Utah Newborn Screening: Towards Improved Timeliness, Accuracy and Operational Efficiency

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I have **no** conflict of interests and **no** personal gains from the outcomes of this work.

Newborn Screening in Utah

- 52,000 births
- 99% of total baby population screened
- Kit fee: $112
- 2-Screen State
- Frontier state with many rural/remote areas
- Utah NBS program operates based on kit fee **alone**

Total NBS Fee $112
$7 Hearing, CCHD; NBS $105

- NBS Testing including Logistics, Testing, Follow-up
- Outsourced MS/MS with ARUP,
- 2nd tier testing (17-OHP (MS/MS), DNA testing),
- Diagnostic testing (except Congenital Hypothyroidism, SCID),
- CF sweat chloride testing & genetic counseling,
- Long-term Follow-up Services (Diet Monitoring),
- Metabolic formula program

Improvement Timeline

2014	2015	2016	2017	2018	2019

$ 103   **$ 112**

Financial deep dive Accounting to the $100 level

$ non-lapsing fund authority

Follow-up Program Integration

cut 2 positions   **replaced 1 position**   **Health Informaticist**   **Molecular Supervisor**

FEDEx program

24h data entry completion

7-day operation

Same day processing completion

Automated timeliness; data warehouse

CF Luminex Validation CF testing in-house

SCID: LDT/EnLite TREC validation/in house

Illumina validation

SMA, Pompe, MPS1, XALD

SMA

Utah's Key Performance Indicators (KPIs) in days

	TAT collection	TAT TESTING	TAT collection to Result	Age at NBS completion	Completion % by day 7 (of life)
2017	1.45	1.93	3.59	**5.04**	**94.2%**

Strategic Prioritization = Understanding Cost Benefit

Like a business: we need to understand revenue, costs of goods sold (expenses directly attributed to the tests), SG&A (Selling, General and Administrative expenses)

Key Performance Indicators (KPIs)

NBS is very much governed by market forces and competition

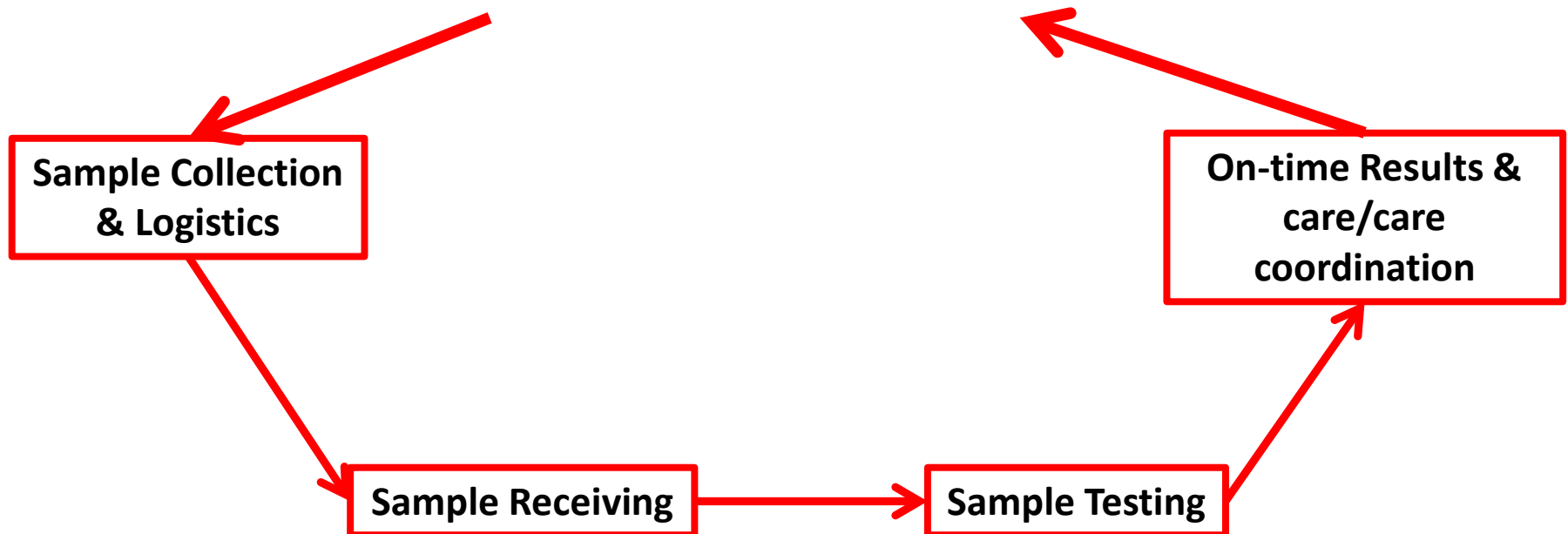Hiding behind "We are Public Health" prevents process improvements

Strategic Prioritization = Understanding Cost Benefit

Improvement 1   Cost 1   Effect on Process/$/baby

Improvement 2   Cost 2   Effect on Process/$/baby

Improvement 3   Cost 3   Effect on Process/$/baby
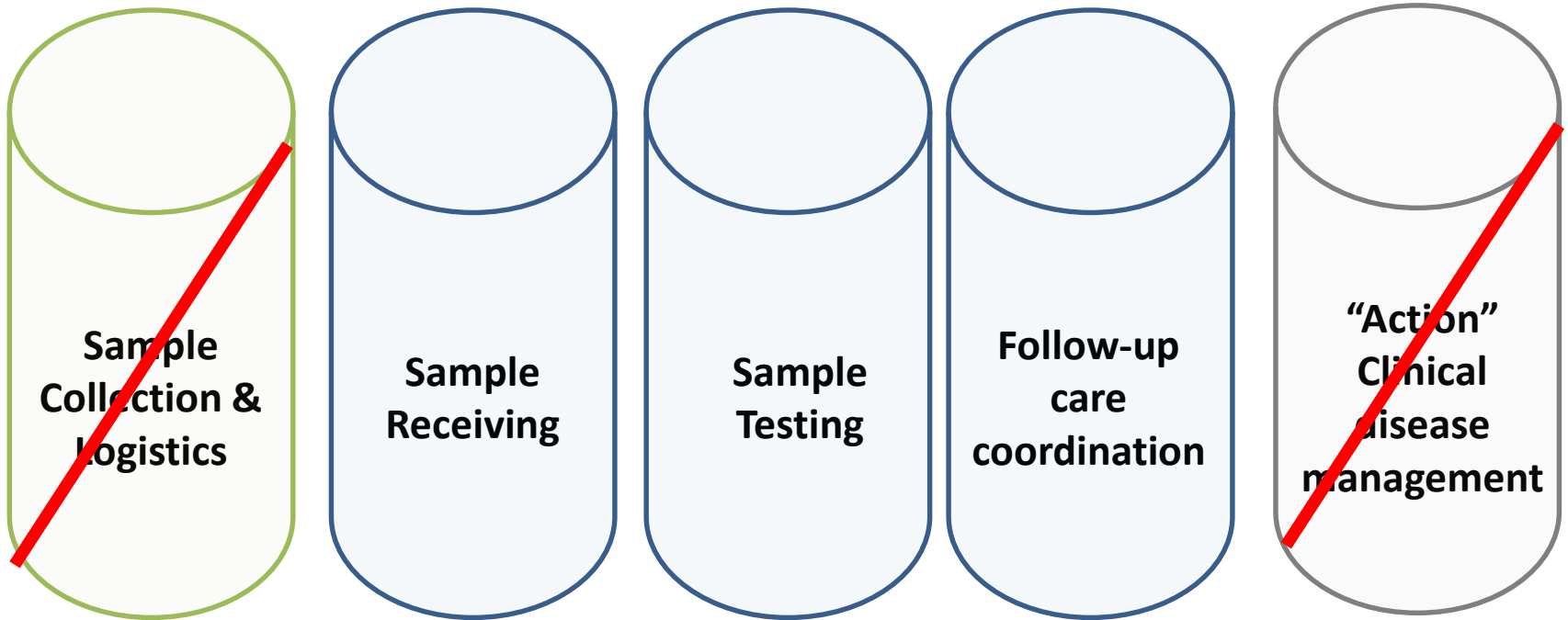
Discuss, Rank, Implement, Remeasure

A customer centric system approach

Who is really the customer?
What exact value do we provide?
Who defines value?

Redefinition of our Services
"Time-to-diagnosis" = insufficient indicator

Sample Collection & logistics

Sample Receiving

Sample Testing

Follow-up care coordination

"Action" Clinical disease management

Eliminate Silo-Perspectives, adopt system view

Assess all steps and their respective utility in the overall process **together** with all parties involved (sample receiving, lab, follow-up, medical care teams, IT, finance)

Redesign Processes and IT infrastructure across silos

Operational Success Stories

FedEx Courier Service for Underperforming Hospitals

Transport time

t = f(distance, corporate status); $p < 0.005$

TAT: from 4.14 days to 2.9 days; costs $19,832

Special Delivery

FedEx offers the world-class solutions our important packages deserve.

The Utah Department of Health is pleased to announce that FedEx is now a carrier for samples shipped to our facility located in Taylorsville, UT, effective May 2014.

All newborn screening samples sent to the Utah Department of Health must now be shipped via FedEx Priority Overnight®.

All shipping labels must be created using FedEx Ship Manager® at fedex.com with Shipping Administration.

A separate invitation has been sent via e-mail from the Utah Department of Health with a log-in user name and password.

Use this login to create a shipping label for FedEx Express® shipments. The shipping label will auto-populate the billing, recipient address and service for you. Simply print the shipping label on 8½ x 11 white paper using a laser printer, insert the sample into FedEx Express packaging, seal the package, fold the label and insert it into the plastic sleeve, and ship.

This simple-to-use online shipping program allows you to quickly create a shipping label and track the status of the shipment. Refer to "Shipping Details" in this PDF for more information.

UTAH DEPARTMENT OF HEALTH

Utah Public Health Laboratory

Thank you, Arizona!

7-Days Operations

February 2015: 7-days operations

Saturday
1. Specimen accessioning
2. Result reporting (Friday testing)
3. On-call Follow-up

Sunday:
1. Full day of testing (all tests)
2. On-call Follow-up

Sample Receiving Problems

Central Problem:

- **Unmatched demand and supply environments**

Solution:

- 2016 same day data entry mandate
- Part-time FTEs on high demand days
- Shift from Mo-Fri 8-5 to staggered 5-on/2-off
- 2017 same day processing AND testing of ALL specimens

Implementation of SCID Testing *in-house*
(from ARUP Laboratories)

Cost Reallocation Issue

Significant TAT improvements $0 net impact

	TAT collection	TAT TESTING	TAT collection to Result	Age at NBS completion	Completion % by day 7 (of life)
2016	1.46	2.46	4.18	**5.64**	**86.1%**
2017	1.45	1.93	3.59	**5.04**	**94.2%**

CF Performance Improvement Story
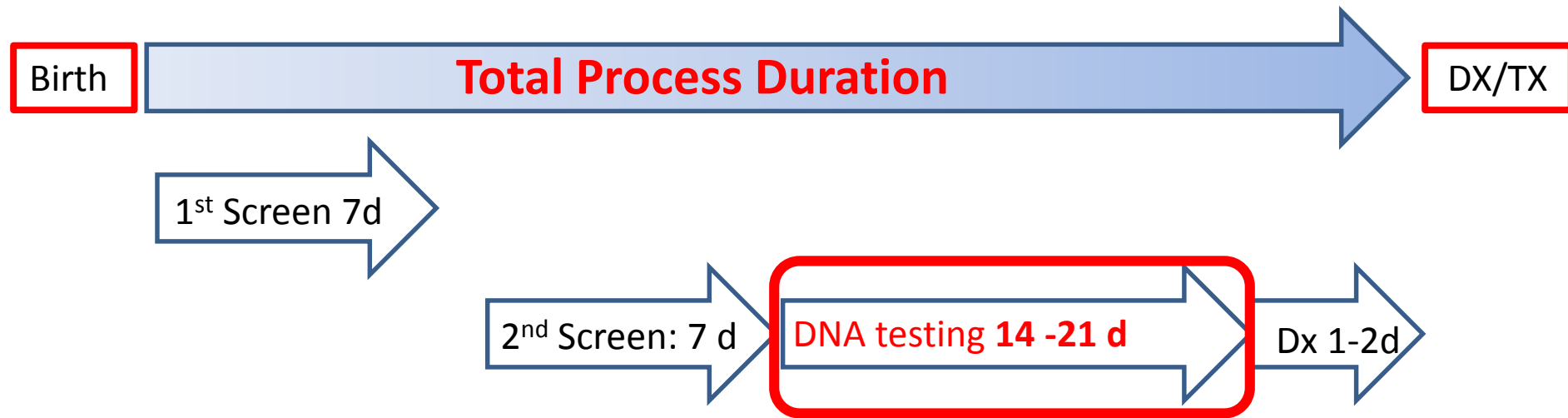
With in-house CF mutation analysis only

age at Dx (DNA **<u>and</u>** sweat chloride):
23.8 days
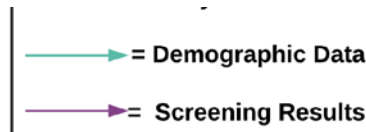(from 30+days; n>100, 8/29/17)

Utah CF Center: same or next business day priority

How can we completely automate timeliness? How can we achieve a complete chain-of-custody environment?

OZ Systems and STACS DNA Enter into Strategic Alliance to Provide Essential Solutions to Newborn Screening Programs
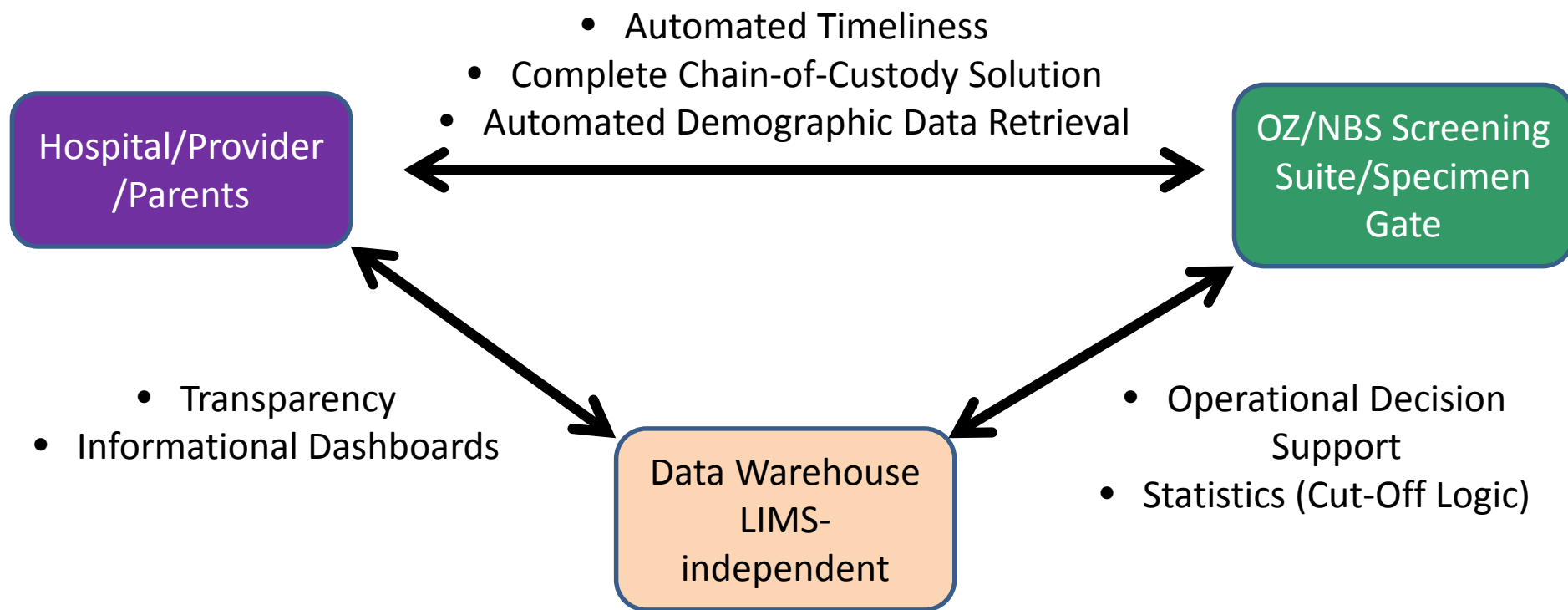
End-to-end systems for timely and accurate newborn screening address previous gaps that put infants at risk

ARLINGTON, TX AND OTTAWA, ON— APRIL 18, 2017—OZ Systems and STACS DNA have partnered to create end-to-end systems specifically designed to achieve timely and accurate newborn screening care. The partnership was inspired by the lack of robust newborn screening IT solutions in the market – a gap that has endangered newborn lives in the past. The collaboration will marry solutions for newborn blood spot screening from OZ Systems with sample tracking from STACS DNA.

→ = Demographic Data

→ = Screening Results

Specimen Gate
from PerkinElmer

Please visit David Jones poster: An Integrated, Interoperable IT Infrastructure **P-131**

Automated Timeliness/Real-time Decision Support

- Automated Timeliness
- Complete Chain-of-Custody Solution
- Automated Demographic Data Retrieval

Hospital/Provider /Parents

OZ/NBS Screening Suite/Specimen Gate

- Transparency
- Informational Dashboards

Data Warehouse LIMS-independent

- Operational Decision Support
- Statistics (Cut-Off Logic)

Thank you!