

# Newborn Data Screening on FHIR

The FHIRFighters Team



# Background


- Legally mandated screening for 39 conditions
  - Two blood samplings
    - 24-48 hours
    - 7-28 days
- Blood samples are placed on specially-designed cards
- Over 100K per year are processed

**Utah Newborn Screening**  
SEE BACK FOR BLOOD SPOT COVER

**SECOND SCREEN:**  
General Instructions  
Collect specimen after 7 days of life.

**COLLECTION INSTRUCTIONS**

1. Legibly print ALL information in spaces provided using block capital letters.
2. Collect specimen with heel stick. See newborn screening handbook for detailed instructions.
3. Fill all 7 circles.
4. Dry 3-4 hours before mailing.

 COLLECT SAMPLE FROM SHADED AREA.

**Mailing Instructions:**

1. When blood is dry, fold stick card (from back of form) over blood spots. The flap should enclose the blood spots and reveal a biohazard symbol.
2. If using the postal service, place form with blood spots covered into envelope.

**Mail to:** NEWBORN SCREENING LABORATORY  
UTAH DEPARTMENT OF HEALTH  
4431 S 2700 W  
TAYLORSVILLE UT 84119  
PHONE: (801) 504-8256

For more information, call, refer to your handbook or visit our website:  
<http://health.utah.gov/newbornscreening>

Retain this sheet for your records.  
ID Number: 549A426

**PEEL AWAY THIS PART HERE**

**UTAH DEPARTMENT OF HEALTH**  
SECOND NEWBORN SCREENING FORM  
BLOCK PRINT ALL CAPITALS - COMPLETE ENTIRE FORM  
PHONE: (801) 504-8256

09/09/2010  
333333  
Wilde Rose  
Med Center 08/26/2010

**Feeding:** ☒ Breast ☐ Formula ☐ Combination  
☐ None ☐ Suckle ☐ Nippleless Box  
☐ Yes ☐ No

**Mark all that apply:**  
☐ Premature ☐ Neonatal Blue  
☐ Sick ☐ Injured ☐ Medication Blue

Wilde Annie  
Thorne  
123 S 456 W  
Anytown UT 84999  
01/16/1992 801/111/1111  
Dr. Harry Moss  
1010 Underhill Dr  
Bywater UT 84999  
801 222 2222

**FOR MAILING ONLY - DO NOT MARK**  
☐ Unacceptable ☐ Acceptable  
Sample Unacceptable

# Problems

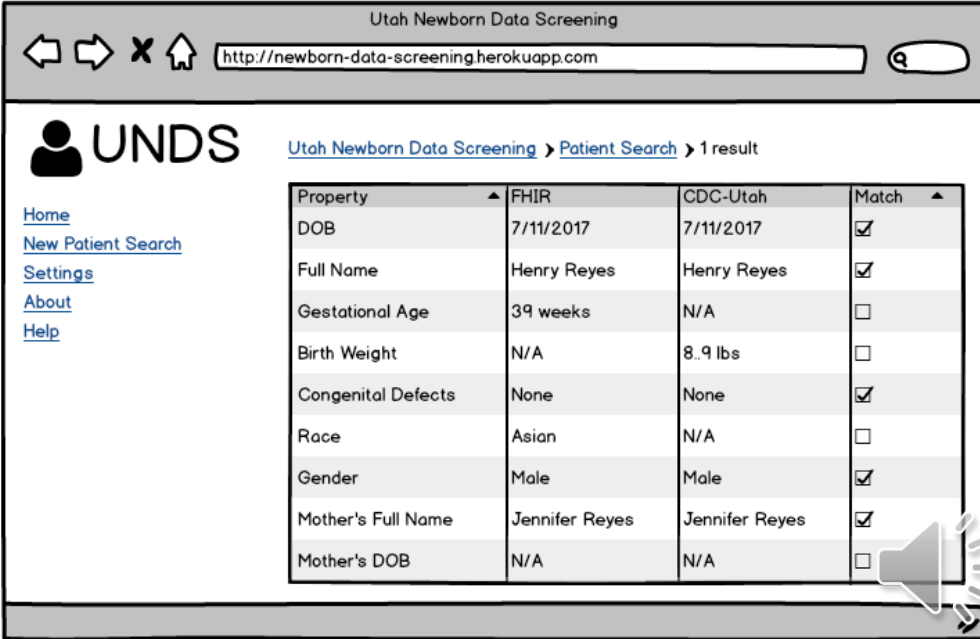
- Two specimens are collected at different times by (probably) different providers
  - 1st -- hospital 2nd -- pediatrician
  - Providers may not have the same information
- Cards filled out by hand, scanned
  - Correct information may be misspelled or illegible
  - Wrong color ink will not show
- Parents given card for second test at birth
  - may get lost -- replacement kit needs to have serial number deleted and replaced with the original serial number
- Current methods for coordinating the data are described as antiquated.



# Our Proposal

Use Utah Office of Vital Records and Statistics data to complete/verify data from cards. Vital statistics used as definitive source

- Newborn's date of birth
- Newborn's full name,
- Newborn's gestational age,
- Newborn's date of death,
- Newborn's birth weight,
- Newborn's congenital defects,
- Newborn's race,
- Newborn's ethnicity,
- Newborn's gender,
- Mother's full name,
- Mother's date of birth



Property	FHIR	CDC-Utah	Match
DOB	7/11/2017	7/11/2017	<input checked="" type="checkbox"/>
Full Name	Henry Reyes	Henry Reyes	<input checked="" type="checkbox"/>
Gestational Age	39 weeks	N/A	<input type="checkbox"/>
Birth Weight	N/A	8.9 lbs	<input type="checkbox"/>
Congenital Defects	None	None	<input checked="" type="checkbox"/>
Race	Asian	N/A	<input type="checkbox"/>
Gender	Male	Male	<input checked="" type="checkbox"/>
Mother's Full Name	Jennifer Reyes	Jennifer Reyes	<input checked="" type="checkbox"/>
Mother's DOB	N/A	N/A	<input type="checkbox"/>

# Risks/Challenges

- “Data is located on a non-FHIR server.” Do we need to help move it?
- External input from stakeholders is critical.
  - (Have emailed mentor, hope to meet with him this week.)

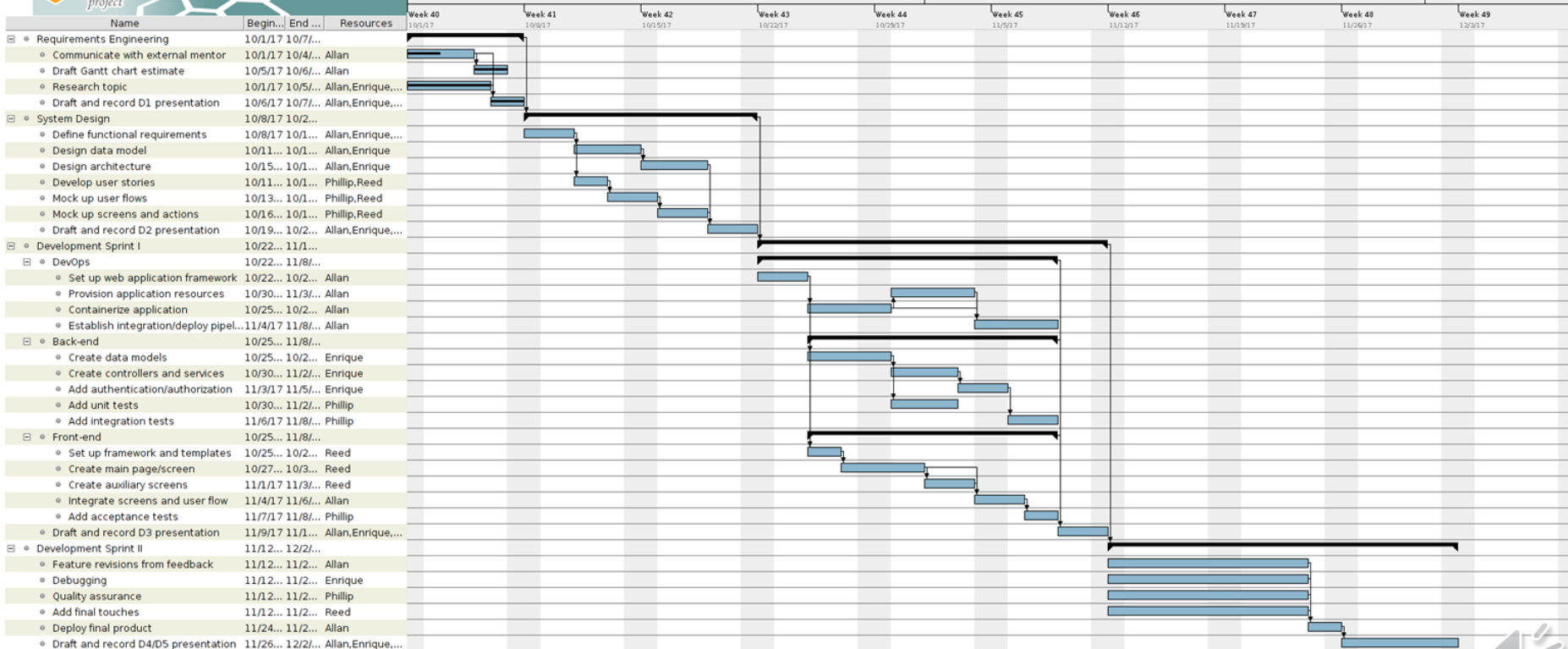




October 2017

November 2017

December 2017



# Conclusion

We on the FHIRFighter team believe that we can make a useful and lasting contribution to Utah's newborn screening program, by delivering a simple but effective method to make the process of coordinating screening data quicker and less tedious.

## References:

The Utah Newborn Screening Program site: <http://health.utah.gov/newbornscreening/>

The project information sheet: <http://cs6440.gatech.edu/wp-content/uploads/sites/634/2017/09/38.-CatalogPageCDCUtahJones-Braun.pdf>

The video of this presentation is at: <https://youtu.be/P-FHZWK15F8>

