Colorado’s Integrated Data System: one state’s approach to a comprehensive health information exchange for short-term and long-term follow-up

Erica L. Wright, MS, CGC
Certified Genetic Counselor, Instructor

Children’s Hospital Colorado
Affiliated with University of Colorado Anschutz Medical Campus
School of Medicine
History of Colorado’s Integrated Data System (IDS)

• Developed in 2000 through an Early Hearing Detection and Intervention (EHDI) grant to develop electronic tracking system for newborn hearing and newborn blood spot screening at the Colorado Department of Public Health and Environment (CDPHE).

• Formally known as CHIRP (Clinical Health Information Records of Patients)
  ▪ Multiple local applications
    • CDPHE Hearing/NBS, Metabolic, Sickle Cell
  ▪ Became web-based in 2010 and renamed IDS.

• Awarded “Effective Follow-up in Newborn Screening” grant in 2009 from HRSA.
Effective Follow-up in NBS

• Colorado was one of 4 grantees awarded
• $1,200,000, 3 year grant
• Joint effort of CDPHE and Children’s Hospital Colorado Inherited Metabolic Diseases (IMD) clinic
  ▪ CDPHE PI: Chris Wells, PhD
  ▪ IMD clinic PI: Janet Thomas, MD
• In summary, all goals focused on improvement and further development of IDS for both short-term and long-term follow-up.
Metabolic Application

• Extensive clinical and laboratory database in collaboration with the staff of the Inherited Metabolic Diseases (IMD) Clinic at Children’s Hospital Colorado/University of Colorado Denver.
• Information populated by multiple applications:
  - IMD clinic
  - Health Care Program for Children with Special Needs
  - Vital Records (electronic birth certificate)
  - CDPHE’s NBS lab via Specimen Gate.
• Newborn Evaluation Screening and Tracking (NEST)
  - Centralized database and integration application
Short-term follow-up (STFU)

- IMD clinic utilizes IDS to track abnormal newborn screens, recommendations, follow-up studies and outcome.
- Only patients with abnormal metabolic screens can be viewed by the IMD clinic.
- Report function
  - Query open NBS cases
  - Track timeliness of follow-up
  - Provide quarterly/yearly updates to CDPHE
- Two-way communication
  - CDPHE follow-up team
  - Local public health nurses
Workflow

Abnormal NBS results verbally reported to IMD clinic for immediate F/U

Follow-up confirmatory testing tracked and entered into IDS by IMD clinic

Outcome of NBS case determined: true vs. false positive

Patient information entered in IDS with NBS results and recommendations

Electronic birth certificate information matched through NEST

CDPHE and local HCP office notified of true positives through IDS

IDS populates and generates fax and requisition forms for PCP of patient

Electronic transfer of NBS results into IDS from Specimen Gate after NBS results finalized

Follow-up closure faxes to PCPs generated through IDS

Outcome of NBS case determined: true vs. false positive

Follow-up closure faxes to PCPs generated through IDS
Metabolic Screen

Dx: 07/07/2013 | Disorders of Fatty Acid Oxidation: Medium-chain acyl-CoA dehydrogenase (MCAD) deficiency: Definite
First Clinic Visit: 04/07/2013
Diet/Treatment Initiation: 04/04/2013

Outcome

Positive: True
Date Closed: 04/06/2013

Record Information
Updated: 4/23/2013 3:32:00 PM
Updated By: eawright
Created: 4/23/2013 3:32:00 PM
Created By: eawright
Long-term follow-up (LTFU)

- Datasets developed by the Mountain States Genetics Regional Collaborative’s (MSGRC) Metabolic Consortium.
  - Performance indicators
    - Benchmark data to measure, track, and compare
    - Age of diet initiation, freq. of clinic visits, growth parameters, ER visits, diet stats, developmental services, etc.
  - Outcome measures
    - End result of the intervention
    - Mortality, IQ, cardiomyopathy, neurological symptoms, bone findings, final adult growth, etc.
Only patients with confirmed diagnoses are entered.
  - Clinically diagnosed patients also included to serve as a control population.
- Patients must be consented prior to data entry.
  - Active IRB approved research protocol
- Data is primarily extracted from chart review by research assistant previously funded by the Effective Follow-up in NBS grant.
- Report function utilized for disease-specific queries
  - How many hospitalizations did our patients with MCAD deficiency have in 2012?
Electronic Health Information Exchange (eHIE) survey

• In 2010, as part of our Effective Follow-up in NBS grant, a survey was conducted with providers throughout Colorado and Wyoming.
  ▪ Pediatricians and family practice physicians surveyed
  ▪ 158 responses

• Queried physicians regarding their obtainment of NBS results
  ▪ 77% check for 1\textsuperscript{st} and 2\textsuperscript{nd} NBS results
  ▪ 2\% check for only the first
  ▪ 16\% check for only the second
  ▪ 5\% don’t look for results
    • “No news is good news”
Resulting

- Don't retrieve: 6%
- Call birth facility: 8%
- Call Lab: 7%
- Mailed: 31%
- Faxed: 48%
Additional survey results

• 80.3% of respondents stated they would benefit from eHIE of NBS results

• Functions that would be most valuable to provider in an eHIE:
  ▪ Access to NBS results: 94%
  ▪ Access to immunization records: 89.7%
  ▪ Access to newborn hearing results: 78.1%

• Conclusion:
  ▪ NBS results + immunizations records = happy physicians
Colorado Immunization Information System (CIIS)

- IDS has been linked to CIIS through NEST
- Data acquisition from Specimen Gate being upgraded and refined
  - Includes LOINC and SNOMED codes
- 3 PCP offices will pilot NBS resulting via CIIS this summer with anticipated full-scale launch in the fall.
This screen will be used to call the Newborn Screening System to display results for children with documented screenings. Click the "Retrieve NBS Data" button to connect to the NBS system and retrieve data.

View: WHITE, JACK (444239) DOB: 09/25/1981 AGE: 3Y 1M 13D

Audiology Section

Initial Screen
- Completed: Yes/No/Unknown
- Date: mm/dd/yyyy
- Result Left: Passed/Failed
- Result Right: Passed/Failed

Follow-Up Screen
- Completed: Yes/No/Unknown
- Date: mm/dd/yyyy
- Result Left: Passed/Failed
- Result Right: Passed/Failed

Evaluation Submitted: mm/dd/yyyy

Audologist: First Middle Last

Hearing Loss: Yes/No

Laboratory Report 1

Accession #: 9999999999999
Specimen Type: First/Second

Patient Information
- Mother's Name: First Middle Last
- Sex: F/M/T/U
- Weight: 99g
- Medical Record: 99999999999
- Date Collected: mm/dd/yyyy
- Date Reported: mm/dd/yyyy
- Date Received: mm/dd/yyyy
- Date Printed: mm/dd/yyyy
- Date Corrected: mm/dd/yyyy

Name: First Middle Last
Address: xx street name
city, state zip

Physician: First Middle Last

Result: 
Reference Range: 
Comment: 

Laboratory Report 2

Accession #: 9999999999999
Specimen Type: First/Second

Patient Information
- Mother's Name: First Middle Last
- Sex: F/M/T/U
- Weight: 99g
- Medical Record: 99999999999
- Date Collected: mm/dd/yyyy
- Date Reported: mm/dd/yyyy
- Date Received: mm/dd/yyyy
- Date Printed: mm/dd/yyyy
- Date Corrected: mm/dd/yyyy

Name: First Middle Last
Address: xx street name
city, state zip

Physician: First Middle Last

Result: 
Reference Range: 
Comment: 

Next Steps for IDS (STFU)

• Continued work to successfully link CIIS with IDS
  ▪ Include follow-up recommendations, outcome, etc.
  ▪ Implement an “alert” mechanism

• Harmonization of data fields with NewSTEPs quality indicators

• Facilitate transfer of data to NewSTEPs

• Continued overall quality improvement of NBS program
Next Steps for IDS (LTFU)

- Transfer legacy data to Newborn Screening Translational Research Network’s Longitudinal Pediatric Data Resource (LPDR)
- Requires new IRB approved protocol and reconsenting of patients
- Requires data matching /harmonization
- Additional funding requested through MSGRC
- Identify additional funding sources for continued data entry of LTFU into LPDR
Acknowledgements

• The Mountain States Genetics Regional Collaborative Center (MSGRCC) is supported by cooperative agreement #U22MC10761 with the United States Department of Health and Human Services, Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau, Genetic Services Branch.

• The Effective Follow-up in Newborn Screening grant is funded by cooperative agreement #2581292, ST 63100006 with HRSA, Maternal and Child Health Bureau, Genetic Services Branch.
Thank you!

• Children’s Hospital/University of Colorado team
  ▪ Janet Thomas, MD

• CDPHE IT team
  ▪ Bruce Straw
  ▪ Paul Turtle
  ▪ Chris Wells, PhD

• CDPHE NBS lab
  ▪ Mark Dymerski
  ▪ Dan Wright