed in 1992 establishing the birth surveillance registry
 - Provide information on the incidence, prevalence, and trends of birth defects.
 - Provide information about possible causes.
 - Facilitate preventive strategies to reduce these conditions and secondary complications.
 - Establish a program to link affected children and families to services.

Legislation

 Mandates hospital reporting for selected genetic and disabling

conditions.

Allows medical record review



KBSR Reportable Codes

All Congenital Anomalies	740 –759	Neurologic Disorders of Brain	
Examples:		and Cord	334
•		Cerebral Palsy	343
Neural tube defects	740-742.0	Teratogen (noxious influences)	760.7
Cleft lip and palate	749	, , , , , , , , , , , , , , , , , , ,	
Gastroschisis/Omphalocele	756.79	Fetal Alcohol Syndrome	760.71
Gastroschists/Onipharocele	130.19	Narcotics	760.72
Chromosome Disorders	758	Hallucinogenic Agents	760.73
Metabolic/Storage Disorders	270-279*	Cocaine	760.75
*Excluding codes 274, 276, 278		Small for Gestational Age	764
Dwarfism,	259.4	Infant of Diabetic Mother	775
Not Elsewhere Classified		Failure to Thrive	783.4
Hereditary Hemolytic Anemia	282		

KBSR Database

- Collect congenital anomaly codes and disabling conditions
- Birth to five years
- Sources
 - Hospital inpatient discharge (UB-92)
 - Vital Statistics (live births, stillbirths, deaths)
 - Genetic Clinics
 - Voluntary outpatient reporting
 - Laboratory (cytogenetics) reporting

Inpatient Hospital Data

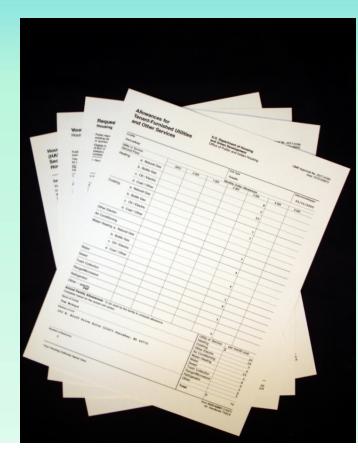
- Hospital Inpatient Discharge Data (UB92)
 - 2000- Data collection began.

- Birthing hospitals sent individual files of data in

excel for 1998 to 2000.

- 8,000 records annually

 Now Hospital Association submits electronic file quarterly.



Vital Statistics

- Vital Statistics Data
 - -Live Birth, Death and stillbirth
 - -Received data after year "closed"
 - Electronic files received twice per year.
 - Now Monthly
 - -600 to 700 annually records.

KBSR Sources

- Voluntary Outpatient Reporting
 - 2004-Legislation to allow voluntary reporting.
 - Minimal records reported.
- Laboratory (Cytogenics) Reporting
 - Mandated Laboratory reporting by cytogentics labs.
 - Challenge to match prenatal to information.
 Laboratory (cytogenetics) reporting 75 to 150 per year
 - Genetics Clinics-report quarterly

First Generation KBSR Database

- Contracted programmer
- Access database
- Select elements from vital statistic records
- Linked to hospital discharge.
- Synchronize

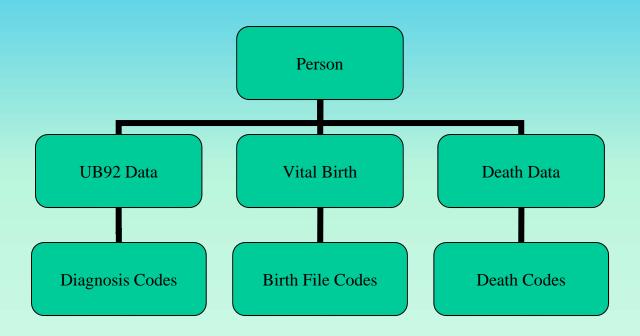


Linkage

- All data tied to "person"
- John Henry Software-DataLever
- Import vital statistic records.
- Currently 92,849 individuals with 95% linked to vital statistic birth records
- Linked to hospital discharge.
 - First and Last Name
 - DOB
 - Sex

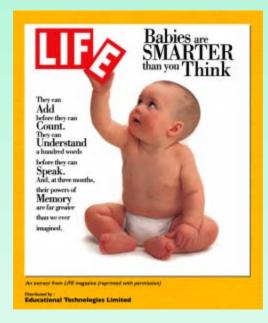


Structure



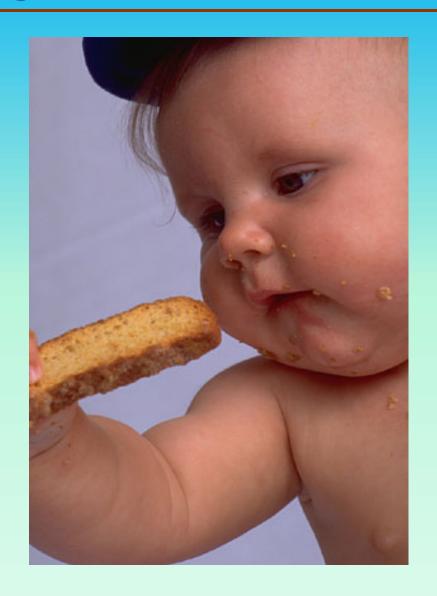
Lessons Learned

- Software Choices Utilized
- Real-time linkage difficult.
- Communication with Programmer Essential.
- Hospital Association streamlined reporting.



Challenges

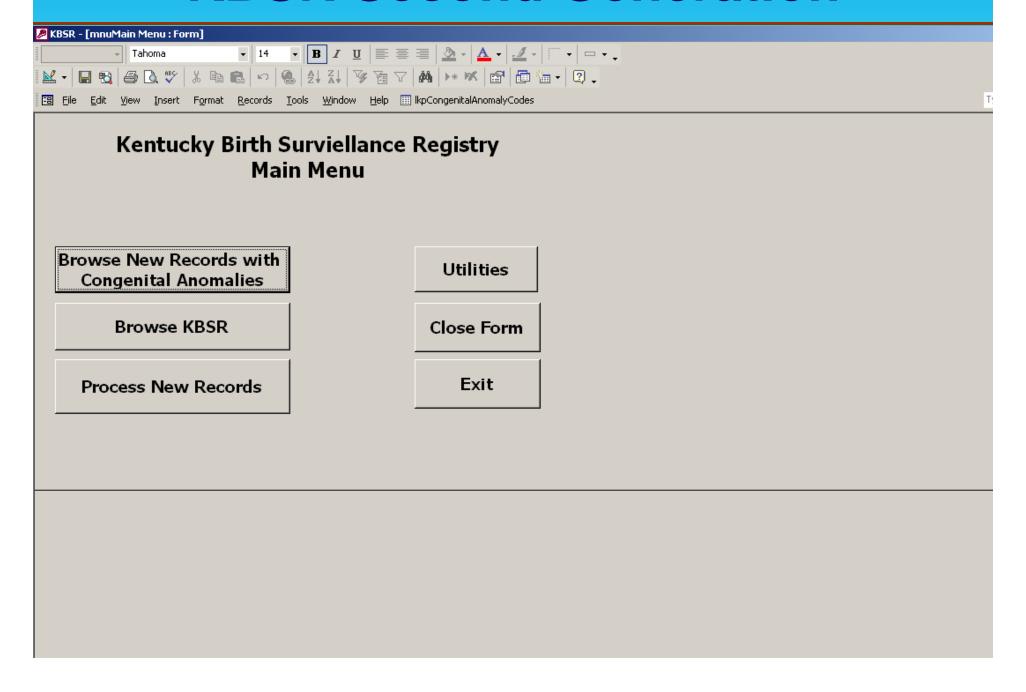
- 2004 Birth
 Certificate file format changed.
- Required database redesign to include new fields
- Input on Birth certificate change.



KBSR Second Generation

- LinkPlus software utilized for probable matching. Still requires manual review.
- All VS data elements imported.
- One common Person ID.
- Retain original data from sources.
- Communication with Programmer Essential.
- Date and Time Stamp for synchronization

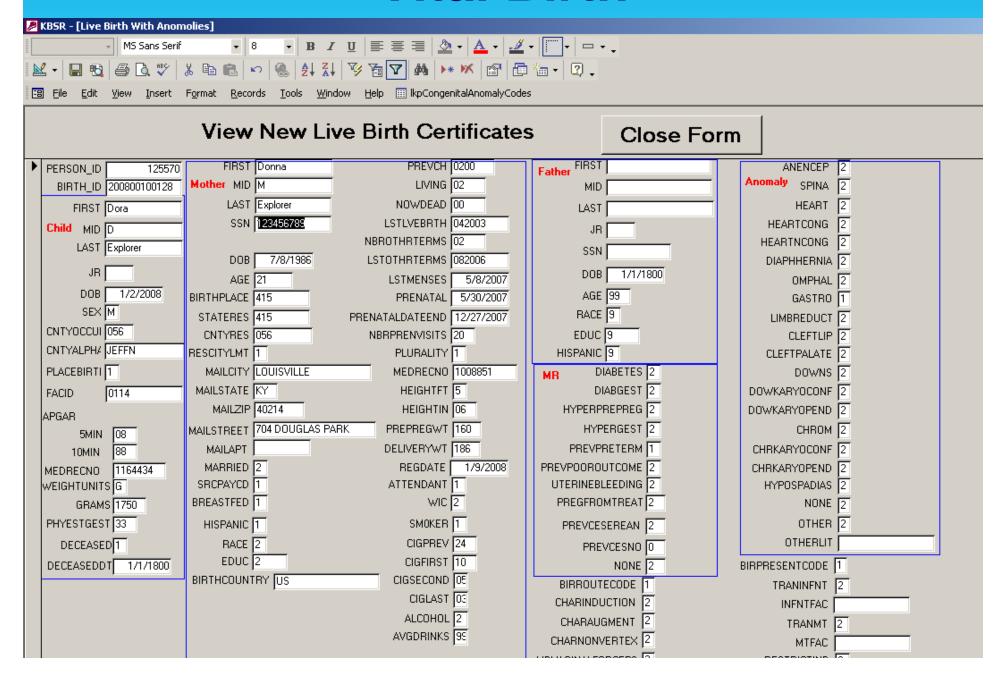
KBSR Second Generation



Person Screen

		KBSR MAS	TER RECORD	Close Form
	Search with known birthdate	Search1, dob: search2	_	
	Search with unknown birthdate	search3	•	
\$	PERSON_ID 125570 BIRTH_ID 200800100128 STILLBIRTH_ID PATIENTCNTL K00005336268 FIRST Dora MI L LAST Explorer ADDRESS 704 DOUGLAS PARK CITY LOUISVILLE COUNTY JEFFN STATE KY ZIP 40214	SSN SEX M KY_BIRTH Mother FIRST Donna LAST Explorer SSN 12345667 Father FIRST LAST SSN	NOTES D411 NKC=gastrichisis-with small bowel, colon, appenidx and right testicle involved. Deve NEC one month post op D0D 2/11/08 SF Prenatal Diagnosis ▼	Family History Comments Has Referral Referral Date 1/1/1800 Referral Outcome Source livebirth Date Created 8/11/2008 Time Stamp 2/26/2012 10:41:50 PM
Recon	DOB 1/2/2008 DOD 2/9/2008 DEATH_ID 200801607714 View Livebirth View Stillbirth View d: □ 1 of 16748 □ N № □ W Unfi	w Death Record View Admissions	Is To Be Deleted View Diagnoses Add New Person Record	Add New Admissions Record

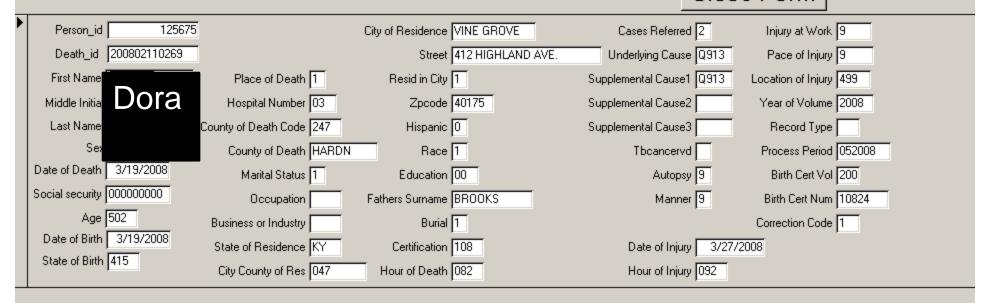
Vital Birth



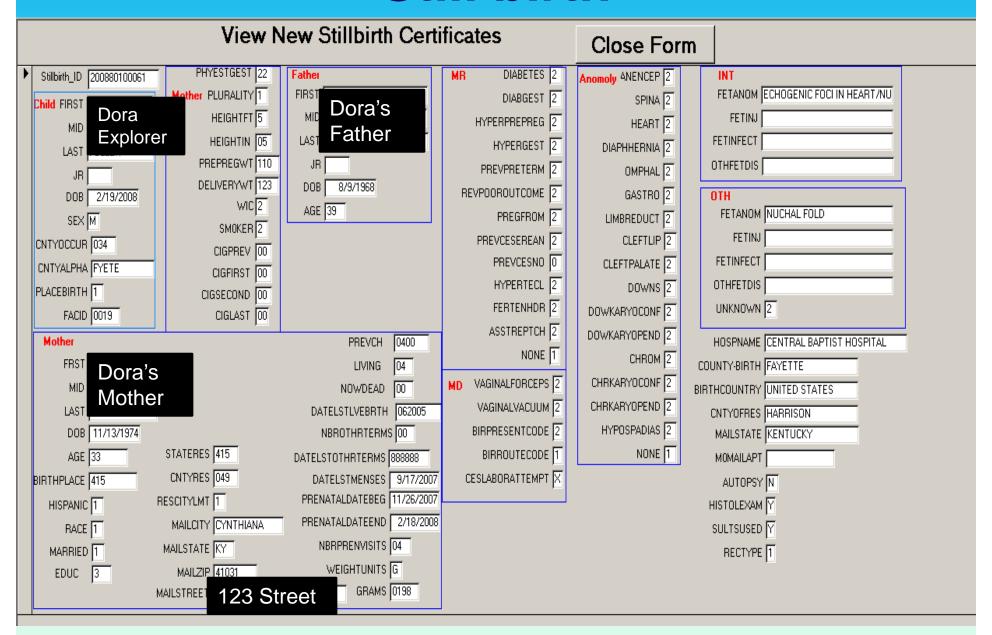
Vital Death

DEATH CERTIFICATES

Close Form



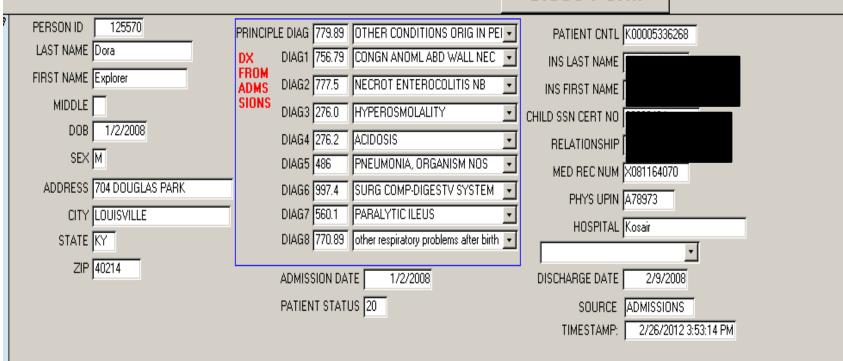
Still birth



Admission Data

ADMISSON DATA

Close Form



Master Diagnosis

	Master Diagnoses List Close Form							orm			
Person_	D Source	ICD-9	ICD-10	Del	ete Description	Birth ID	Stillbirth ID	Death ID	PATIENTCNTL	Timestamp	
125570	livebirth	756.79		₽	CONGN ANOML ABD WALL NEC	200800100128				4/21/2011 10:03:07	
125570	death cer		Q793		Congenital malformations of muscoloskeletal system, no elsewhere			200801607714		8/11/2008 3:57:09 PM	
125570	death cer		Q793		Congenital malformations of muscoloskeletal system, no elsewhere			200801607714		8/11/2008 3:57:09 PM	
125570	death cer		K529					200801607714		8/11/2008 3:57:09 PM	
125570	Admission	779.89			OTHER CONDITIONS ORIG IN PERINATAL				K00005336268	2/26/2012 3:55:25 PM	
125570	Admission	756.79		V	CONGN ANOML ABD WALL NEC				K00005336268	4/21/2011 10:03:13	
125570	Admission	777.5			NECROT ENTEROCOLITIS NB				K00005336268	2/26/2012 3:55:37 PM	
125570	Admission	276.0			HYPEROSMOLALITY				K00005336268	2/26/2012 3:55:44 PM	
125570	Admission	276.2			ACIDOSIS				K00005336268	2/26/2012 3:55:50 PM	
125570	Admission	486			PNEUMONIA, ORGANISM NOS				K00005336268	6/16/2009 2:00:22 PM	
125570	Admission	997.4			SURG COMP-DIGESTV SYSTEM				K00005336268	2/26/2012 3:56:00 PM	
125570	Admission	560.1			PARALYTIC ILEUS				K00005336268	2/26/2012 3:56:06 PM	
125570	Admission	770.89			other respiratory problems after birth				K00005336268	2/26/2012 3:56:19 PM	
Record: 14	Record: M ◆ 1 of 15 → M № Y Filtered Search										

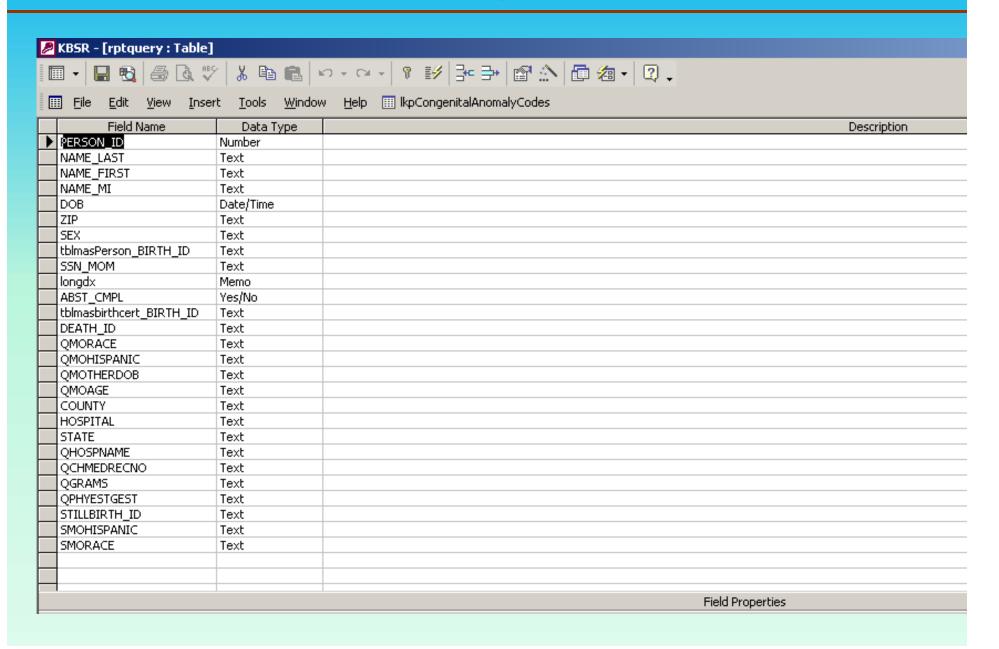
Reporting

Record Selection for Reports

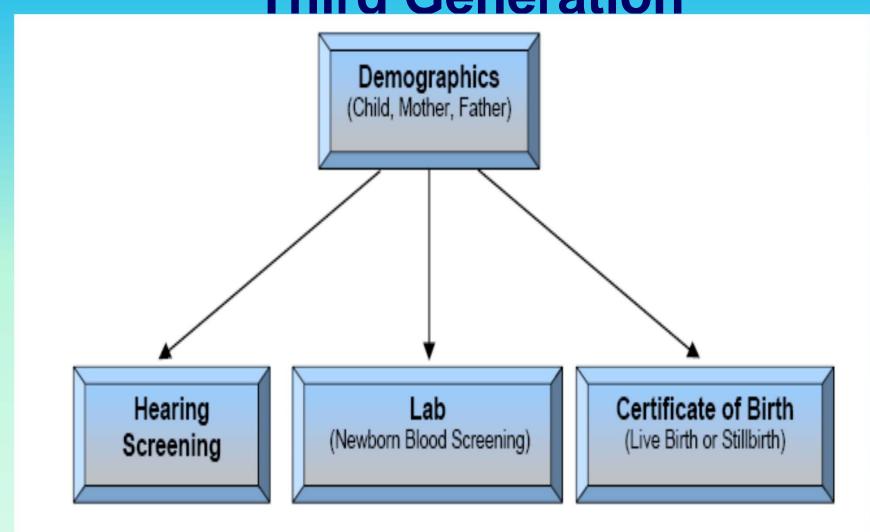
Before running make sure the long dx's are up to date!!

I	(Run 'Create Horizontal Dx Table' if needed)									
	Birth date from: 1/1/1990 Birth date to dx from: dx to	o: C ICD10								
		ver select specific hospitals in both Birth Certs and Admissions r	records at the same time.							
	Birth Cert Hospital: All Th	nis uses hospital field on Birth Certificates								
	At least one of these must be All Admissions Hospital All Name:	OR Admissions Hospital Number:	, These use the hospital field on admisssions For admission hospital searches, you must have both name and number							
	Output table name: rptquery	Display Sql								
I	Run Query	Close Form								

Reporting Output



Moving to Web-based system KBSR Third Generation







e-Health Information Systems

e-Health Information Systems



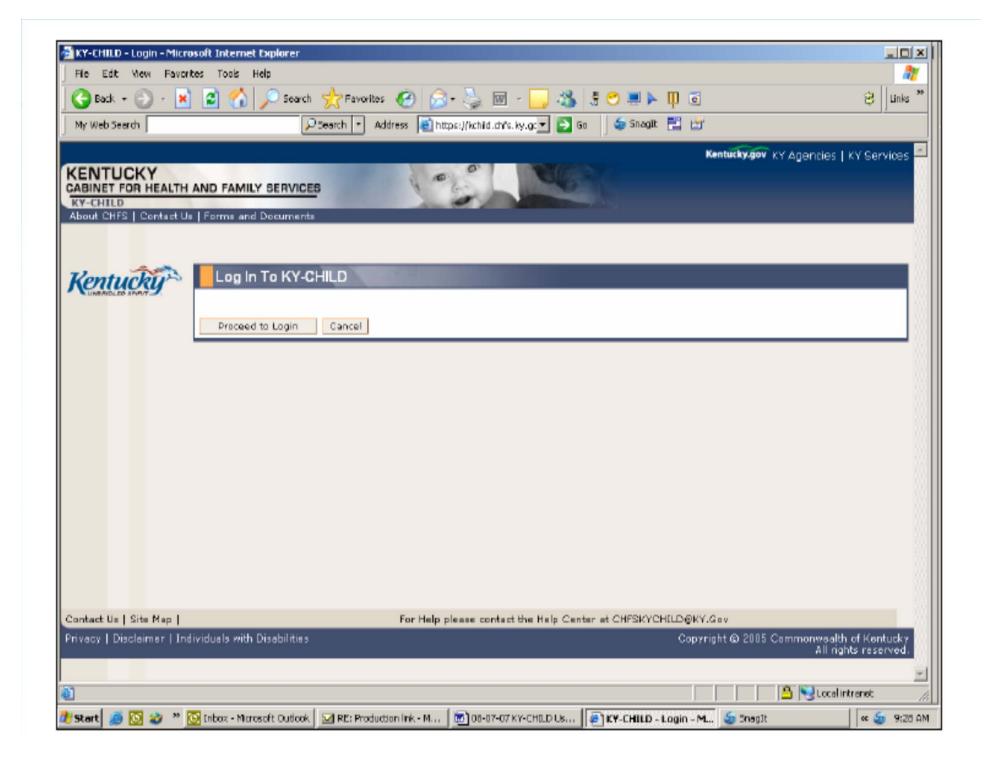
KY-EPHRS (Kentucky Electronic Public Health Record System)

KY-Electronic Public Health Record System is an Internet-based, centralized public health data repository. It is intended to be used by health care professionals to record public health data for the over four million Kentucky residents. To protect patient/person information, technologies such as secure socket layer and rolebased access are used to protect confidential information and ensure patient privacy.



KY-CHILD (Kentucky Child Hearing Immunization and Laboratory Data)

Login - More Information KY-CHILD is used by Kentucky's 56 birthing facilities to begin a child's health record. Using one system to collect birth information. helps eliminate duplication of data and ensures data integrity between public health programs.





Accept

Cancel

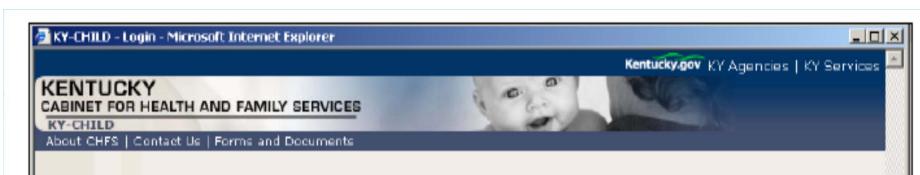
Contact Us | Site Map | CHESKYCHILD®KY.Gov

For Help please contact the Help Center at

Privacy | Disclaimer | Individuals with Disabilities

Copyright © 2005 Commonwealth of Kentucky All rights reserved.

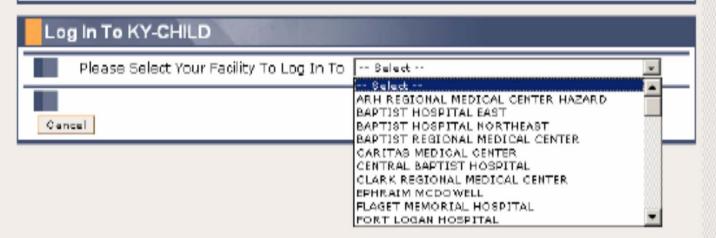






ALERTS!

Reminder: KY-CHILD is unavailable from 4:30pm to 7:30pm ET every Thursday for system enhancement and maintenance.



Contact Us | Site Map | CHESKYCHILD@KY.Gev

For Help please contact the Help Center at

Privacy | Displaimer | Individuals with Disabilities

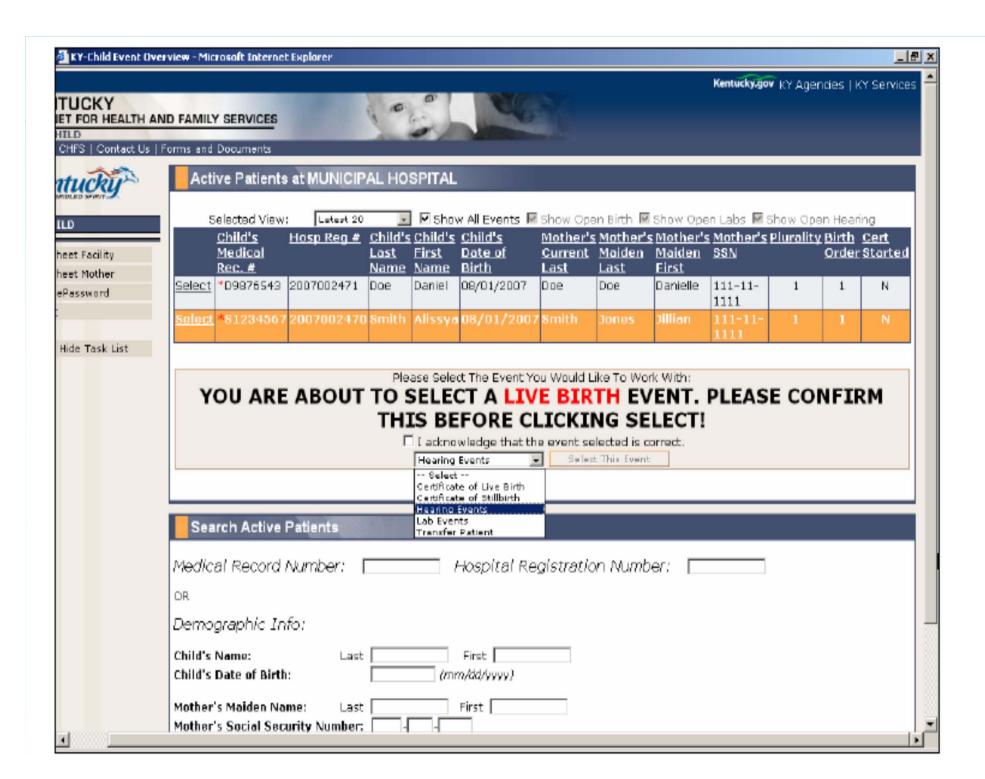
Copyright © 2005 Commonwealth of Kentucky All rights reserved.



Active Patients at MUNICIPAL HOSPITAL														
Selected View: 13tost 20														
	Select	Child's Medical Rec. #	Hosp Reg	Child's Last Name	<u>Child's</u> <u>First</u> <u>Name</u>	Child's Date of Birth	Mother's Current Last	Mother's <u>Maiden</u> <u>Last</u>	Mother's <u>Maiden</u> <u>First</u>	Mother's SSN	Plurality	<u>Birth</u> Order	<u>Cert</u> Started	Delete
	<u>5elect</u>	*53456789	2008000067	Smythe	5amantha	02/04/2007	SMYTHE	5mythe	Robyn	111-11- 1111	1	1	И	
	<u>Select</u>	*J5678901	2008000066	Jones	Joan	03/01/2008	Jones	Jackson	Juanita	111-11- 1111	1	1	N	<u>Delete</u>
	Select	*S1234567	2008000065	Smith	Alyssa	02/20/2008	Smith	Jones	Jillian	111-11- 1111	1	1	N	<u>Delete</u>
	<u>Select</u>	*09876543	2008000064	Оов	Daniel	02/14/2008	Doe	Jones	Jane	111-11- 1111	1	1	N	<u>Delete</u>
4	ck ist P	age < Prev	Page 1 of 1	Next >	Last Page	>>								
_														
L	Sear	ch Active F	atients											
		l Record N	lumber: [Hos	pital Regi:	stration (Number:						
OR Lab/Hearing ID: select ID:														
or Demographic Info:														
Child's Name: Lest First Child's Date of Birth: (mm/dd/vvvv)														
м	Child's Date of Birth: (mm/dd/yyyy) Mother's Maiden Name: Last First Mother's Social Security Number:													

Search

Reset



KENTUCKY

CABINET FOR HEALTH AND FAMILY SERVICES

KY-CHILD

About CHFS | Contact Us | Forms and Documents



Child's Information
1. *Medical Record Number of the Child:
2, *Child's Name: Last First Middle Suffix
3. *Date of Birth: (mm/dd/yyyy)
4. *Time of Birth (24-hour):
5, *Gender of Child: 💌
6. *Facility Name: MUNICIPAL HOSPITAL
7. *City, Town or Location of Birth: LOUISVILLE
8, *County of Birth: JEFFERSON .
9, *Plurality: Single 🗷
10. *Birth Order: First
11. Mother's Name Prior to First Marriage (Maiden Name) Last First Middle Suffix
12. *Emergency Contact Name Last First Middle Suffix
*Contact Phone ()
Address
Address Line 1
Address Line 3 Address Line 3
City
State Select
Country UNITED STATES Postal Code (For US Zip Code use 12345-6789 or 12345)
*Relationship seled
Accept Cancel

Contact Us | Site Map |

For Help please contact the Help Center at CHFSKYCHILD@KY.Gov

Privacy | Disclaimer | Individuals with Disabilities

Copyright © 2005 Commonwealth of Kentucky All rights reserved.

KENTUCKY CABINET FOR HEALTH AND FAMILY SERVICES

KY-CHILD

About CHFS | Contact Us | Forms and Documents



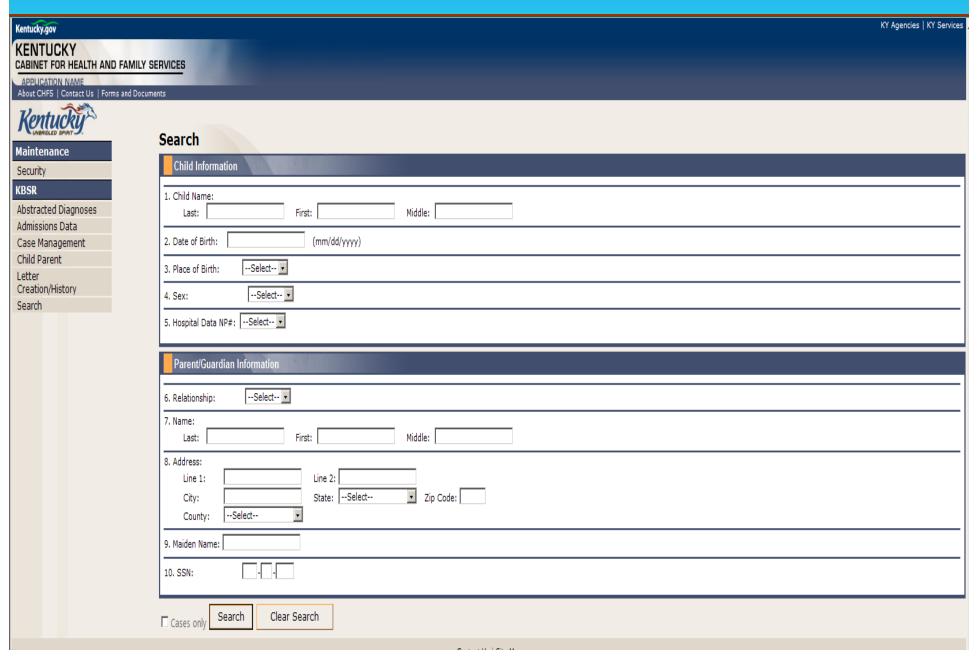
Child	's Name: Joan Jones	Date Of Birth: 08/03/2007
□м	lother Unknown	

Mother's Information
1. *Mother's Current Name Last First Juanita Middle Suffix
2. *Mother's 55N:
3. *Mother's Date of Birth: (mm/dd/yyyy)
4. *Name Prior to first Marriage Last Dackson First Duanita Middle Suffix
Suite/Apt. Number Address Line 1 Address Line 2 Address Line 3 City State KENTUCKY Country UNITED STATES Zip Code (For US Zip Code use 12345-6789 or 12345) Country Select - In Inside City Limits
*Mailing Address Same as Residence? Mother's Mailing Address: Address Line 1 Suite/Apt. Number Address Line 2 Address Line 3 City State Select Country UNITED STATES Postal Code (For US Zip Code use 12345-6789 or 12345)
Mother's Home Phone: ()

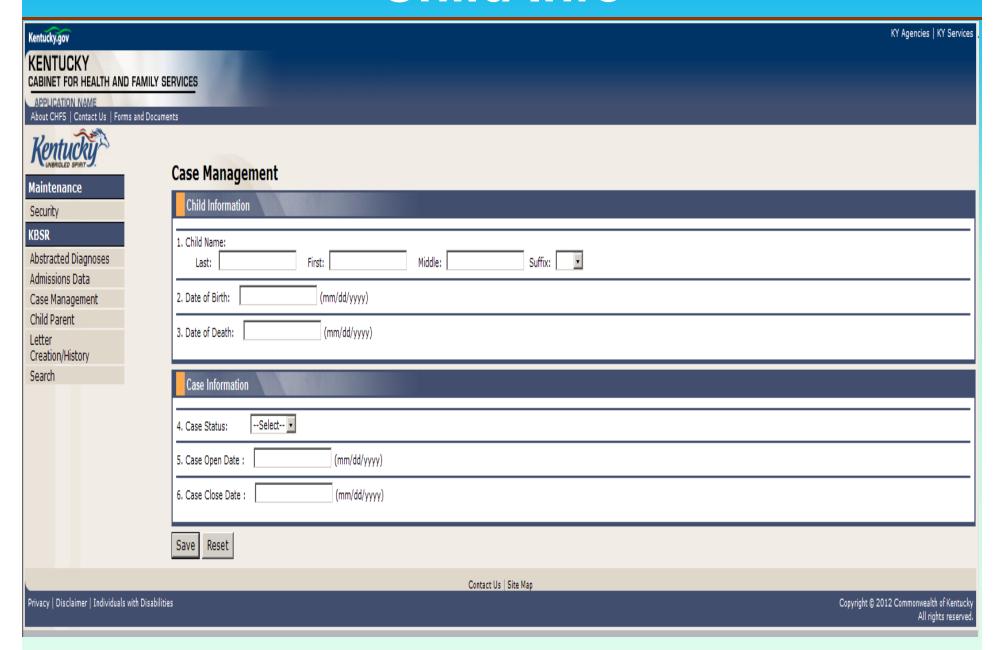
Contact Us | Site Map |

For Help please contact the Help Center at CHFSKYCHILD@KY.Gov

Web-based Start



Child Info



Child/Parent

KENTUCKY

CABINET FOR HEALTH AND FAMILY SERVICES

APPLICATION NAME

About CHFS | Contact Us | Forms and Documents



Maintenance

Security

KBSR

Abstracted Diagnoses Admissions Data

Case Management

Child Parent

Letter

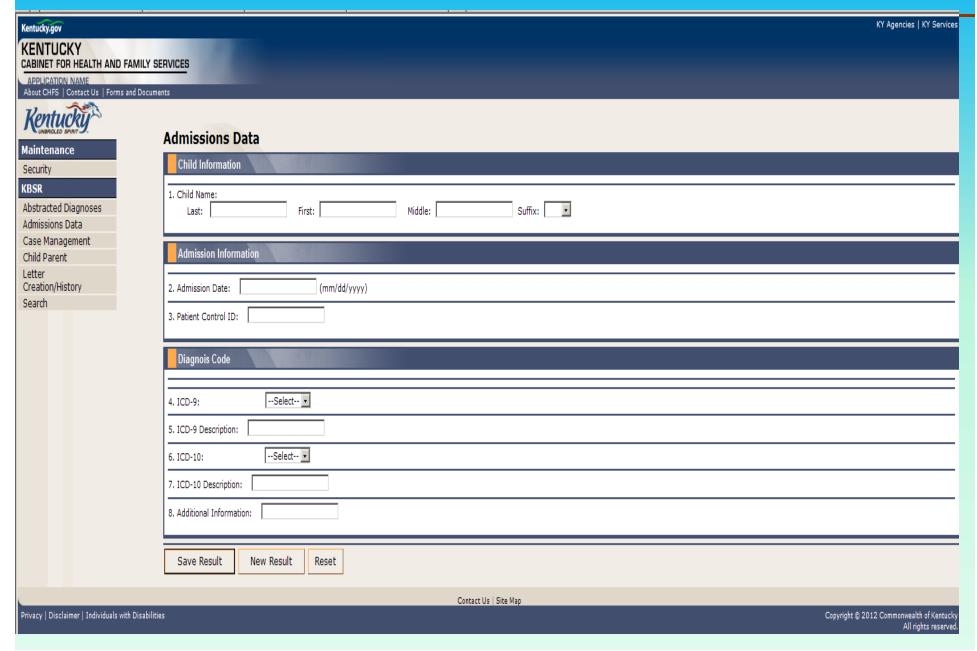
Creation/History

Search

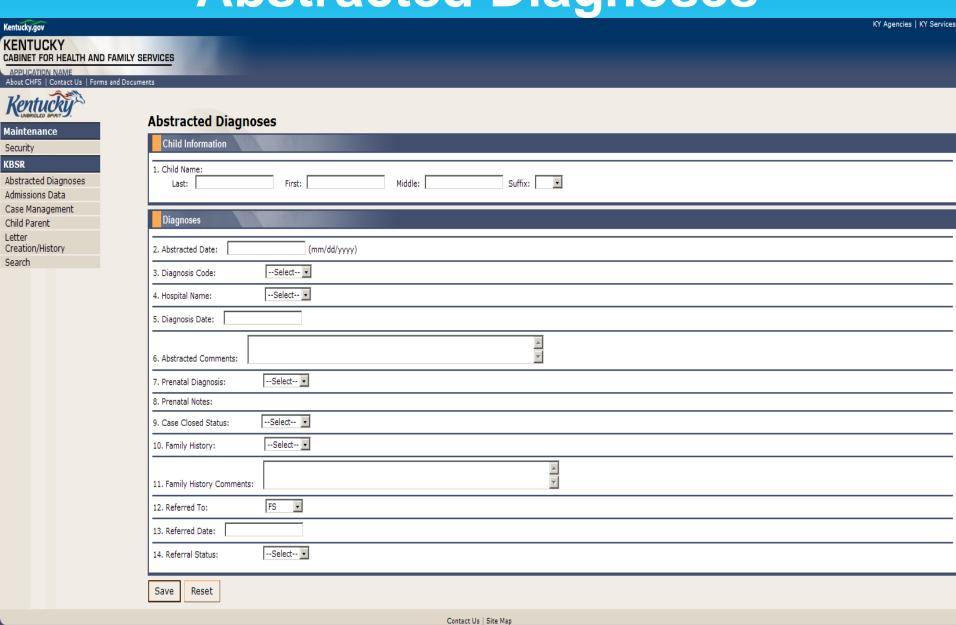
Child/Parent

1. Child Name: Last:	First:	Middle:	Suffix:
2. Date of Birth:	(mm/dd/yy	yy) Time of Birth (hh.	:mm)
3. Place of Birth(Facility Name):	Select		
4. Medical Record#:			
5. Sex:	•		
6. Hispanic Origin:	•		
7. Primary Language used at Ho	me:		
8. Race:			
9. Gestational Age: (We	eks)		
10. Plurality:			
11. Birth Weight: (0	Grams)		
Parent/Guardian Information	on Television		
12. Parent/Guardian Name: Last:	First:	Middle:	Suffix:
13. Relation Type:	•		
1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1	r		

Admission Data



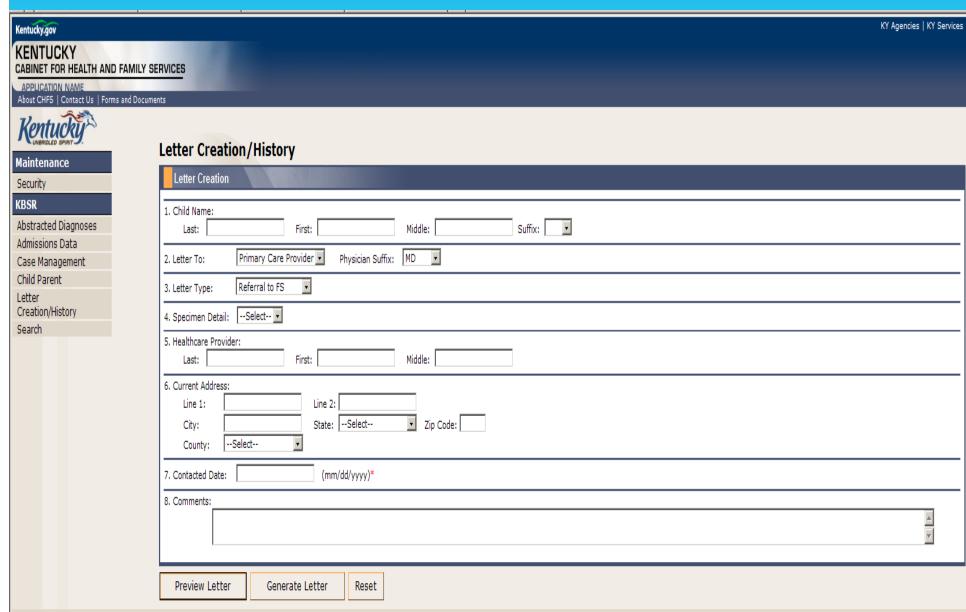
Abstracted Diagnoses



Copyright © 2012 Commonwealth of Kentucky

Privacy | Disclaimer | Individuals with Disabilities

Letter Creation



Contact Us | Site Map

Copyright © 2012 Commonwealth of Kentucky

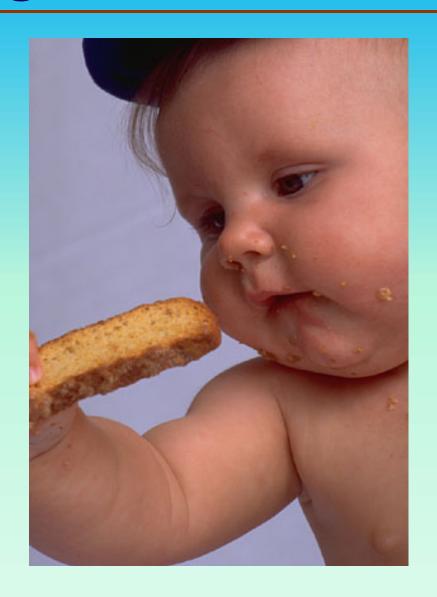
Privacy | Disclaimer | Individuals with Disabilities

Benefits...

- Potential for improved timeliness
- Sustainability
- Reduction in transcriptional errors
- Less clerical staff needed
- Linkage real time.
- Business Objects-Vital queries.

Challenges

- Web-based connectivity in rural areas.
- Linking Hospital discharge data.
- Remote access to hospital records.



Lessons Learned

- Complicated process.
- Software licenses can be expensive.
- Data always changing.
- Currently still the only consecutively linked system in MCH.
- Work with Vital statistics-MRN#





The KHIE Connection: Partnering to Improve Patient Health Outcomes

February 2012

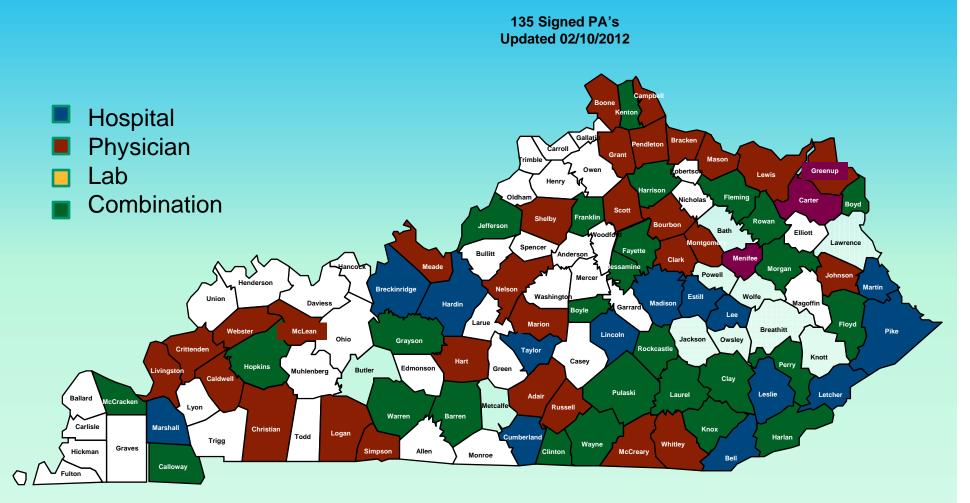


Primary Goal

Provide HIE Connectivity
 to as many providers as possible
 over the next two years with little or
 no startup cost to the providers

Participation Agreements

Hospitals/Physicians by County



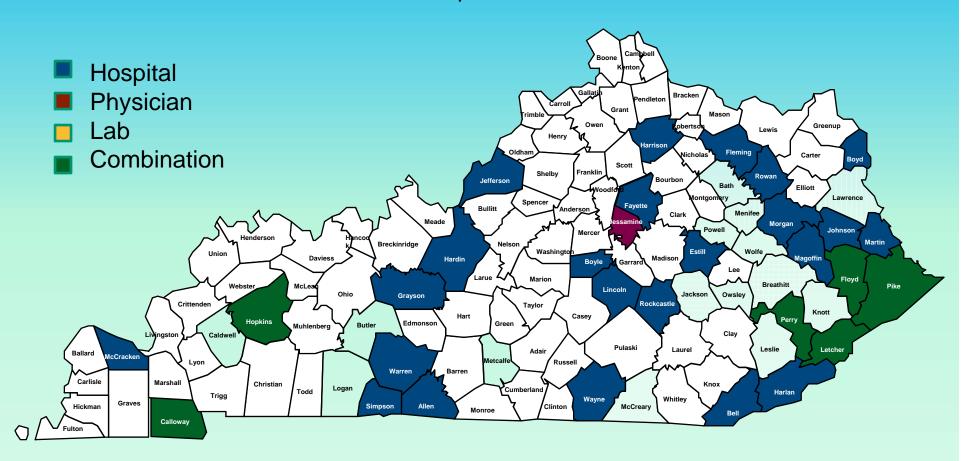
Other Participation Agreements:

- •Kentucky Immunization Registry
- •Kentucky Cancer Registry
- •Kentucky State Laboratory
- •Cumberland Medical Lab
- Labcorp

LIVE Connections

Hospitals/Physicians/Labs by County

Updated 02/10/2012



Others:

- •Kentucky Immunization Registry
- •State Lab (Microbiology)
- •Grundy, VA

KHIE A Value Added Proposition

- Impacting the Healthcare of Kentuckians
- Use of Policy Levers
 - Medicaid Claims Data
 - KHIE was seeded with two years worth /now three years
 - State Laboratory Results
 - Microbiology LIVE since July 2011
 - Newborn screenings in TEST projected LIVE Q 2 2012
 - Kentucky Immunization Registry
 - KHIE offers a LIVE interface for providers to report vaccinations and populate the immunization registry
 - Managed Care Organizations
 - Medicaid requires providers to connect to KHIE
 - Access provided to Case Managers for comprehensive case management/improved continuity of care



Contacts

Sandy Fawbush sandy.fawbush@ky.gov



