

Newborn Screening Data

Final Presentation
FHIRfighters



Agenda

- The Problem at Hand
- Our Solution: Artemis
- Demo
- Deployment
- Next Steps

Background

- Utah Newborn Screening Program
- Legally mandated screening
- Over 100K per year are processed
- Samples on specially-designed cards
- <http://health.utah.gov/newbornscreening>



Utah Public Health Laboratories
46 North Medical Drive
Salt Lake City, UT 84113-1105
Telephone: (801) 584-8400
FAX: (801) 584-8501

YOUR HOSPITAL
ATTN: MEDICAL RECORDS
100 N SOMEROD
ANYTOWN UT 84000-0000

BABY

Infant's Name : SMITH
Sex : MALE
Birth Date : 01/01/2007
Birth Record # : 000A100
Hospital MR # : 99999999
Mother's Name : SMITH, JANE

SPECIMEN INFORMATION

Type : FIRST
Asc# Number : F0010100200702
Date Collected : 01/02/2007
Date Received : 01/04/2007
Date Reported : 01/06/2007
Date Printed : 01/06/2007

NEWBORN SCREENING RESULTS

DISORDER/TEST	DATE TESTED	RESULTS	DETERMINATION	NORMAL RANGE
Biotinidase Deficiency <i>Enzyme activity</i>	10/26/07	Normal	Normal	Full enzyme activity
Congenital Adrenal Hyperplasia <i>17-OHP ELISA</i>	10/26/07	00.0 ug/dL	Normal	Based on baby's birth weight
Galactosemia <i>G-1-P uridylyltransferase activity</i>	10/26/07	0.0 U/gHb	Normal	> 4.0 U/gHb
Hemoglobinopathies <i>Isoelectric Focusing</i>	10/26/07	Normal - FA	Normal	FA
Congenital Hypothyroidism <i>T4</i>	10/26/07	00.0 ug/dL	Normal	> 4.0 ug/dL
Acylcarnitine Disorders <i>MS/MS screening</i>	10/26/07	Abnormal	ABNORMAL	Based on baby's birth weight
Amino Acid Disorders <i>MS/MS screening (Including PKU)</i>	10/26/07	Normal	Normal	Based on baby's birth weight

*Footnote: This is where any specifics about results, actions needed and notes from the lab will be entered; not all disorders will have a footnote.

A newborn screening result should not be considered diagnostic, and cannot replace the individualized evaluation and diagnosis of an infant by a well-trained, knowledgeable health care provider.

If you have questions regarding these results, please contact the Newborn Screening Staff at the Utah Public Health Laboratories or Visit our website <http://health.utah.gov/newbornscreening>

Problems

- Cards are filled by hand
- Parents are given cards at birth
- A second sample needs to be collected
- Cards get lost
- Information may be incorrect

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 GRADED AREA.

Mailing Instructions:

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

Mail to: NEWBORN SCREENING LABORATORY
UTAH DEPARTMENT OF HEALTH
4031 S 2700 W
TAYLORSVILLE UT 84119
PHONE: (801) 554-2295

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

2

549A426

549A426

UTAH DEPARTMENT OF HEALTH
NEWBORN SCREENING LABORATORY FORM
BLOOD SPOT ALL CAPS—COMPLETE EVERY FORM

335333 09/09/2010
Wilde Rose
Med Center 08/20/2010

Feeding: ☒ Breast ☐ Formula ☐ Transition Diet
☐ Solid ☐ Mixed ☐ Unknown Diet
☐ N/A

Mark all that apply:
☐ Premature ☐ Transition Diet
☐ Multiple Birth ☐ Unknown Date

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

PEEL AWAY THIS PART HERE

The Current Solution

- Use Utah Office of Vital Records and Statistics to verify data
- Data from both systems pulled into access DB monthly
- Manually identify discrepancies to fix

Artemis

- Portable
- Simple to use
- Enables future improvements
- Scalable

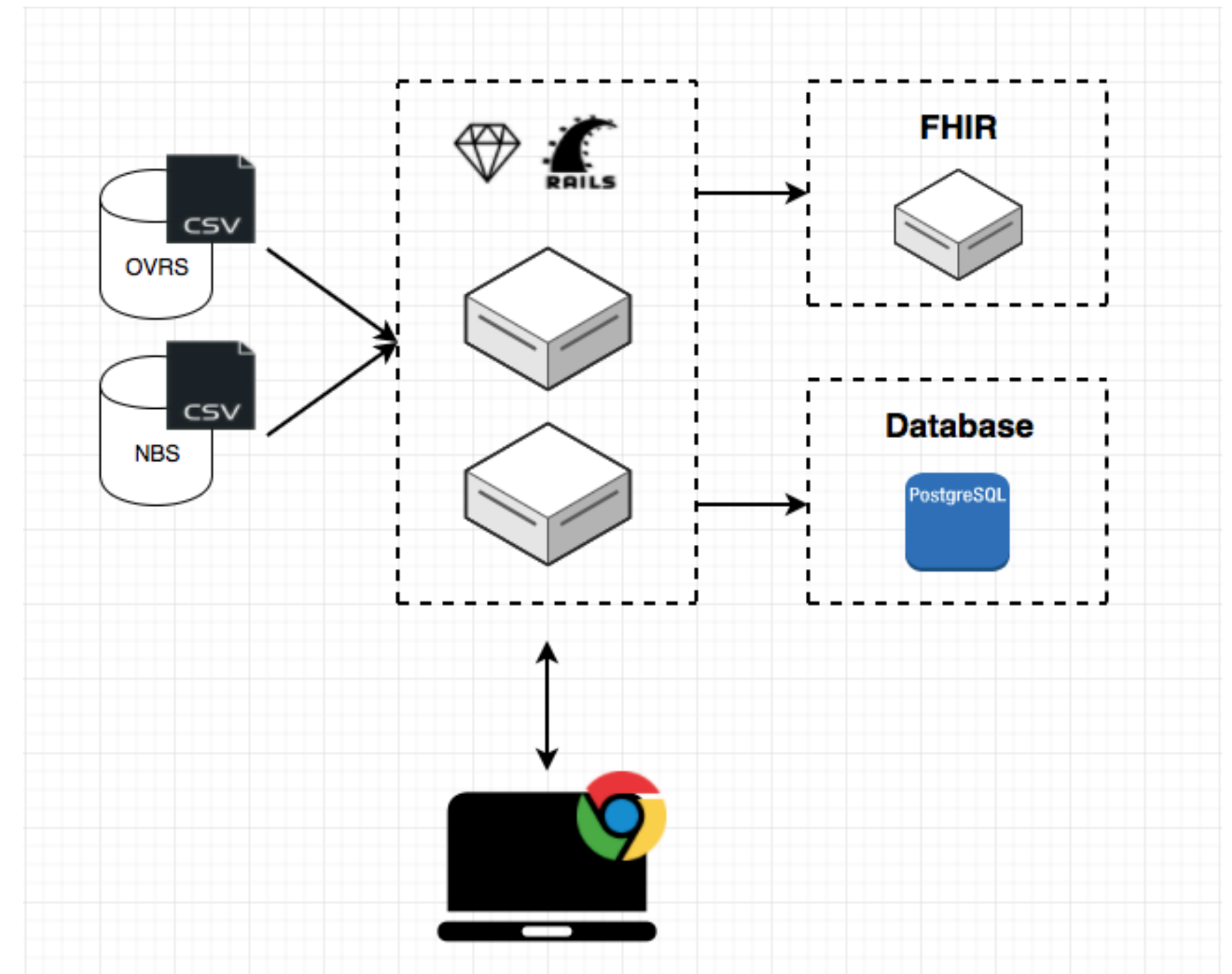
Discrepancy Report

Created 2017-11-30 04:32:38 UTC

#	Kit ID	Attribute	NBS	OVR5
1	UT850A001	First Name Last Name	[blank] [blank]	James Kirk
2	UT850A020	Mothers Last Name Birth Weight	Adams 2807	[blank] [blank]
3	UT850A010	Mothers Birthdate	[blank]	1989-10-09
4	UT850A006	Kit Sex	UT850A006 M	[blank] [blank]
5	UT850A018	Sex	F	M
6	UT850A086	Multiple Birth First Name Last Name	1 James Adams	[blank] [blank] [blank]
7	UT850A007	First Name Last Name	[blank] [blank]	Boy Tester
8	UT850A098	Mothers Last Name First Name	Maine Leslie	[blank] [blank]
9	UT850A044	Birthdate	2015-08-11	[blank]
10	UT850A093	Birth Weight First Name	2200 Early	[blank] [blank]
11	UT850A008	Birthdate	[blank]	2015-11-01
12	UT850A002	Mothers Birthdate Birth Weight	[blank] [blank]	1985-01-08 2881

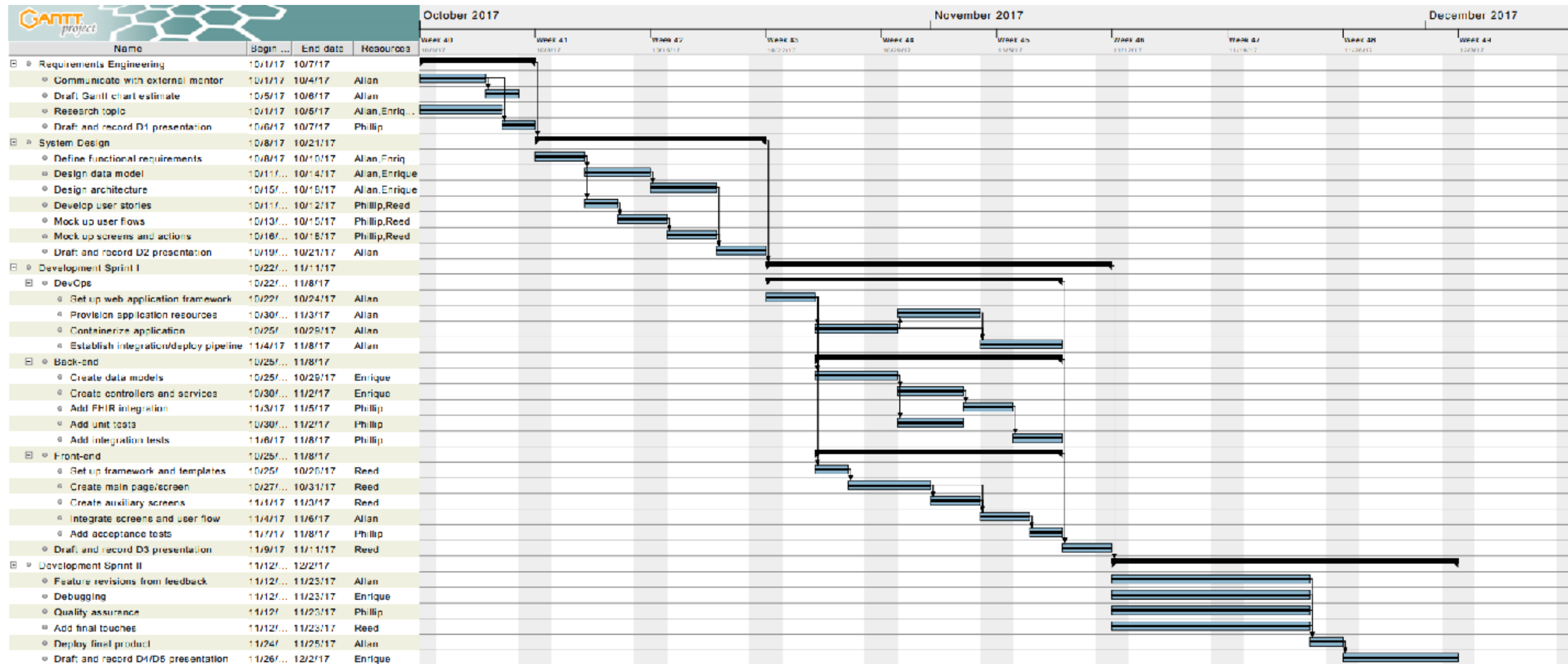
Technical Details

- Ruby on Rails
- PostgreSQL
- FHIR



On FHIR

- Data producer
- Patient: newborn
- RelatedPerson: mother
- Observation: birth weight and length



Project Status

Gantt Chart

Demo

Deployment

- On-Premise
- Run a local web server
- Simple deploy with Docker
- But we had to compromise...

The Cloud

- Deployed to a small Heroku Dyno
- Accessible at: <http://artemis-fhirfighters.herokuapp.com>
- Great for validating

User On-Boarding

- Keep interface simple
- Provide detailed documentation
- Good error handling



Next Steps

- Deploy application locally
- Integrate Artemis into automated feeds
- Push notifications on discrepancy
- Machine learning to automate discrepancy fix

Final Thoughts

