



Reducing Time from Referral to Treatment: Strengthening the Weak Links in the Newborn Screening Chain of Events

Amanda Kimura, MPH

Washington State Department of Health
Newborn Screening Program

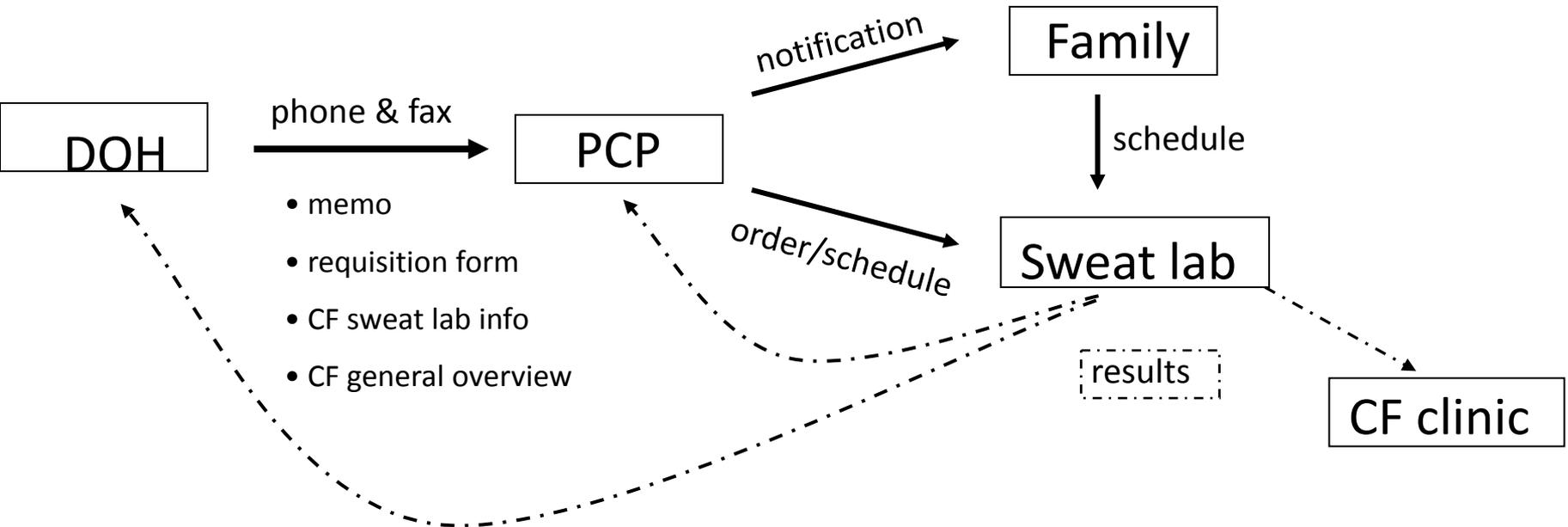


WA CF NBS Algorithm

- IRT/IRT
- In-house F508del if:
 - LBW and/or clinically unstable and persistently elevated IRT
 - IRT > 150 ng/mL on 1st screen or persistently elevated IRT and family/clinic is non-compliant



WA CF NBS Follow-Up: SwCI Referral



1-2d 1d



WA CF NBS Follow-Up: Abnormal Results

We monitor:

- Date of birth
- Birthweight
- Race
- Sex
- NICU status
- IRT value
- Age at collection

*If referred for a sweat test,
we also monitor:*

- SwCl facility
- Date of referral
- Date of resolution
- QNS results



WA CF NBS Follow-Up: True Positives

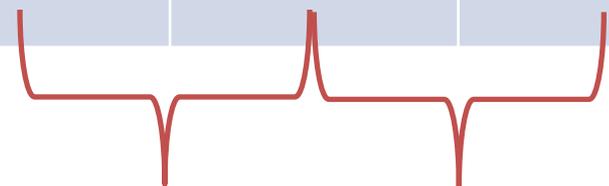
We monitor...

- Date of birth
- Birthweight
- IRT value
- Age at collection
- Race
- Sex
- SwCl value
- Date of diagnosis
- Date of 1st clinic visit
- Genotype
- Pancreatic status
- Meconium ileus
- CF center



Timeline of Infants Diagnosed with CF 2012 –2013

	Age at reporting 1st elevated IRT n=16	Age at collection of 2 nd NBS n=19	Age at referral n=19	Age at SwCl n=19	Age at 1st clinic visit n=19
Median (days)	8	9	19	24	28



5 days

4 days



SwCI Referrals by Time between Referral and 1st SwCI

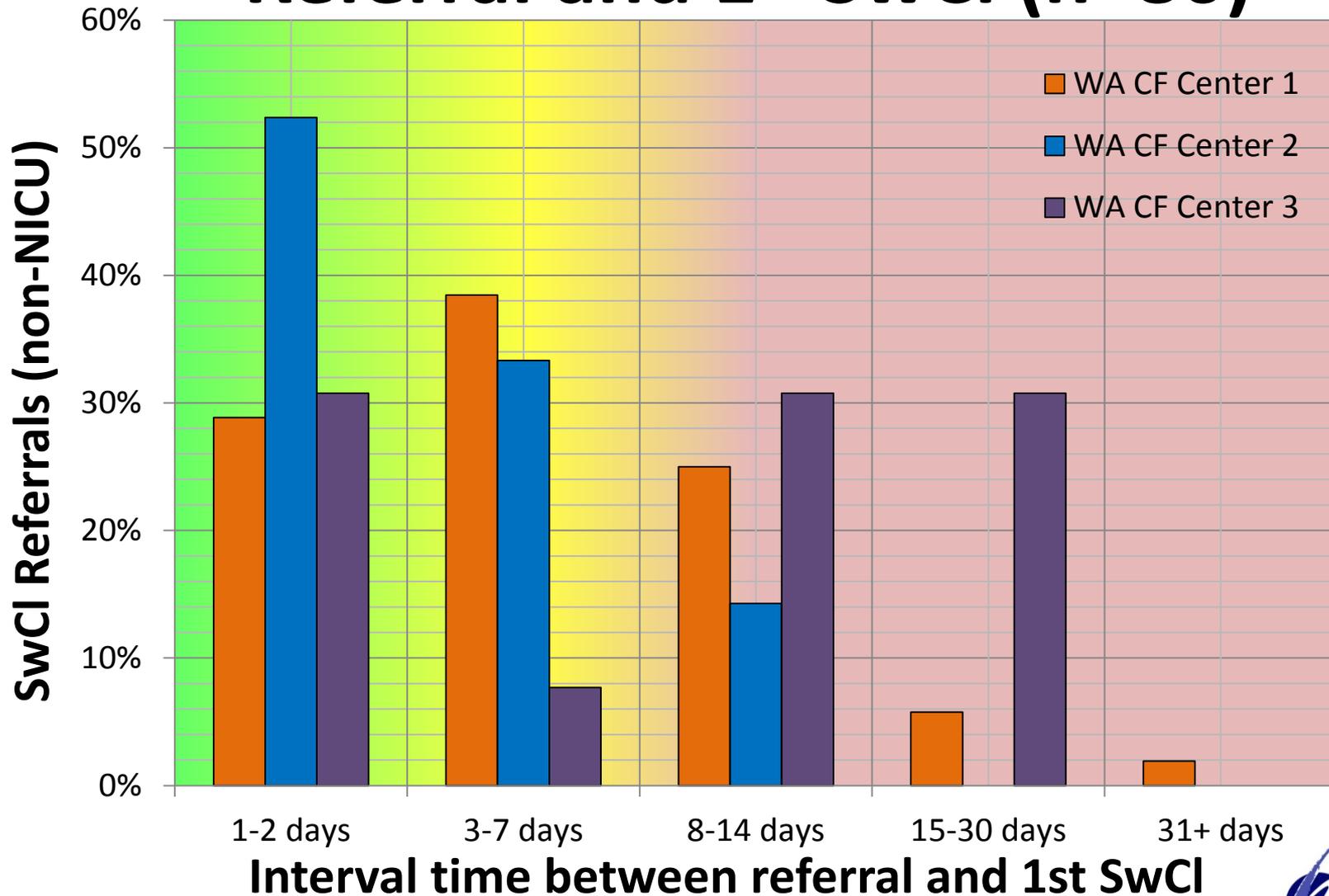
Retrospective secondary data analysis

January 2011 – December 2013

Non- NICU infants requiring sweat testing

Stratified by CF Center

SwCI Referrals by Time between Referral and 1st SwCI (n=86)



Timeline for Newborns Referred for SwCI – Median Days

	All WA CF Centers
Days from referral to 1 st SwCI	4 (n=86)
Days from positive SwCI to 1 st clinic visit	3 (n=25)
Days from referral to resolution	5 (n=85)

Timeline for Newborns Referred for SwCI – Median Days

	All WA CF Centers	WA CF Center 1	WA CF Center 2
Days from referral to 1 st SwCI	4 (n=86)	4.5 (n=52)	2 (n=21)
Days from positive SwCI to 1 st clinic visit	3 (n=25)	3 (n=17)	4 (n=6)
Days from referral to resolution	5 (n=85)	5 (n=52)	3 (n=21)

Timeline for Newborns Referred for SwCl – Median Days

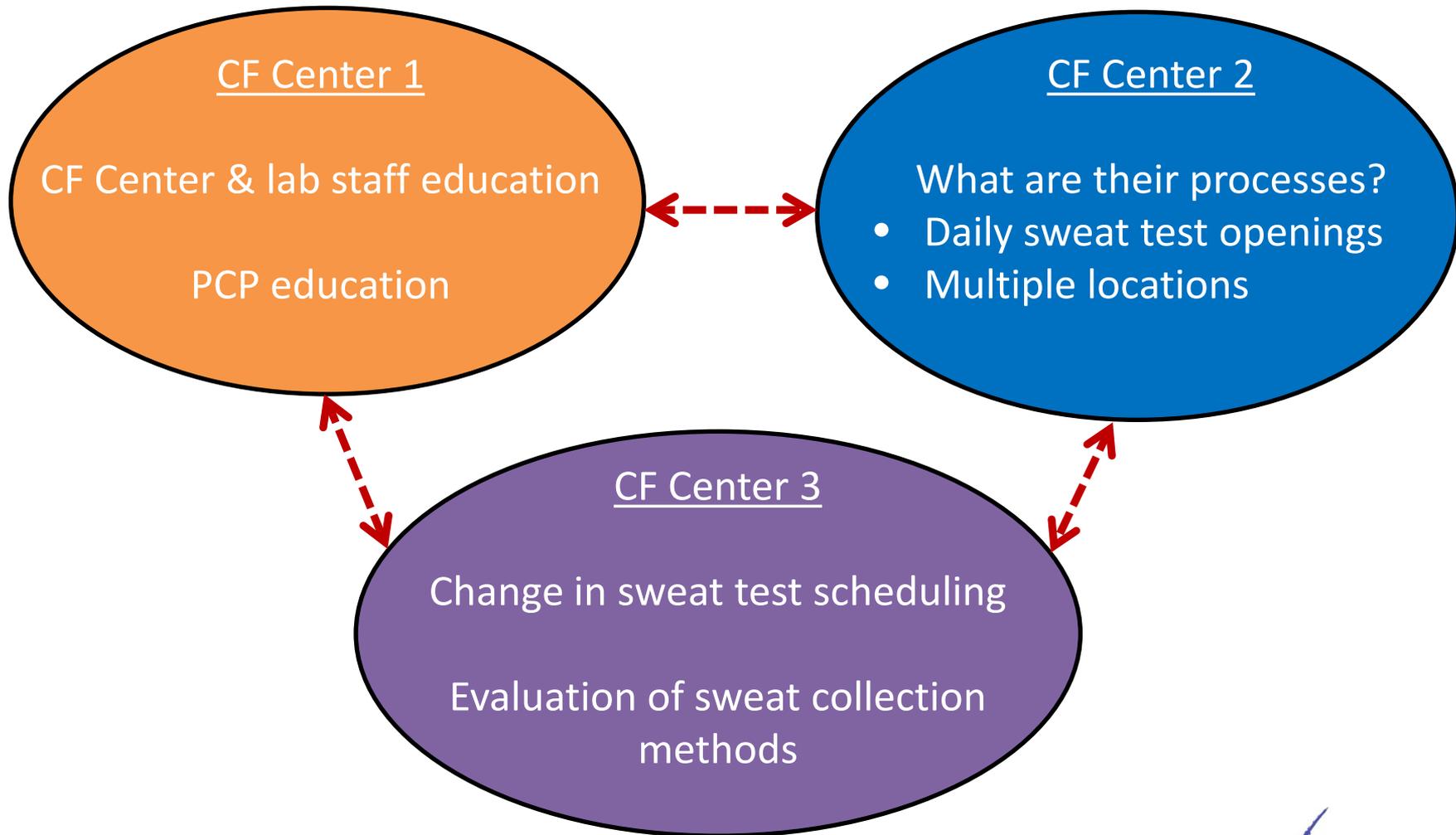
	All WA CF Centers	WA CF Center 1	WA CF Center 2	WA CF Center 3
Days from referral to 1 st SwCl	4 (n=86)	4.5 (n=52)	2 (n=21)	12 [range 1-25] (n=13)
Days from positive SwCl to 1 st clinic visit	3 (n=25)	3 (n=17)	4 (n=6)	1.5 (n=2)
Days from referral to resolution	5 (n=85)	5 (n=52)	3 (n=21)	10 [range 1-194] (n=12)



Quantity Not Sufficient (QNS) Results

- 10% (n=12) of newborns sweat tested had QNS results
- 6 cases (50%) with QNS results were diagnosed with CF (all dx by DNA)
- ALL true positive cases with QNS results had at least 1 copy of F508del
- The median time between the 1st QNS result and 1st repeat sweat test is 24 days (n=6)

CF Center Outreach Efforts





Changes in NBS Follow-Up

- Tighter follow-up for referrals
- In-house test for F508del after QNS result
- PCP education on sweat testing



Next Steps: Evaluation

In progress!



Final Thoughts

- ✓ Relationship with NBS clinical consultants
- ✓ Consistent surveillance of abnormal results
- ✓ Applicable to follow-up of other NBS disorders!



Thank You!

Washington state NBS Program

John D. Thompson, PhD, MPH, MPA

Sheila Weiss, MS, CGC

Mike Glass, MS

Washington state CF Centers

Ron Gibson, MD, PhD

Margaret Rosenfeld, MD, MPH

Questions?

amanda.kimura@doh.wa.gov

(206) 418-5523

Washington State Newborn Screening

www.doh.wa.gov/nbs

(206) 418-5410

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