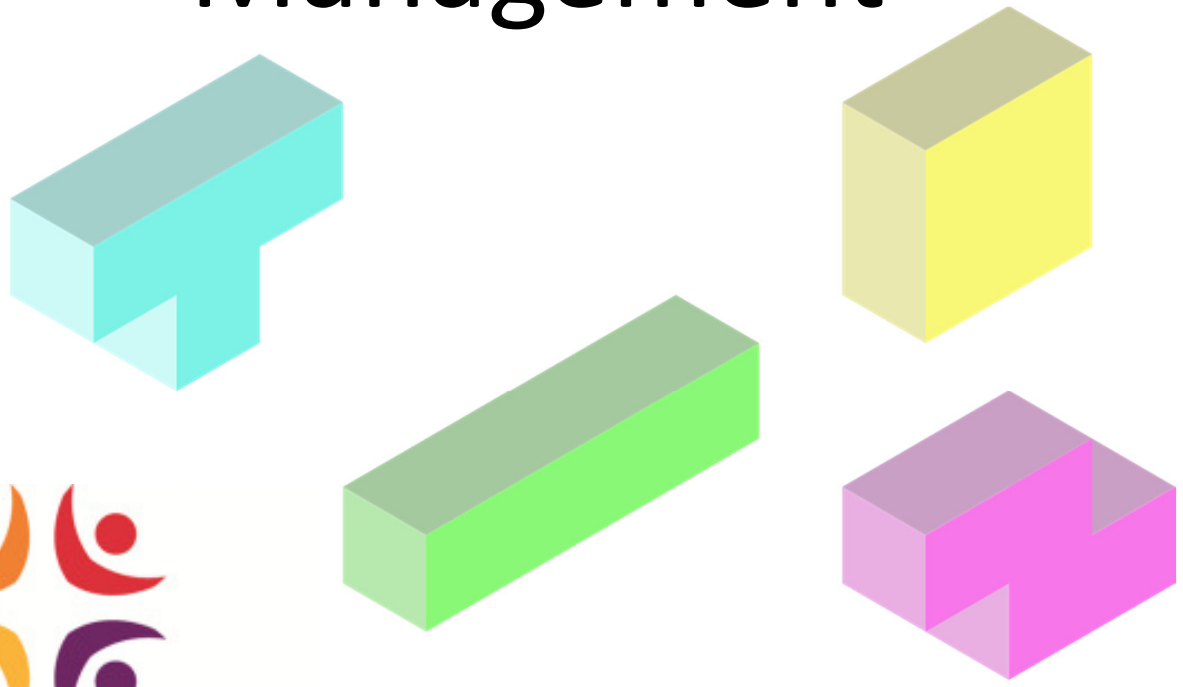
Adding CMV to EHDI Data Management



UTAH DEPARTMENT OF HEALTH
Early Hearing Detection & Intervention

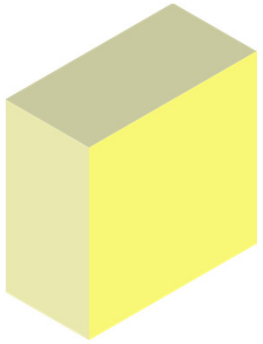
HiTrack
EHDI Data Management System

Utah HB 81 (2013 General Session) Cytomegalovirus Public Health Initiative

26-10-10 UCA, “Cytomegalovirus (CMV) Public Education and Testing”

- **UDOH** establish and conduct public education program to inform *pregnant women and women who may become pregnant* about CMV (incidence, transmission, birth defects, diagnostic methods, preventative measures)

- Provide information to: *child care providers*, *school nurses*, *health educators*, *health care providers, religious organizations offering children’s programs as part of worship services*



26-10-10 UCA, “Cytomegalovirus (CMV) Public Education and Testing”

If a newborn infant fails the newborn hearing screening test(s)……

Medical Practitioner shall:

- *Test the newborn infant for CMV before 21 days of age…*unless the parent objects; **and**
- *Provide to the parents information* re: birth defects caused by congenital CMV and available methods of treatment.

UTAH DEPARTMENT OF HEALTH
Early Hearing Detection & Intervention

H.B. 81 (2013 General Session) Cytomegalovirus Public Health Initiative (UCA 26-10-10) Sequence of Events

INFANT FAILS INPATIENT NEWBORN HEARING SCREENING (NBHS)

Hospital NBHS Program notifies family their infant failed hearing screen and **schedules outpatient re-screen to take place prior to 14 days of age** emphasizing importance of completing this appointment at the scheduled time.

Hospital NBHS Program obtains complete primary care provider (PCP) information from family and enters it in Infant's Hi*Track record. If complete information is not in the physician database "drop down" menu , it can be added/updated by contacting Utah Early Hearing Detection & Intervention (EHDI) Hi*Track Data Coordinator at (801) 584-8221.

Hospital NBHS Program notifies PCP of **initial screen failure** using the "Newborn Hearing Screening / CMV Status Report FAX" form or other mutually agreed upon method of notification . The method of notification must be documented in Hospital Program Summary.

INFANT FAILS 2ND (OUTPATIENT) HEARING SCREENING

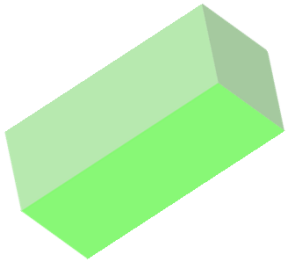
Hospital NBHS Program immediately notifies PCP of the **follow-up hearing screening failure** via fax using the "Newborn Hearing Screening / CMV Status Report FAX" form, 2)phone message. Notification must be documented in HiTrack), or 3)other preferred method of notification must be documented in Hospital Program documented in HiTrack). The method of notification must be documented in Hospital Program Summary. Family is told to contact PCP if does not hear from MD within 24 hours.

PCP discusses congenital CMV with family and orders CMV PCR assay testing via saliva or urine on infant unless parents object.

TESTING OCCURS PRIOR TO 21 DAYS OF AGE

After test results are received, PCP faxes "Newborn Hearing Screening / CMV Status Report FAX" Form to Hospital NBHS Program and to UDOH at (801) 584-8492. PCP consults with family on next steps.

If questions, please contact the Utah Department of Health (UDOH) EHDI program at (801) 584-8215. Created 6/25/13.



UTAH DEPARTMENT OF HEALTH
Early Hearing Detection & Intervention

Newborn Hearing Screening (NBHS) / CMV Status Report FAX (1 form with 3 options)

Date: _____

PILOT
Version: August 26, 2013
COMPLETE ONE OPTION ONLY

TO: _____

FROM: _____ **CLINIC/HOSPITAL:** _____ **FAX:** _____ **PHONE:** _____

OPTION 1 (NBHS Program)

PER H.B. 81 (2013 General Session) UCA 26-10-10 Cytomegalovirus (CMV) Public Health Initiative, the following infant who lists you as their Primary Care Physician, has **FAILED** the **INITIAL** newborn hearing screen and will require a follow-up re-screen. This follow-up appointment is scheduled as noted. Should you have contact with the family prior to the follow-up date please encourage them to keep the appointment as this should be completed ***no later than 14 days of age***. Otherwise, no action on your part is necessary at this time.

Notification of failed *INITIAL* HEARING SCREEN – *to be completed by HOSPITAL*

Infant's Name	D.O.B.	Mother's Name	Contact#	Follow-up Appt.

OPTION 2 (NBHS Program)

This is to advise the PCP that the following infant has **FAILED** the **FOLLOW-UP (2nd) HEARING SCREENING** and is a candidate for **congenital CMV testing before 21 days of age** per H.B. 81. He/she has also been referred to a pediatric audiologist for a diagnostic hearing evaluation.

Notification of failed *FOLLOW-UP* HEARING SCREEN – *to be completed by HOSPITAL*

Infant's Name	D.O.B.	Mother's Name	Contact#	Diagnostic Appt.

OPTION 3 (Primary Care Provider)

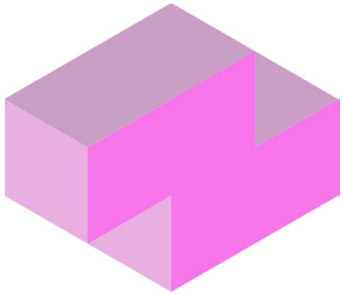
After congenital CMV PCR assay testing has been completed, PCP office should fax this form back to the Hospital NBHS program at the above listed fax # AND to the Utah Department of Health Early Hearing Detection and Intervention (EHDI) program at (801) 584-8492.

Notification of CMV TEST RESULTS – *to be completed by PHYSICIAN*

Infant's Name	D.O.B.	Urine (U) or Saliva (S)	RESULT: Pos (+) or Neg (-)

If questions, please contact the Utah Department of Health Early Hearing Detection and Intervention program at (801) 584-8215.

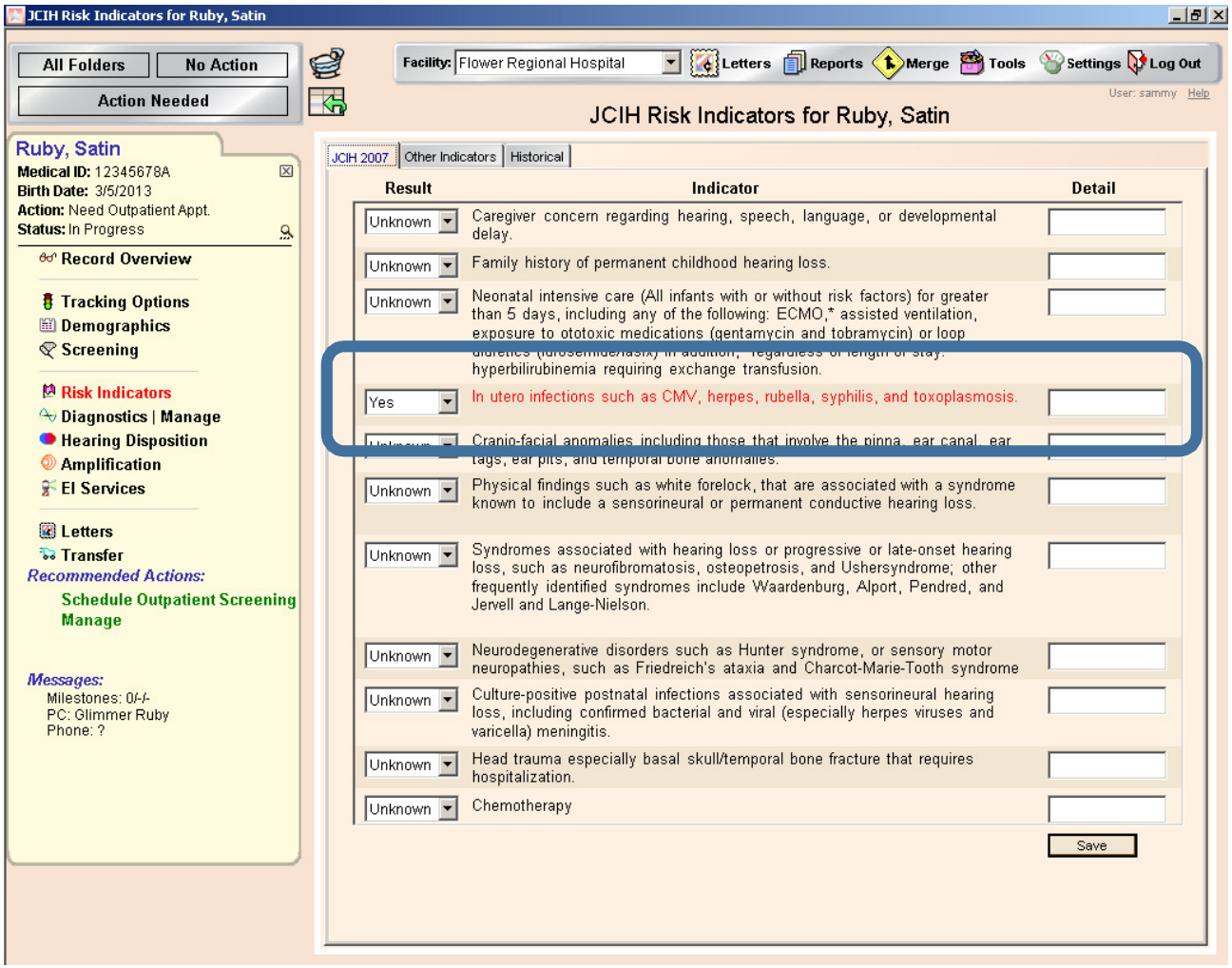
“Notebook” Data: First 6 Months



Babies eligible for CMV testing = 183
# of CMV tests reported back to UDOH = 27

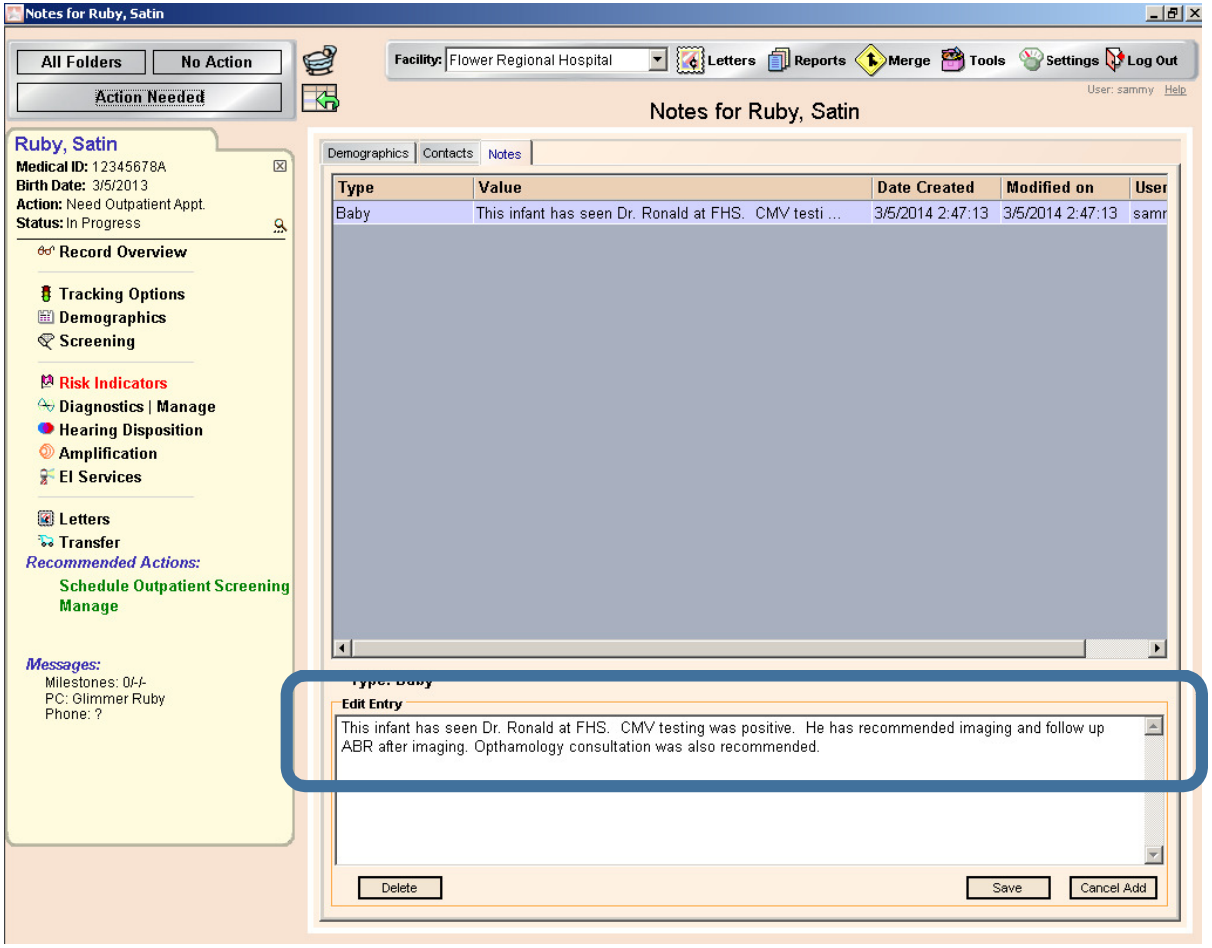
Prior Implementation: Overview

- Risk Indicator Data Entry



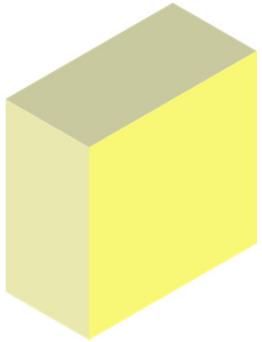
Prior Implementation: Overview

- Notes Data Entry



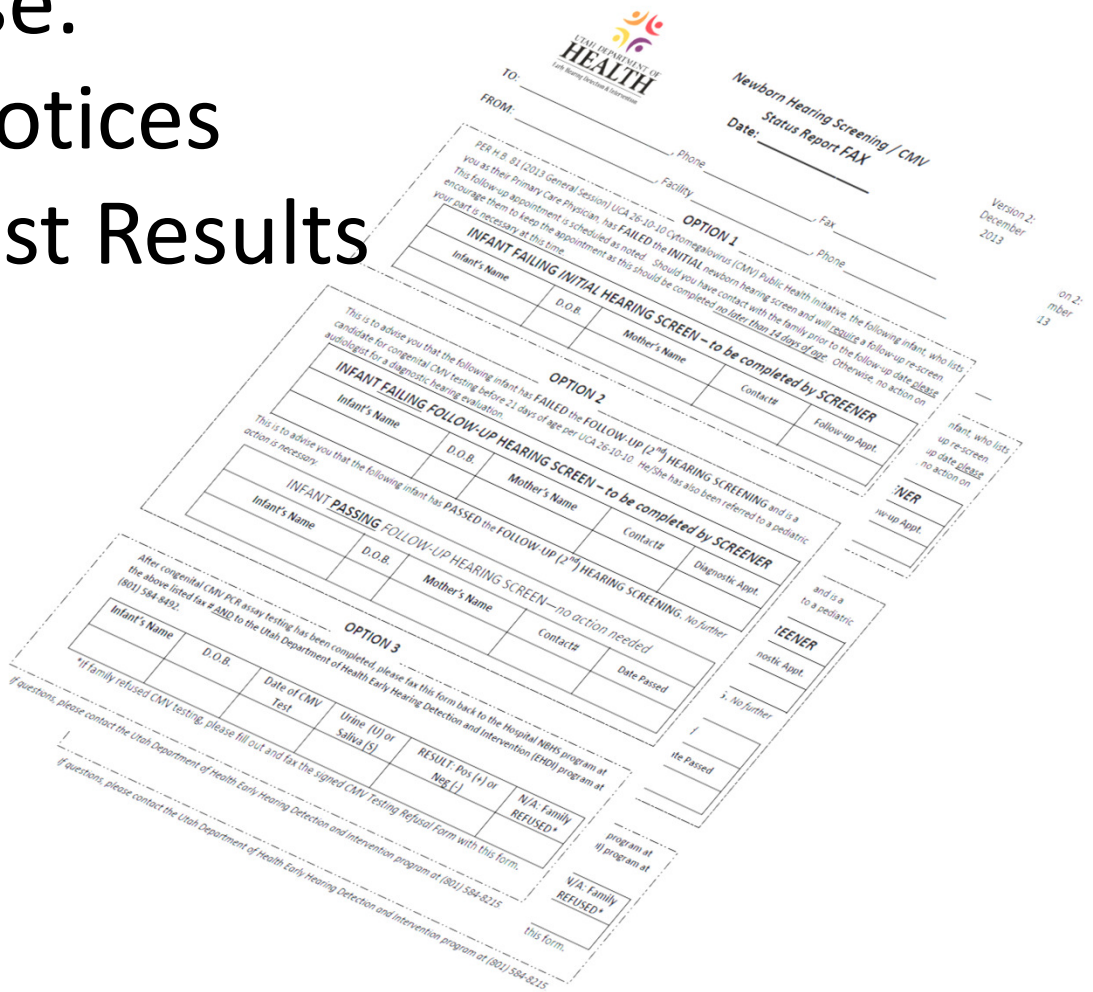
Prior Implementation: Limitations

- Limited Reporting Capacity
- Free text entries make hard to quantify the data



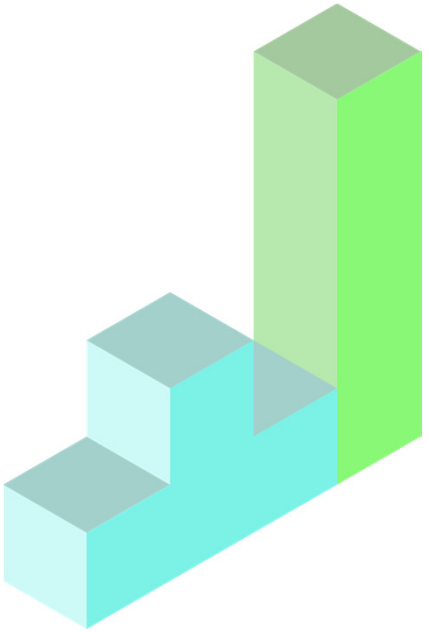
User Requirements: Data Elements

- Studied hard-copy forms currently in use.
  - Physician Notices
  - CMV Lab Test Results



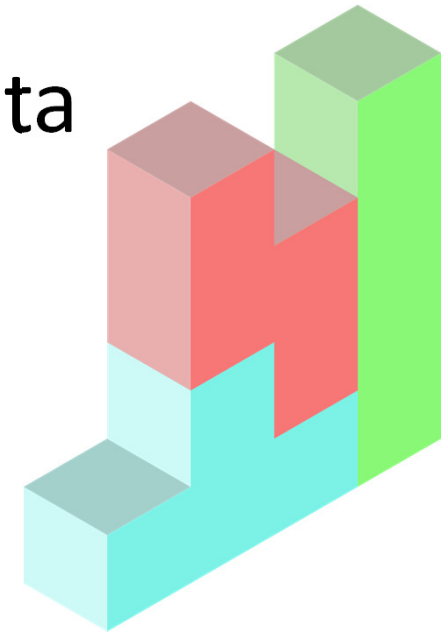
User Requirements: Ease of Use

- “Up front” on the User Interface
- Consistent with current User Interface culture.



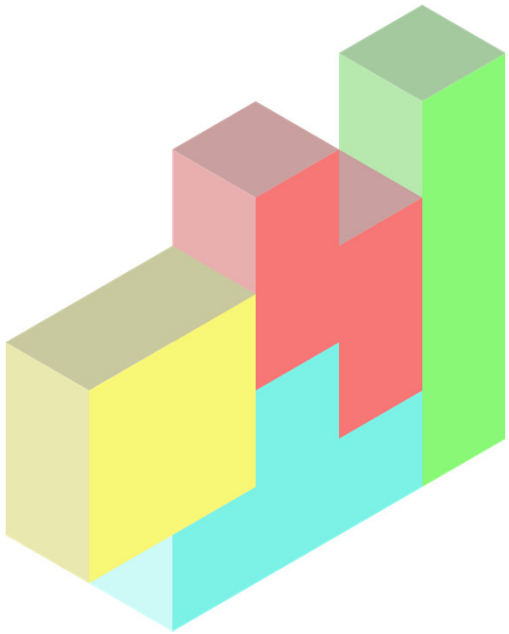
User Requirements: Reporting & Exporting

- Built in Lab Result Report
- Flexible Lab Result filter for existing EHDI-related Reports
- Exporting Functionality
- XML for data exchange with data other systems



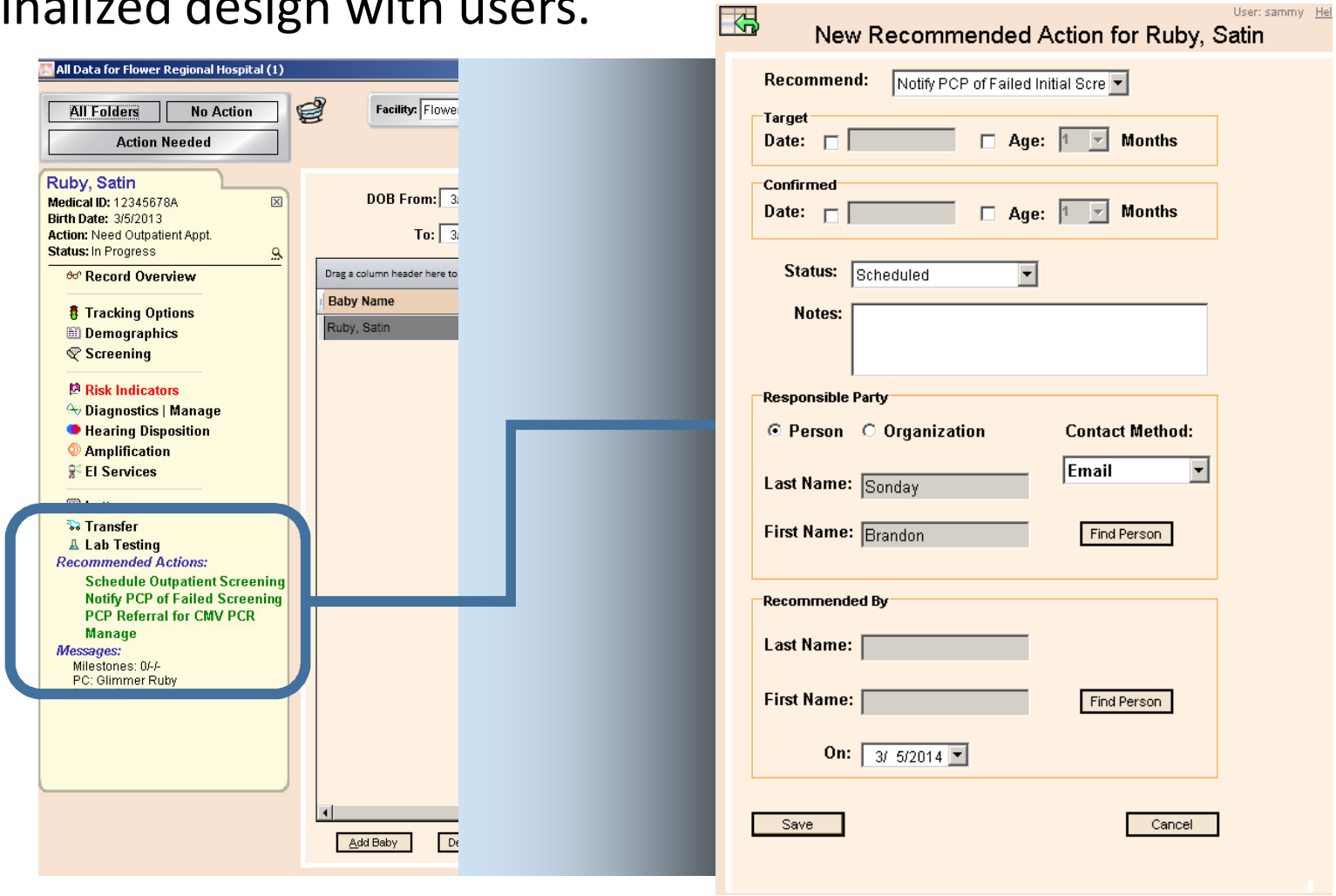
Implementation: Data Fields

- Analyzed current system to determine optimal long-term database placement.
- Leveraged HiTrack's existing tables and code with little system impact.
  - Introduced new Lab Testing types and outcomes.
  - Introduced new CMV specific Recommendation Types.



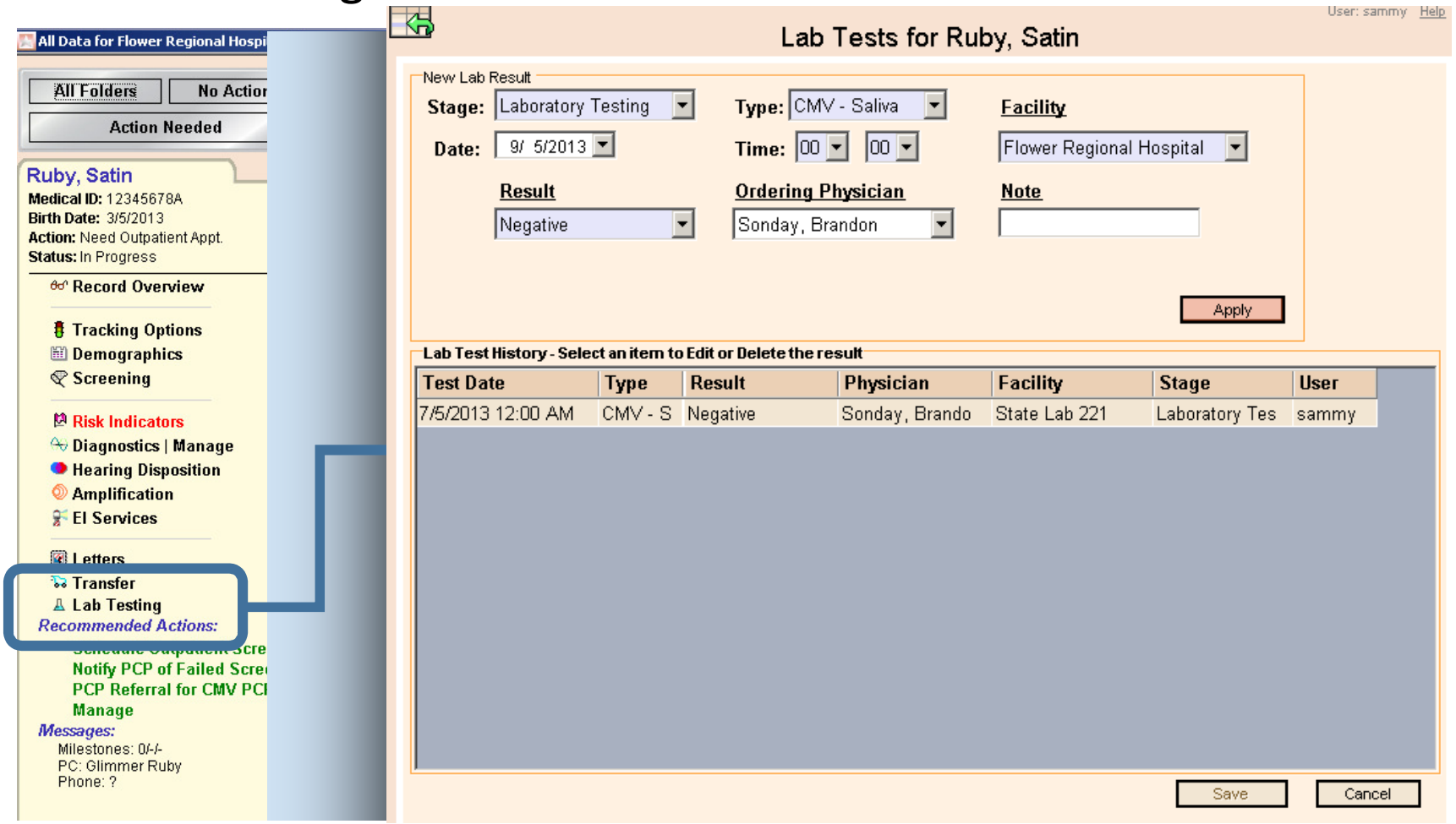
Implementation: Data Collection

- Iterated User Interface prototypes for Notice data entry.
- Finalized design with users.



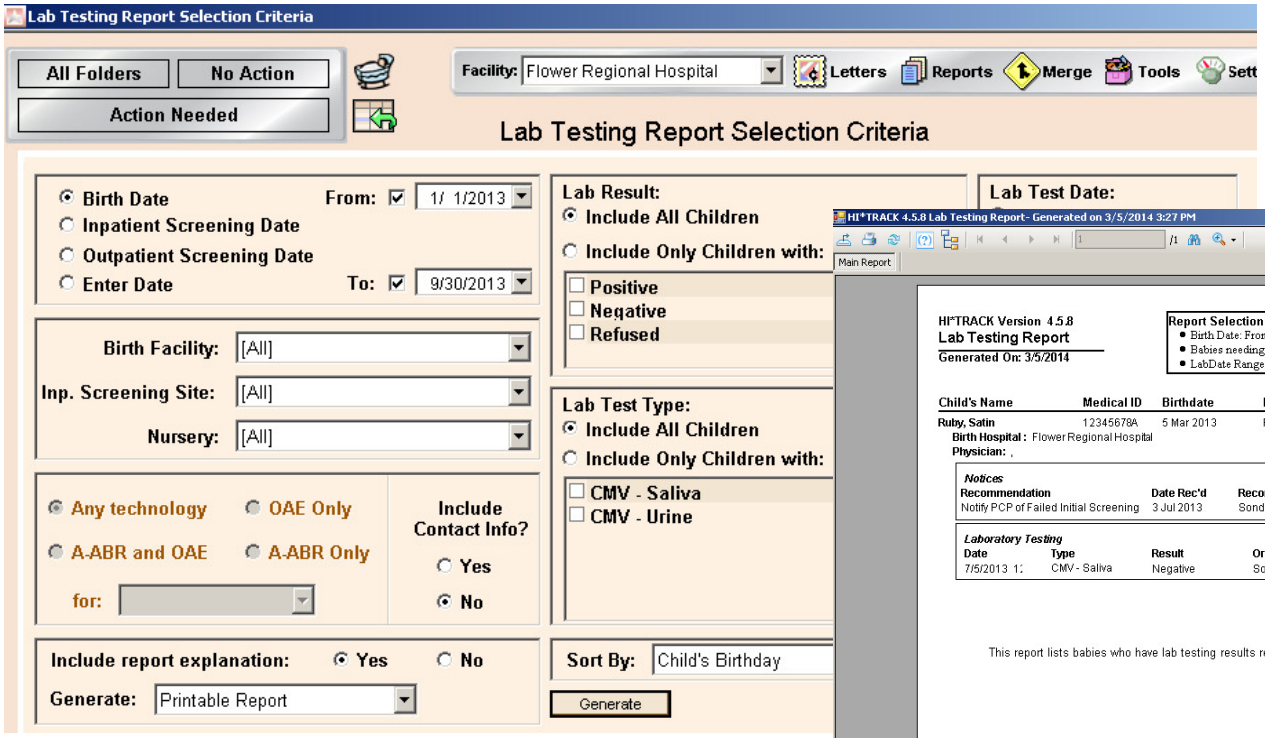
Implementation: Data Collection

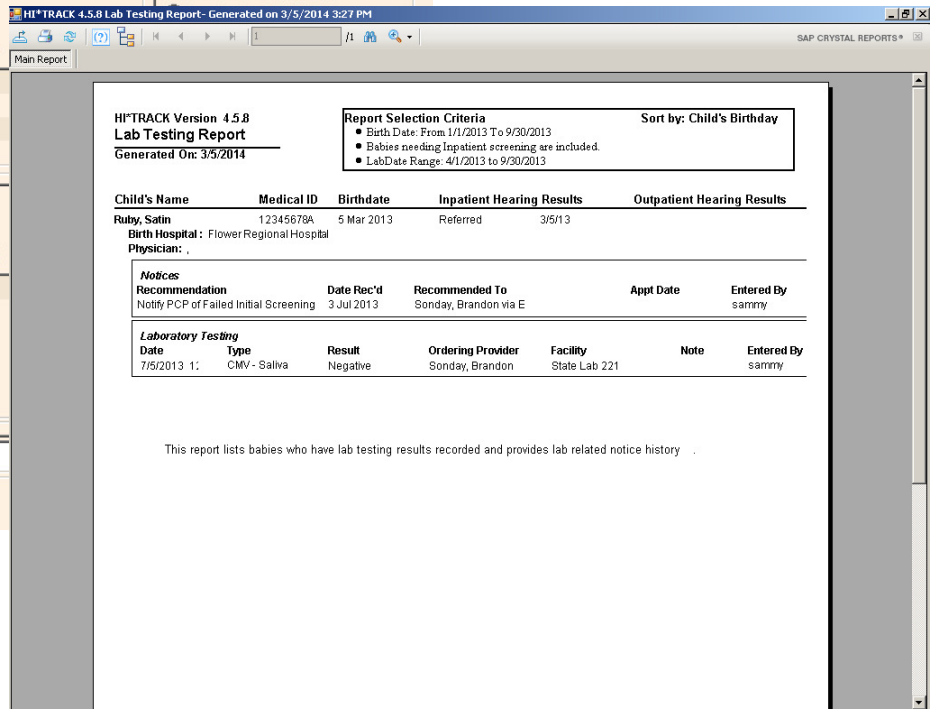
- Iterated User Interface prototypes for Lab Results.
- Finalized design with users.



Implementation: Reporting

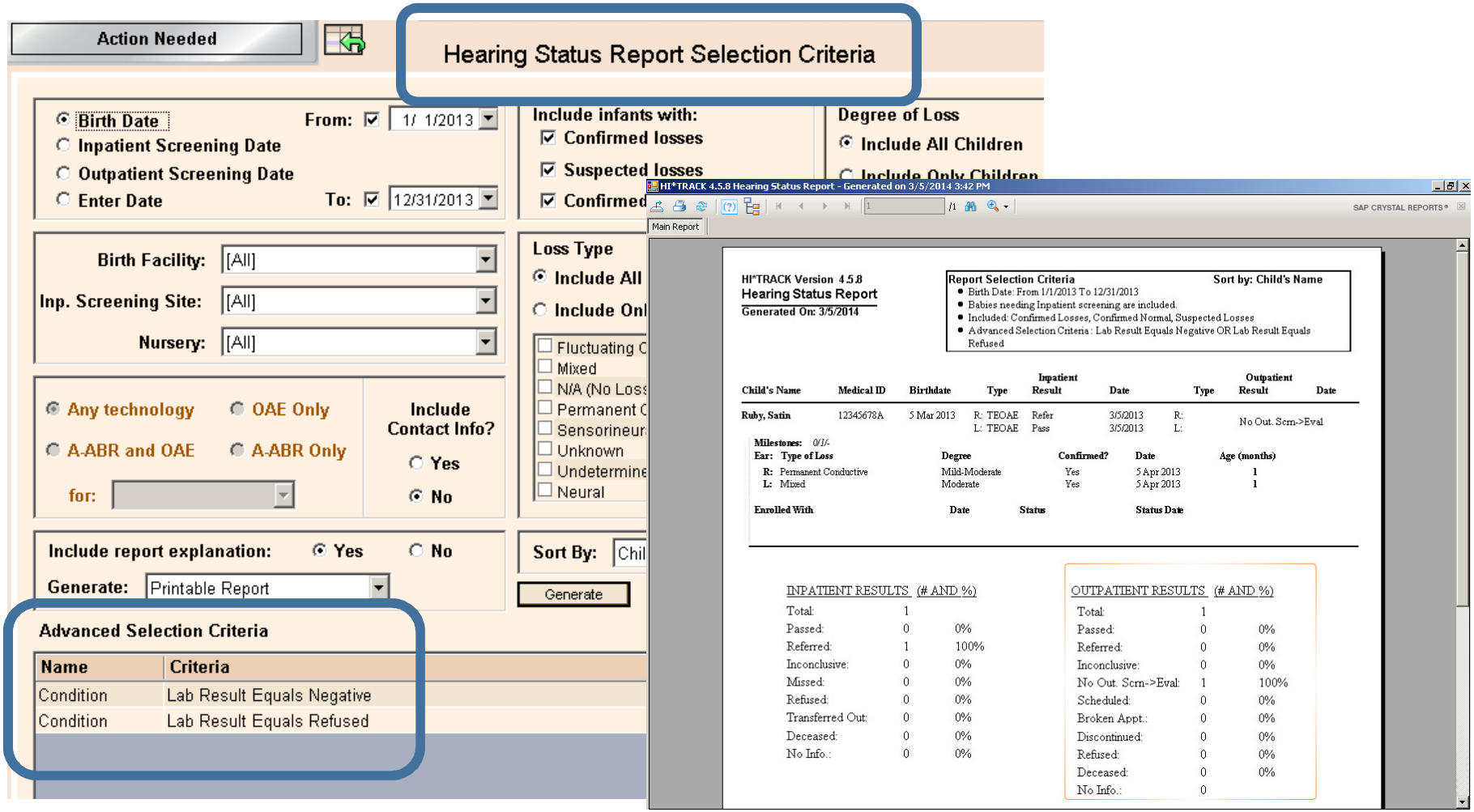
- Iterated Report Design prototypes.
- Finalized design with users.





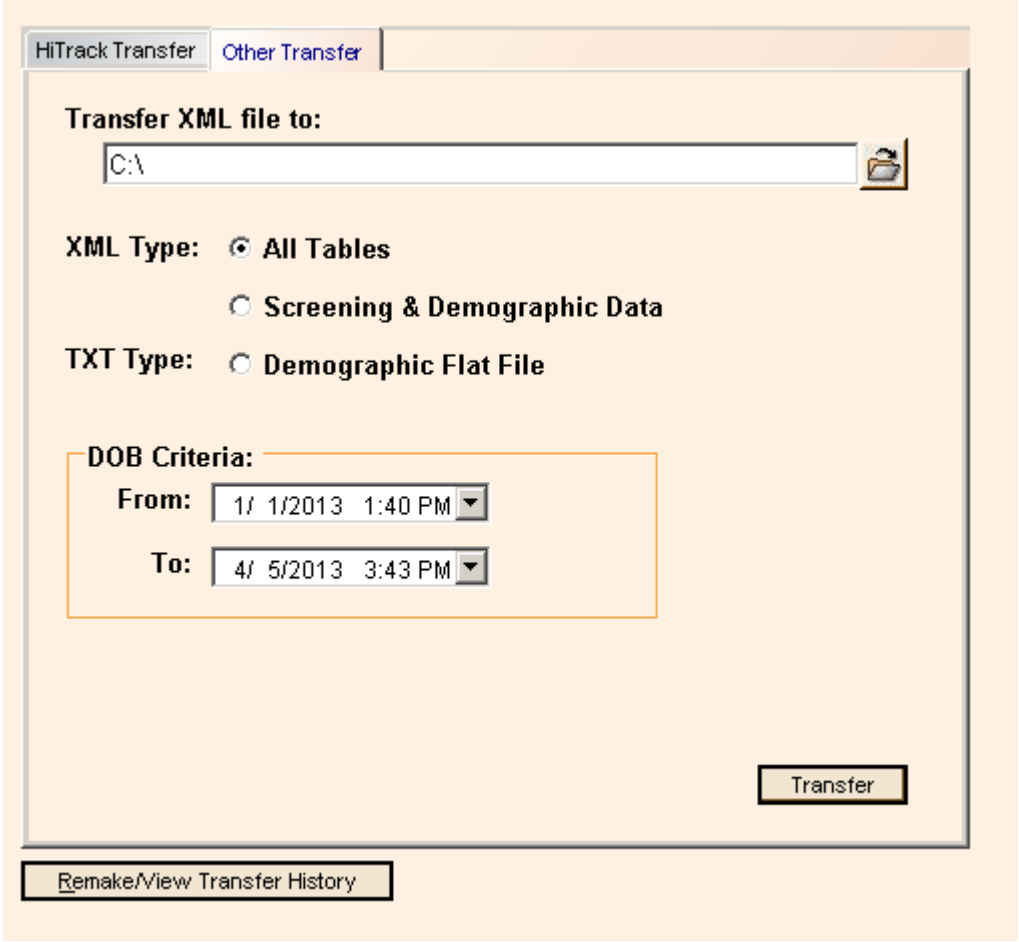
Implementation: Reporting

- Iterated filter designs for EHDI-related Reports
- Finalized design with users.



Implementation: Exporting

- Existing XML exporting functionality.
- Reviewed new Lab Testing types and outcomes.



Learning Experiences

- Challenge
  - Learned that “Detected” / “Not Detected” terminology is preferred by users over “Positive” / “Negative”
- Solution
  - Flexible system allowed real-time update of the labels with no negative impact.
- Challenge
  - Blood test types were received although the State of Utah prefers CMV diagnosis based on saliva or urine.
- Solution
  - TBD, however, HiTrack allows for customization with little negative impact

Future Work:

- Collaboration with Laboratories
  - Electronic Data Interchange – e.g. HL7
  - Establish Matching Rules
    - Statewide Unique ID
    - Mother Demographics, DOB, etc.
  - Ensure Privacy
- Follow-through data entry in HiTrack by Healthcare providers
  - Web access user interface for providers

CMV Data Management Summary

- Effective Collaboration
  - Involve the User at Every Step
  - Include Knowledge Experts
  - Communicate effectively
  - Know when to upgrade the mode of communication as needs arise.
- Plan for future growth
- Use a data system with flexible database components and features