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.
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**

**Kentucky Division of Laboratory Services Current Status with the Kentucky Health Information Exchange (KHIE)**

- **11/09/10**: PHLIP - “Live” with electronic submission of flu data to CDC
- **06/07/11**: LOINC/Regenstreif - free code mapping workshop
- **08/15/11**: Micro & Adult Clinical Chemistry “Live” in the KHIE - tens of thousands of tests passed
- **11/01/11**: Using PHLIP protocol
  - 2-day hands-on LOINC training
  - “Live” to KHIE!
  - NBS

Currently, hundreds of “Live” NBS records pushed to the KHIE “Test” environment. “Live” NBS records to KHIE “Live” environment is next!
What does a HL7 message look like?
## Mapping

<table>
<thead>
<tr>
<th>Local code name</th>
<th>Local code system</th>
<th>Mapped code name</th>
<th>Mapped code system</th>
</tr>
</thead>
<tbody>
<tr>
<td>FS</td>
<td>L</td>
<td>Hb SS–disease (sickle cell anemia), LA12614–6</td>
<td>LN</td>
</tr>
<tr>
<td>FSa</td>
<td>L</td>
<td>Hb S beta–thalassemia, LA12615–3</td>
<td>LN</td>
</tr>
<tr>
<td>FSC</td>
<td>L</td>
<td>Hb SC–disease, LA12616–1</td>
<td>LN</td>
</tr>
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<td>FAC</td>
<td>L</td>
<td>Hb C–carrier, LA12602–1</td>
<td>LN</td>
</tr>
<tr>
<td>FAD</td>
<td>L</td>
<td>Hb D–carrier, LA12603–9</td>
<td>LN</td>
</tr>
<tr>
<td>FAE</td>
<td>L</td>
<td>Hb E–carrier, LA12604–7</td>
<td>LN</td>
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<td>FAS</td>
<td>L</td>
<td>Hb S (sickle)–carrier, LA12606–2</td>
<td>LN</td>
</tr>
<tr>
<td>FDA</td>
<td>L</td>
<td>Hb D beta–thalassemia, LA12610–4</td>
<td>LN</td>
</tr>
<tr>
<td>FEA</td>
<td>L</td>
<td>Hb E beta–thalassemia, LA12613–8</td>
<td>LN</td>
</tr>
</tbody>
</table>
What does a report in a HIE look like?
Demographics Section

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

Name: BABY, BOY  Gender: M  Age: 4 Months  
Address: 123 ANYWHERE DRIVE  
FRANKFORT, KY 44444  
Born: 01-JAN-2011  
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

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

<table>
<thead>
<tr>
<th>Observation</th>
<th>Value</th>
<th>Reference Range</th>
<th>Units</th>
<th>Note</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reason for lab test in Dried blood spot</td>
<td>Initial screen</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sample quality of Dried blood spot</td>
<td>Acceptable</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Newborn screening report - overall interpretation</td>
<td>All screening is normal.</td>
<td>See INDIVIDUAL</td>
<td></td>
<td>TEST PANEL.</td>
</tr>
<tr>
<td>Newborn conditions with positive markers [Identifier] in Dried blood spot</td>
<td>None</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Newborn conditions with equivocal markers [Identifier] in Dried blood spot</td>
<td>None</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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

<table>
<thead>
<tr>
<th>Observation</th>
<th>Value</th>
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<th>Units</th>
<th>Note</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reason for lab test in Dried blood spot</td>
<td>Initial screen</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sample quality of Dried blood spot</td>
<td>Acceptable</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Newborn screening report - overall interpretation</td>
<td>Not normal requiring further filter paper testing for at least one condition. <strong>SEE INDIVIDUAL TEST PANEL.</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Newborn conditions with positive markers [Identifier] in Dried blood spot</td>
<td>None</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Newborn conditions with equivocal markers [Identifier] in Dried blood spot</td>
<td>☀️ BIO</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Date/time of specimen: 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**

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

- Date/time of specimen: 01-MAY-2011 08:00 AM
- Date/time of report: 01-MAY-2011 03:00 PM
- Relevant Clinical Information: NBS CORRELATION
**Amino acid newborn screen panel**

<table>
<thead>
<tr>
<th>Observation</th>
<th>Value</th>
<th>Reference Range</th>
<th>Units</th>
<th>Note</th>
</tr>
</thead>
<tbody>
<tr>
<td>Amino acidemias newborn screen interpretation</td>
<td>Normal</td>
<td>Within Profile Range</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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

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**Fatty acid oxidation newborn screen panel**

<table>
<thead>
<tr>
<th>Observation</th>
<th>Value</th>
<th>Reference Range</th>
<th>Units</th>
<th>Note</th>
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</thead>
<tbody>
<tr>
<td>Fatty acid oxidation defects newborn screen interpretation</td>
<td>Normal</td>
<td>Within Profile Range</td>
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<td></td>
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</tbody>
</table>

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

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**Organic acid newborn screen panel**

<table>
<thead>
<tr>
<th>Observation</th>
<th>Value</th>
<th>Reference Range</th>
<th>Units</th>
<th>Note</th>
</tr>
</thead>
<tbody>
<tr>
<td>Organic acidemias newborn screen interpretation</td>
<td>Normal</td>
<td>Within Profile Range</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Date/time of specimen: 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

<table>
<thead>
<tr>
<th>Cystic fibrosis newborn screening panel</th>
<th>Sample taken on: 28-APR-2011 09:30 AM</th>
</tr>
</thead>
<tbody>
<tr>
<td>Observation</td>
<td>Value</td>
</tr>
<tr>
<td>Cystic fibrosis newborn screen</td>
<td>Normal</td>
</tr>
<tr>
<td>interpretation</td>
<td></td>
</tr>
<tr>
<td>Trypsinogen I Free</td>
<td>9.5</td>
</tr>
<tr>
<td>[Mass/volume] in Dried blood spot</td>
<td></td>
</tr>
</tbody>
</table>

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
## Congenital Adrenal Hyperplasia Newborn Screening Panel

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

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

**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

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Date/time of specimen: 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**

<table>
<thead>
<tr>
<th>Observation</th>
<th>Value</th>
<th>Reference Range</th>
<th>Units</th>
<th>Note</th>
</tr>
</thead>
<tbody>
<tr>
<td>Congenital hypothyroidism newborn screen interpretation</td>
<td>Normal</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Thyroxine [Mass/volume] in Dried blood spot</td>
<td>16.1</td>
<td>Age Based</td>
<td>ug/dL</td>
<td>See note 3</td>
</tr>
<tr>
<td>Thyrotropin [Units/volume] in Dried blood spot</td>
<td>4.5</td>
<td>&lt;20 uU/mL</td>
<td>uU/mL</td>
<td></td>
</tr>
</tbody>
</table>

**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
<table>
<thead>
<tr>
<th>Observation</th>
<th>Value</th>
<th>Reference Range</th>
<th>Units</th>
<th>Note</th>
</tr>
</thead>
<tbody>
<tr>
<td>Galactosemia newborn screen interpretation</td>
<td>Normal</td>
<td>Full Enzyme Activity</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Date/time of specimen: 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

<table>
<thead>
<tr>
<th>Observation</th>
<th>Value</th>
<th>Reference Range</th>
<th>Units</th>
<th>Note</th>
</tr>
</thead>
<tbody>
<tr>
<td>Biotinidase deficiency newborn screen interpretation</td>
<td>Normal</td>
<td>Full Enzyme Activity</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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

- **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

<table>
<thead>
<tr>
<th>Observation</th>
<th>Value</th>
<th>Reference Range</th>
<th>Units</th>
<th>Note</th>
</tr>
</thead>
<tbody>
<tr>
<td>Biotinidase deficiency newborn screen interpretation</td>
<td>Partial Enzyme Activity</td>
<td>Full Enzyme Activity</td>
<td></td>
<td>See note 4</td>
</tr>
</tbody>
</table>

### Note 4

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

**Date/time of specimen:** 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

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

<table>
<thead>
<tr>
<th>Observation</th>
<th>Value</th>
<th>Reference Range</th>
<th>Units</th>
<th>Note</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hemoglobin disorders newborn screening comment/discussion</td>
<td>See Additional Notes</td>
<td></td>
<td></td>
<td>FA</td>
</tr>
</tbody>
</table>

Date/time of specimen: 01-MAY-2011 08:00 AM  
Date/time of report: 01-MAY-2011 03:00 PM  
Relevant Clinical Information: NBS CORRELATION
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 (2MBDH)
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.
Acknowledgements

- Department Heads
  - DPH
  - DLS
  - OIT

- Partners
  - APHL
  - NLM
  - CAP
  - CDC
  - Regenstreif

- Vendors (LIS and HIE)
Questions?