



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

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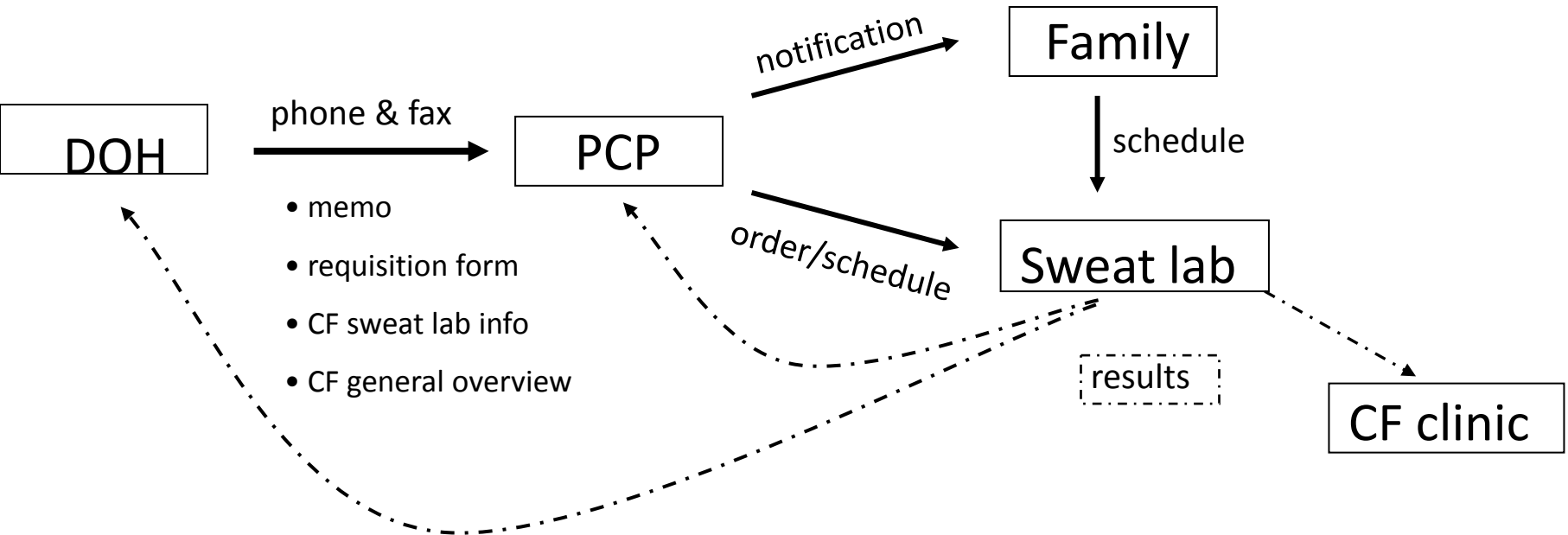


WA CF NBS Algorithm

- 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

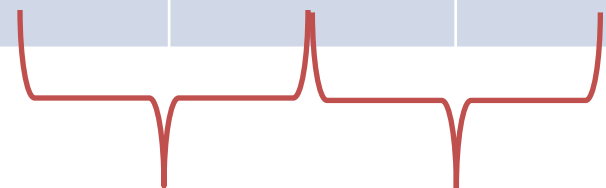
We monitor...

- 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

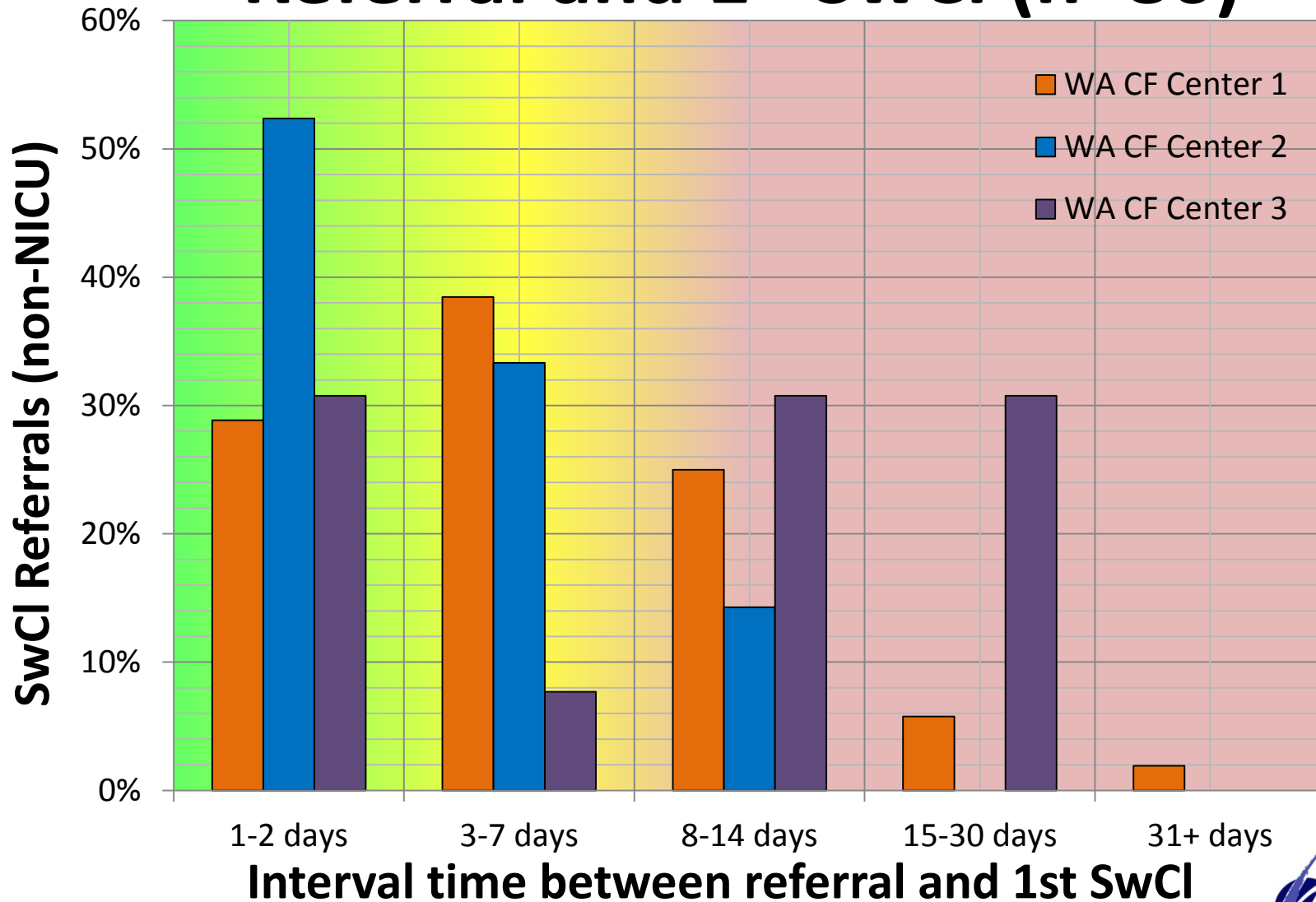
Retrospective secondary data analysis

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

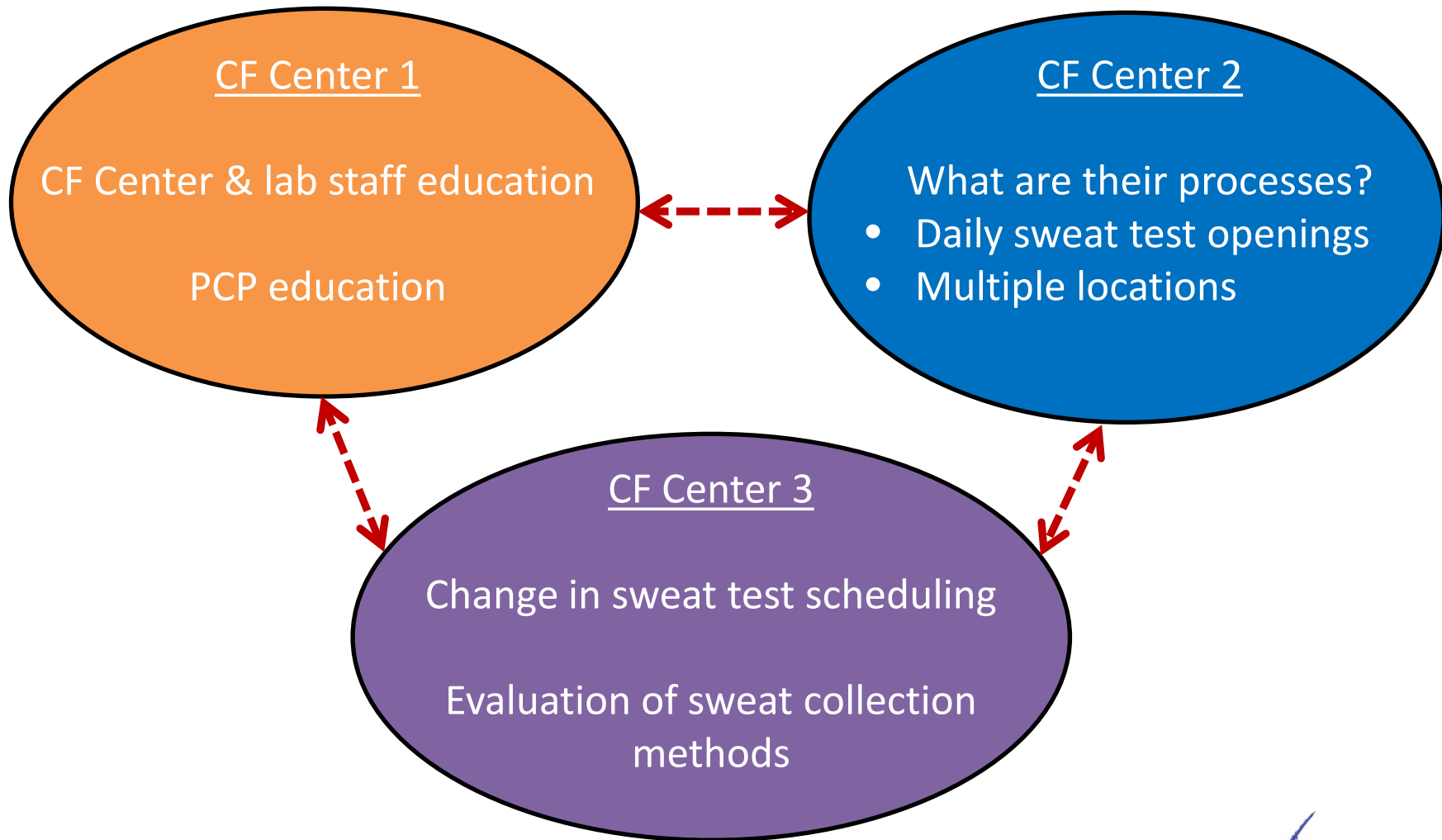
	All WA CF Centers	WA CF Center 1	WA CF Center 2	WA CF Center 3
Days from referral to 1 st SwCl	4 (n=86)	4.5 (n=52)	2 (n=21)	12 [range 1-25] (n=13)
Days from positive SwCl to 1 st clinic visit	3 (n=25)	3 (n=17)	4 (n=6)	1.5 (n=2)
Days from referral to resolution	5 (n=85)	5 (n=52)	3 (n=21)	10 [range 1-194]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

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