



Kentucky's Health Information Exchange Start-up Guide for Public Health Laboratories

W. Baker, J. Lee, K. Fomundam, M. Kinley, S. Mayfield Gibson
Kentucky Division of Laboratory Services
Frankfort, KY

What is an Electronic Medical Record?

An electronic medical record (**EMR**) is:

- ▶ A computerized medical record (such as a digital newborn screening report).
- ▶ Created in an organization that delivers care.
 - Hospital
 - Provider's office
 - Public Health Laboratory

What is an Electronic Health Record?

- ▶ An electronic health record (EHR) is a **systematic collection of electronic health information** about individual patients or populations.

What is a Health Information Exchange?

- ▶ Health Information Exchange (**HIE**) is defined as the **mobilization of the EHR** electronically across organizations within a region.
- ▶ The overarching goal is county to county and state to state sharing of EHRs.

What is meant by “Meaningful Use”?

- ▶ Meaningful use describes the use of health information technology (HIT) in a manner that furthers the goals of information exchange.
- ▶ To become “Meaningful Users”, providers need to demonstrate that they're using certified EHR technology in ways that can be measured significantly in quantity and in quality.

Meaningful Use

- ▶ The Health Information Technology for Economic and Clinical Health (HITECH) Act enacted as part of...
- ▶ American Recovery and Reinvestment Act (ARRA) of 2009 specifies three main components of Meaningful Use:

Meaningful Use

1. The use of a certified EHR in a meaningful manner.
2. The use of certified EHR technology to improve the quality of health care.
3. The use of certified EHR technology to submit clinical quality assurance and other measures.

Meaningful Use and Newborn Screening

Newborn screening is an excellent area to demonstrate **Meaningful Use** since it is the first EMR and the beginning of the EHR for an individual.

- Rapid sharing of newborn screening results has obvious potential for improved health care.
- Newborn screening reduces healthcare disparities and improves population and public health.

Where to Begin?

▶ Organization Buy-in

- Stakeholder support is a necessity.
- These key players are essential for budgetary matters.
- These key players communicate the need and benefits of “change” and maintaining continued commitment and support.

Getting Started

- ▶ **Architecture...**this will vary depending on your existing Laboratory Information System (LIS) and its ability to transmit Health Level 7 (HL7) messages.
- ▶ The basic requirements...are an electronic LIS, a HL7 interface, servers and other hardware and Electronic Medical Record (EMR) and Virtual Health Record (VHR) software.

Getting Started

Personnel

▶ Internal

- IT Manager
- Vocabulary Specialist
- Customer Service Staff

▶ External

- HL7 specialists
- Programmers
- Technical architects
- Vendors
- State HIE administrative personnel
- The state's IT legal officers

Getting Started

Budget

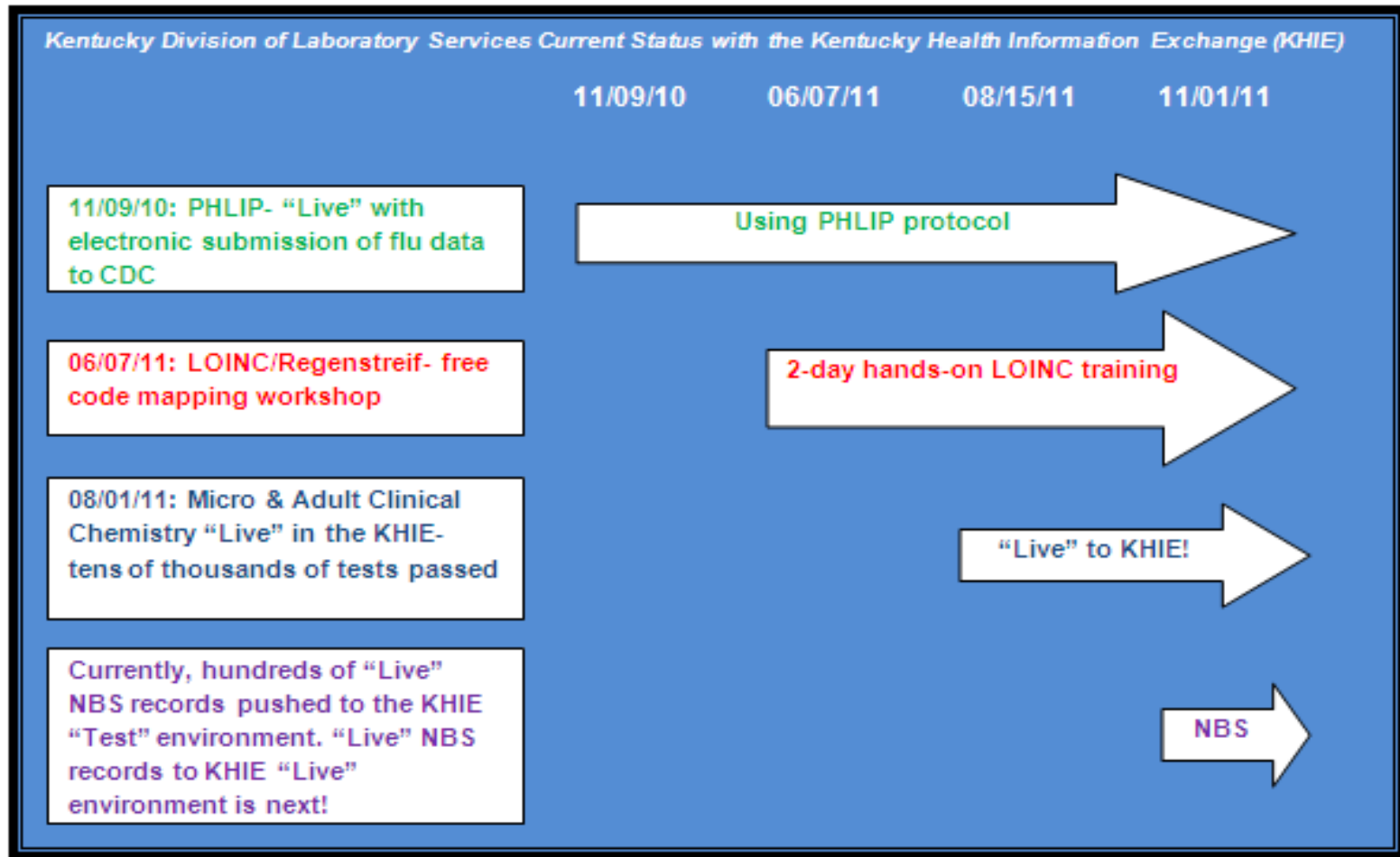
- ▶ State support
- ▶ Federal grants
 - Epidemiology and Laboratory Capacity for Infectious Diseases (ELC)
 - Epidemiology and Laboratory Capacity for Infectious Diseases, Affordable Care Act (ELC ACA)
 - Public Health Emergency Preparedness (PHEP)
 - Others awarded to the state for “Outreach” efforts
 - **2007 Medicaid Transformation Grant (\$4.9M)**
 - **State HIE Cooperative Agreement (\$9.75M)**

Getting Started

Networking

- ▶ Participation in workgroups
- ▶ Conferences
- ▶ Association for Public Health Laboratories (APHL)
- ▶ National Library of Medicine (NLM)
- ▶ College of American Pathologists (CAP)

Timeline



What does a HL7 message look like?



Sample HL7 message

```
MSH|^~\&|PE||LAB|KSL|201111111111||ORU^R01|00080100|P|2.5.1|||  
PID||12345678|12345678||BABY^BOY||20110101|M||123 ANYWHERE  
DRIVE^^FRANKFORT^KY^444444444|||12345678|||  
PV1||O|||FRANKLIN^^|RD^^|^|20110101|  
|  
OBR|1||1234567|44444-5^NEWBORN SCREEN CARD DATA PANEL  
TESTING^LN|R||201108281412|||201109011327||SKH^SOME KENTUCKY  
HOSPITAL||012345|||201111111111||F|^201101011111^^R|||HIS||  
OBX|0001|ST|0^SPECIMEN TYPE^LN||DRIED BLOOD SPOT|||F|||  
OBX|0002|ST|0^COLLECTOR^LN||WHB|||F|||  
OBX|0003|ST|0^STATE OF ORIGIN^LN||KENTUCKY|||F|||  
OBX|0004|ST|0^BIRTH PLURALITY^LN||SINGLETON|||F|||  
OBX|0005|ST|0^GESTATIONAL AGE^LN||37 WEEKS|||F|||  
OBX|0006|ST|0^CHART NUMBER^LN||C01234567/C1234567|||F|||  
OBX|0007|ST|44444-5^NEWBORN  
SCREEN^LN||NORMAL|||F|||201111111111||NTE|0001|| THIS REPORT  
CONTAINS PATIENT INFORMATION THAT MUST BE PROTECTED IN ACCORDANCE WITH  
THE HEALTH INSURANCE PORTABILITY AND ACCOUNTABILITY ACT. |
```



Mapping

Local code name	Local code system	Mapped code name	Mapped code system
FS	L	Hb SS-disease (sickle cell anemia), LA12614-6	LN
FSa	L	Hb S beta-thalassemia, LA12615-3	LN
FSC	L	Hb SC-disease, LA12616-1	LN
FAC	L	Hb C-carrier, LA12602-1	LN
FAD	L	Hb D-carrier, LA12603-9	LN
FAE	L	Hb E-carrier, LA12604-7	LN
FAS	L	Hb S (sickle)-carrier, LA12606-2	LN
FDA	L	Hb D beta-thalassemia, LA12610-4	LN
FEA	L	Hb E beta-thalassemia, LA12613-8	LN

What does a report in a HIE look like?



Demographics Section

Elysium **FINAL LAB RESULTS FROM KENTUCKY DIVISION OF LABORATORY SERVICES SPECIMEN GATE**

CHART COPY



Name: **BABY, BOY** Gender: **M** Age: **4 Months**

Address: **123 ANYWHERE DRIVE** Born: **01-JAN-2011**
FRANKFORT, KY 44444 Alias:

Home: **(859) 555-5555** Work:

Mobile: Email:

MRN or ID: **1111111111 [DLS-NBS]**
2222222222 [Elysium]

▶ Ordered by **DIVISION OF LABORATORY SERVICES**

Attending: **S. MAYFIELD GIBSON**



Newborn Screening Report Summary Panel

Newborn Screening Report summary panel Sample taken on: 28-APR-2011 09:30 AM

Name of Mother: DOE, JANE

Ordering Provider: GIBSON, S. MAYFIELD

Phone: (859)555-5555

SOME KENTUCKY HOSPITAL

LABORATORY

123 ANYWHERE DRIVE

FRANKFORT, KY 44444

Observation		Value	Reference Range	Units	Note
Reason for lab test in Dried blood spot		Initial screen			
Sample quality of Dried blood spot		Acceptable			
Newborn screening report - overall interpretation		All screening is normal. SEE INDIVIDUAL TEST PANEL.			
Newborn conditions with positive markers [Identifier] in Dried blood spot		None			
Newborn conditions with equivocal markers [Identifier] in Dried blood spot		None			

Date/time of specimen receipt: 01-MAY-2011 08:00 AM

Date/time of report: 01-MAY-2011 03:00 PM

Relevant Clinical Information: NBS CORRELATION



Newborn Screening Report Summary Panel

Newborn Screening Report summary panel Sample taken on: 28-APR-2011 09:30 AM

Name of Mother: DOE, JANE
 Ordering Provider: GIBSON, S. MAYFIELD
 Phone: (859)555-5555
 SOME KENTUCKY HOSPITAL
 LABORATORY
 123 ANYWHERE DRIVE
 FRANKFORT, KY 44444

Observation		Value	Reference Range	Units	Note
Reason for lab test in Dried blood spot		Initial screen			
Sample quality of Dried blood spot		Acceptable			
Newborn screening report - overall interpretation		Not normal requiring further filter paper testing for at least one condition. SEE INDIVIDUAL TEST PANEL.			
Newborn conditions with positive markers [Identifier] in Dried blood spot		None			
Newborn conditions with equivocal markers [Identifier] in Dried blood spot	◆	BIO			

Date/time of specimen receipt: 01-MAY-2011 08:00 AM

Date/time of report: 01-MAY-2011 03:00 PM

Relevant Clinical Information: NBS CORRELATION



Newborn Screen Card Data Panel

Newborn screen card data panel

Sample taken on: 28-APR-2011 09:30 AM

Observation		Value	Reference Range	Units	Note
State of origin [Identifier] in NBS card		KY			
Body weight Measured --at birth		3000		g	
Birth time		1200			
Birth date		20110101			
Birth plurality of Pregnancy		Singleton			
Obstetric estimation of gestational age		>= 37		weeks	
Clinical events that affect newborn screening interpretation		None			
Unique bar code number of Current sample		1111111111			

Date/time of specimen receipt: 01-MAY-2011 08:00 AM

Date/time of report: 01-MAY-2011 03:00 PM

Relevant Clinical Information: NBS CORRELATION

MS/MS Panels

Amino acid newborn screen panel

Sample taken on: 28-APR-2011 09:30 AM

Observation		Value	Reference Range	Units	Note
Amino acidemias newborn screen interpretation		Normal	Within Profile Range		

Date/time of specimen receipt: 01-MAY-2011 08:00 AM
 Date/time of report: 01-MAY-2011 03:00 PM
 Relevant Clinical Information: NBS CORRELATION

Fatty acid oxidation newborn screen panel

Sample taken on: 28-APR-2011 09:30 AM

Observation		Value	Reference Range	Units	Note
Fatty acid oxidation defects newborn screen interpretation		Normal	Within Profile Range		

Date/time of specimen receipt: 01-MAY-2011 08:00 AM
 Date/time of report: 01-MAY-2011 03:00 PM
 Relevant Clinical Information: NBS CORRELATION

Organic acid newborn screen panel

Sample taken on: 28-APR-2011 09:30 AM

Observation		Value	Reference Range	Units	Note
Organic acidemias newborn screen interpretation		Normal	Within Profile Range		

Date/time of specimen receipt: 01-MAY-2011 08:00 AM
 Date/time of report: 01-MAY-2011 03:00 PM
 Relevant Clinical Information: NBS CORRELATION

Cystic Fibrosis Newborn Screening Panel

Cystic fibrosis newborn screening panel **Sample taken on: 28-APR-2011 09:30 AM**

Observation		Value	Reference Range	Units	Note
Cystic fibrosis newborn screen interpretation		Normal			
Trypsinogen I Free [Mass/volume] in Dried blood spot		9.5	Age Based	ng/mL	See note 1

Note 1

IRT - Normal for initial specimens from infants <4 weeks of age is <58ng/mL

IRT - Normal for initial specimens from infants > or = 4 weeks of age is <50ng/mL

IRT - Normal for repeat specimens (regardless of age) is <50ng/mL

Date/time of specimen receipt: 01-MAY-2011 08:00 AM

Date/time of report: 01-MAY-2011 03:00 PM

Relevant Clinical Information: NBS CORRELATION



Congenital Adrenal Hyperplasia Newborn Screening Panel

**Congenital adrenal hyperplasia newborn
screening panel**

Sample taken on: 08-Jun-2011 03:30 AM

Observation		Value	Reference Range	Units	Note
Congenital adrenal hyperplasia newborn screen interpretation		Normal			
17- Hydroxyprogesterone [Mass/volume] in Dried blood spot		3.5	Weight Based	nmol/L	See note 2

Note 2

Congenital Adrenal Hyperplasia 17OHP normal weight based limits: <1500g <70ng/mL; <1500g-2500g <40ng/mL; <2500g <25ng/mL; Normal for repeat specimens is <25ng/mL

Date/time of specimen receipt: 01-MAY-2011 08:00 AM

Date/time of report: 01-MAY-2011 03:00 PM

Relevant Clinical Information: NBS CORRELATION



Thyroid Newborn Screening Panel

Thyroid newborn screening panel

Sample taken on: 28-APR-2011 09:30 AM

Observation		Value	Reference Range	Units	Note
Congenital hypothyroidism newborn screen interpretation		Normal			
Thyroxine [Mass/volume] in Dried blood spot		16.1	Age Based	ug/dL	See note 3
Thyrotropin [Units/volume] in Dried blood spot		4.5	<20 uU/mL	uU/mL	

Note 3

T4- Normal for specimens from infants < 4 weeks of age is 5-27 ug/dL

T4- Normal for specimens from infants > or = 4 weeks of age is 5-19 ug/dL

TSH- Normal is < 20uU/mL

Date/time of specimen receipt: 01-MAY-2011 08:00 AM

Date/time of report: 01-MAY-2011 03:00 PM

Relevant Clinical Information: NBS CORRELATION



Galactosemia Newborn Screening Panel

Galactosemia newborn screening panel

Sample taken on: 28-MAY-2011 09:30 AM

Observation		Value	Reference Range	Units	Note
Galactosemia newborn screen interpretation		Normal	Full Enzyme Activity		

Date/time of specimen receipt: 01-MAY-2011 08:00 AM

Date/time of report: 01-MAY-2011 03:00 PM

Relevant Clinical Information: NBS CORRELATION

Biotinidase Newborn Screening Panel

Biotinidase newborn screening panel

Sample taken on: 08-Jun-2011 03:30 AM

Observation		Value	Reference Range	Units	Note
Biotinidase deficiency newborn screen interpretation		Normal	Full Enzyme Activity		

Date/time of specimen receipt: 01-MAY-2011 08:00 AM

Date/time of report: 01-MAY-2011 03:00 PM

Relevant Clinical Information: NBS CORRELATION

Biotinidase Newborn Screening Panel

Biotinidase newborn screening panel

Sample taken on: 08-Jun-2011 03:30 AM

Observation		Value	Reference Range	Units	Note
Biotinidase deficiency newborn screen interpretation		Partial Enzyme Activity	Full Enzyme Activity		See note 4

Note 4

Equivocal: Recollect specimen and send to KY Division of Laboratory Services (State Lab).

Date/time of specimen receipt: 01-MAY-2011 08:00 AM

Date/time of report: 01-MAY-2011 03:00 PM

Relevant Clinical Information: NBS CORRELATION



Hemoglobinopathies Newborn Screening Panel

Hemoglobinopathies newborn screening panel

Sample taken on: 28-APR-2011 09:30 AM

Observation		Value	Reference Range	Units	Note
Hemoglobin disorders newborn screening comment/discussion		See Additional Notes			FA

Date/time of specimen receipt: 01-MAY-2011 08:00 AM

Date/time of report: 01-MAY-2011 03:00 PM

Relevant Clinical Information: NBS CORRELATION



Reference Ranges

Reference Ranges

Effective January 10, 2011- Congenital Adrenal Hyperplasia 17OHP normal weight based limits: <1500g < 70ng/mL; 1500g-2500g < 40ng/mL; >2500g < 25ng/mL. Normal for repeat specimens is <25ng/mL.

T4- Normal for specimens from infants < 4 weeks of age is 5-27ug/dL.
Normal T4 for specimens from infants > or = 4 weeks of age is 5-19ug/dL.
Normal TSH is <20uU/mL.

IRT - Normal for initial specimens from infants < 4 weeks of age is <58ng/mL.

IRT - Normal for initial specimens from infants > or = 4 weeks of age is <50ng/mL.

IRT - Normal for repeat specimens (regardless of age) is <50ng/mL.



Tests Conducted

TESTS CONDUCTED:

Enzyme Immunoassay: Congenital Adrenal Hyperplasia (CAH), Congenital Hypothyroidism (CH), Cystic Fibrosis (CF)
Colorimetric Assay: Biotinidase Deficiency
Fluorometric Assay: Galactosemia
High Performance Liquid Chromatography (HPLC): Hemoglobinopathies

Tandem Mass Spectrometry (MS/MS):

Fatty Acid Oxidation Disorders: Medium-chain acyl-CoA dehydrogenase deficiency (MCADD), Very long-chain acyl-CoA dehydrogenase deficiency (VLCADD), Long-chain 3-hydroxyacyl-CoA dehydrogenase deficiency (LCHADD), Trifunctional protein deficiency (TFP), Carnitine uptake defect (CUD), Carnitine acylcarnitine translocase deficiency (CACT), Carnitine palmitoyl transferase I deficiency (CPT-I), Carnitine palmitoyl transferase II deficiency (CPT-II), Glutaric acidemia type II (GA-II), Short-chain acyl-CoA dehydrogenase deficiency (SCADD)

Amino Acid Disorders: Argininosuccinic acidemia (ASA), Citrullinemia Type I (CIT-I), Tyrosinemia Type I (TYR-I), Maple syrup urine disease (MSUD), Homocystinuria (HCY), Phenylketonuria (PKU), Argininemia (arginase deficiency) (ARG), Citrullinemia Type II (CIT-II), Hyperphenylalaninemia (H-PHE), Hypermethioninemia (MET), Tyrosinemia Type II (TYR-II), Tyrosinemia Type III (TYR-III), Nonketotic Hyperglycinemia (NKHG)

Organic Acid Disorders: Beta-ketothiolase deficiency (BKT), Isovaleric acidemia (IVA), Glutaric acidemia Type I (GA-I), 3-Hydroxy-3-methylglutaric aciduria (HMG), Multiple carboxylase deficiency (MCD), 3-Methylcrotonyl-CoA carboxylase deficiency (3MCC), Methylmalonic acidemia (MMA Cbl A, B, C, D), Methylmalonyl-CoA mutase deficiency (MUT), Propionic acidemia (PA), 2-Methyl-3-Hydroxybutyric aciduria (2M3HBA), 3-Methylglutaconic aciduria (3MGA), Isobutyryl-CoA dehydrogenase deficiency (IBD), Malonic acidemia (MAL), Methylmalonic encephalopathy (EE), 2-Methylbutyryl-CoA dehydrogenase deficiency (2MBCD)



Disclaimer and Report Footer

The laboratory values in this report represent screening test results and are intended to identify infants at risk for selected disorders and in need of more definitive testing. The above results should be correlated clinically with consideration of age at the time of collection, nutrition, birth weight, prematurity, health status, and treatments. It is very important for physicians to be aware that a negative screening result does not indicate with certainty the absence of the above listed disorders. The physician should be alert to the clinical symptoms of these conditions, so that diagnosis and treatment can take place as early as possible in infants who are not identified through the newborn screening program.

Biotinidase and Galactosemia results obtained using validated research procedures or research reagents. The results must not be used as the sole criteria for diagnosis, treatment, or the assessment of a patient's health. Clinical correlation is required.

This report contains patient information that must be protected in accordance with the Health Insurance Portability and Accountability Act.

20111111111111_365.lab

DLS - NBS

Lab Director, Stephanie K Mayfield Gibson, MD FCAP

Kentucky Cabinet for Health and Family Services

Department for Public Health

Division of Laboratory Services

100 Sower Blvd, Suite 204

Frankfort, KY 40601





Acknowledgements

- ▶ Department Heads
 - DPH
 - DLS
 - OIT
- ▶ Partners
 - APHL
 - NLM
 - CAP
 - CDC
 - Regenstreif
- ▶ Vendors (LIS and HIE)

Questions?

