USF HEALTH COLLEGE OF PUBLIC HEALTH
UNIVERSITY OF SOUTH FLORIDA

Zika: A Case Study for Examining Florida Systems of Care for Children with Special Needs

University of South Florida

College of Public Health

Department of Community & Family Health

Dr. Jennifer Marshall, Jennifer Delva, Henna Patani, Grace Butler, Carlos Parra, Sara Yalla, Jean Paul Tanner, Dr. Russ. Kirby.

As a part of the Birth Defects Surveillance Program, we are the University of South Florida Zika Research Team

Overview of Birth Defects in the U.S.

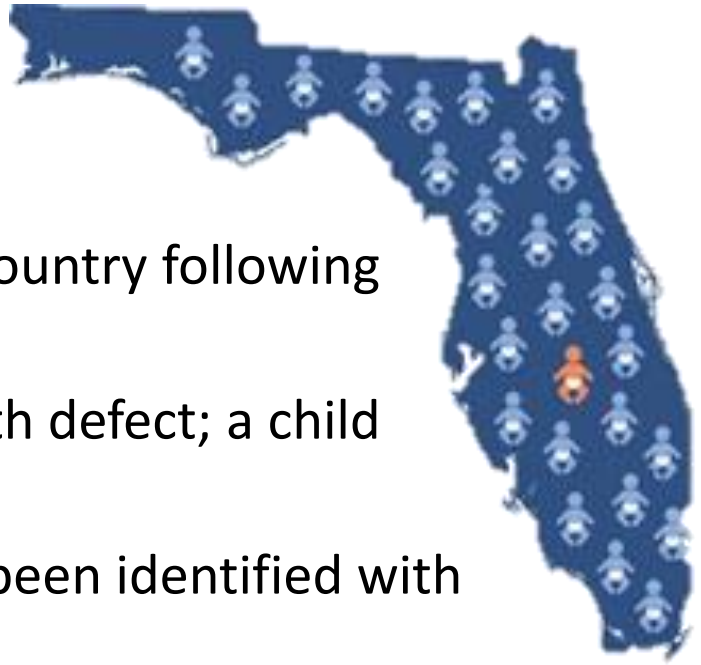
Birth defects are conditions present at birth that cause structural changes in one or more parts of the body

- They are not uncommon: 1 in 33 babies is born with a birth defect
- Birth defects are a leading cause of death in the US (1 in 5)

Birth defects are identified through prenatal screening, at birth, or with newborn screening

Beginning in the U.S. 50 years ago; today, all states screen babies for at least 29 disorders that can be detected through laboratory testing.

Florida



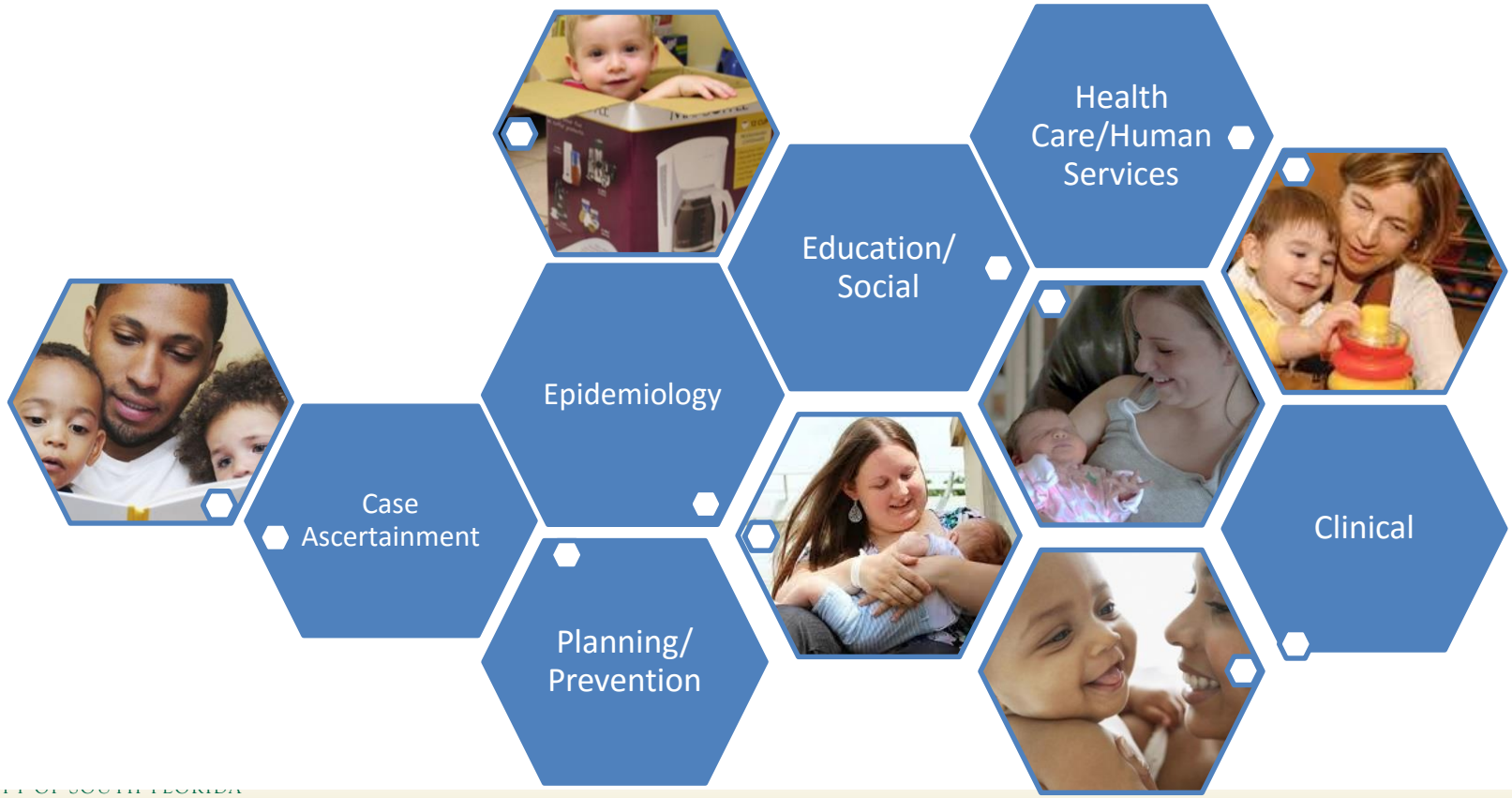
- ~220,000 births per year, 4th highest in the country following CA, TX, NY. Racially & ethnically diverse
- 1 in 28 babies born in Florida has a major birth defect; a child is born with a birth defect every hour
- Since 1998, more than 110,000 infants have been identified with major birth defects
- The Florida Birth Defects Registry (FBDR) was established in 1998 as a response to concerns in the community about risks for poor pregnancy outcomes and birth defects

- Collect and analyze information
- Respond to concerns about potential clusters
- Prevention programs
- Research
- Education

fbdr
Florida Birth Defects Registry

USF Birth Defects Surveillance Program

- Partners with the Florida Department of Health to conduct birth defects surveillance activities & research

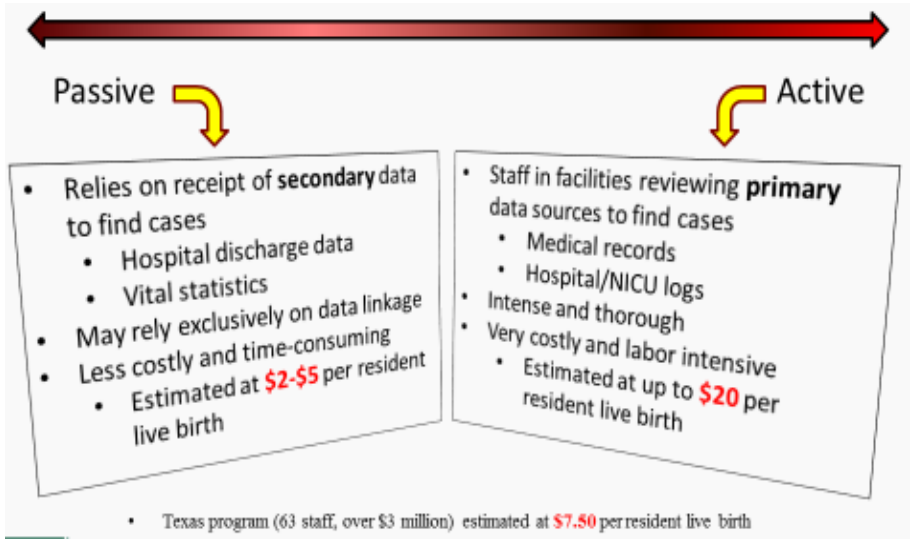


USF Birth Defects Surveillance Program

- Partnership with the FBDR
- Birth defects Prevalence
- Outcomes
- Service access & utilization
- Community-based research

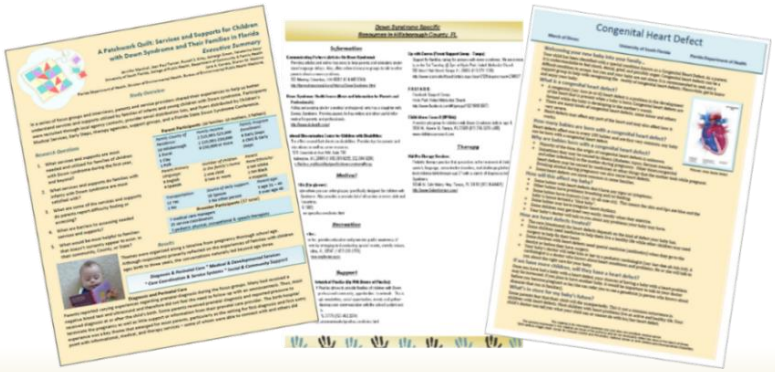
Case confirmation & epidemiologic research

Approaches to Case Ascertainment



USF Birth Defects Surveillance Program

- Epidemiology
  - Florida Birth Defects Registry (FBDR), Enhanced Surveillance
  - Environmental Public Health Tracking (EPHT)
  - Other projects (Hemoglobinopathies Registry, Timeliness of and Access to Health Care, Cancer Registry linkage)



- Community-based Research
  - A Patchwork Quilt: Services and supports for children with Down syndrome and their families
  - The Family Experiences Surveys
  - Resource Guides
  - Family-centered management of birth defects diagnosis and referral in hospital settings
    - Best practices survey
    - Birth defects brochure

BDSP Zika & Microcephaly Project

1. **Zika Pregnancy Registry**

   Retrospective medical record review of microcephaly and other associated conditions to investigate/understand causes, measure the accuracy of ICD-9-CM & ICD-10-CM codes, and provide a baseline for comparison.

   Prospective data from pregnant women with laboratory confirmation of Zika virus. This information includes all pregnancy outcomes, and include the review of maternal, fetal, and infant prenatal, diagnostic, hospital, and vital statistics records.

2. **System of Care Evaluation**

Today's Topic

What is Zika?

- The Zika virus is part of the Flaviviradea family of viruses

What is Zika?

The Zika virus is part of the Flaviviradea family of viruses

How can I get Zika?

People often get Zika through a mosquito infected with the virus.

Two types of mosquito carriers:

Aedes aegypti and *Aedes albopictus*

How else can I get Zika?

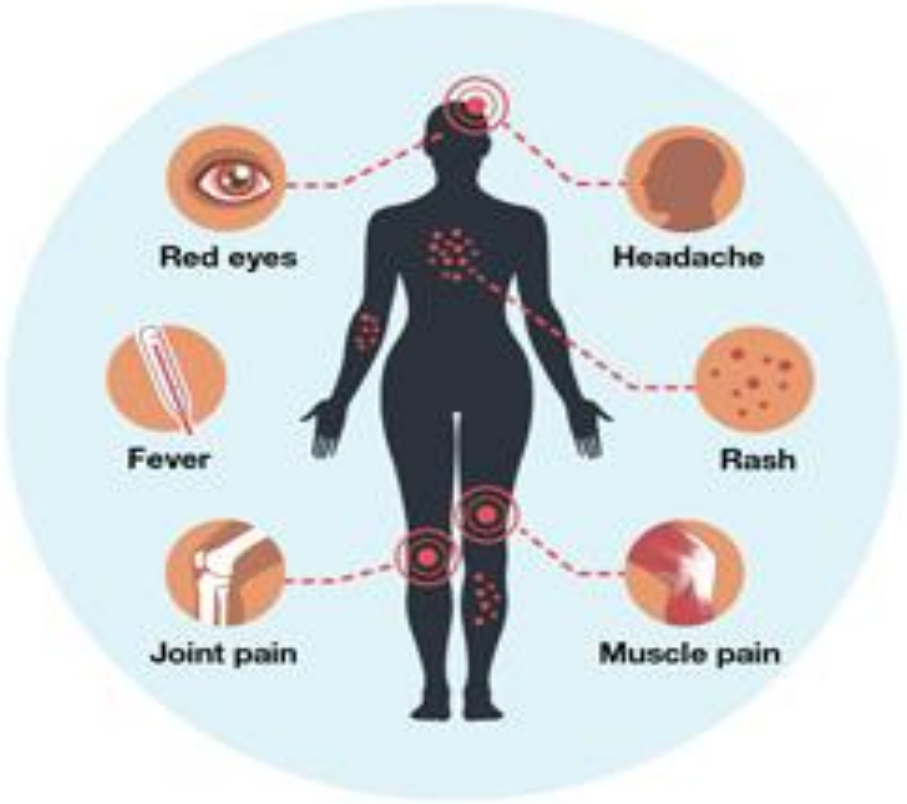
- It can also be spread:
  - From a pregnant woman to her fetus
  - Through sex with infected partner
  - Through blood transfusion

https://www.cdc.gov/zika/pdfs/zika-transmission-infographic.pdf

Signs and Symptoms

Mild symptoms **last up to a week and include**:

- Fever
- Rash
- Headache
- Joint pain
- Red eyes
- Muscle pain



https://www.cdc.gov/zika/symptoms/symptoms.html

Effects On Adults

- In addition to mild symptoms, research has shown a Zika virus infection can:
  - Possibly affect memory and cognitive skills
  - Increase association of Guillain-Barré Syndrome
    - A potentially fatal condition where the immune system attacks the nerves causing muscle weakness.
    - Symptoms include a tingling sensation of the feet and can spread throughout the body. In severe cases, paralysis is possible.

https://www.cdc.gov/zika/healtheffects/gbs-qa.html

Clinical Manifestations in Infants

- It is believed that the virus attacks the neural progenitor cells of the fetus
- Congenital Zika Syndrome
  - Issues with eye development, hearing loss, and decreased motor abilities (clubfoot)
  - Microcephaly
  - Reduced brain tissue replaced by identifiable calcifications
  - Feeding problems
  - Seizures
  - Hypertonia

https://www.cdc.gov/zika/hc-providers/infants-children/zika-syndrome-birth-defects.html

What is Microcephaly?

- Clinical finding, not a disease
  - Defined by a head circumference residing 3 SD below mean for age
- Caused by a range of etiologies
- Primary diagnostic tests
  - Head circumference at birth
  - Prenatal ultrasound
- No treatment
  - Early identification is imperative
  - Continuous education, evaluation, therapy, and guidance
- Prognosis depends on severity of the microcephaly

Baby with Typical Head Size

Baby with Microcephaly

Baby with
Severe Microcephaly

https://www.cdc.gov/zika/healtheffects/birth_defects.html

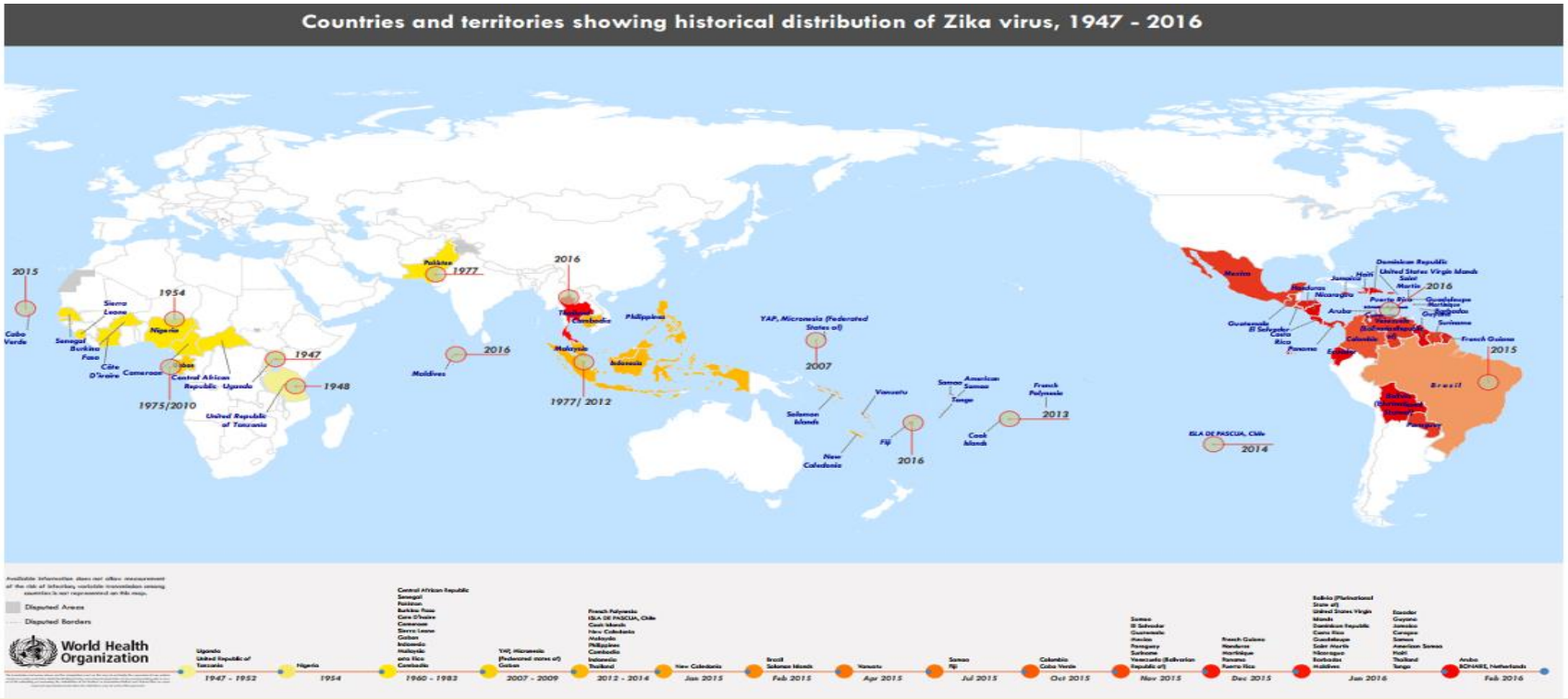
Potential Effects

- MMWR Data
  - Laboratory Confirmed Zika cases in 1st Trimester: Birth Defects reported in 15% of cases
  - Laboratory Confirmed Zika cases throughout pregnancy: 10% of cases reported birth defects
  - In 2016 postnatal imaging was reported for 25% of cases
  - Zika virus testing was performed on 65% of cases

https://www.cdc.gov/mmwr/volumes/66/wr/mm6613e1.html

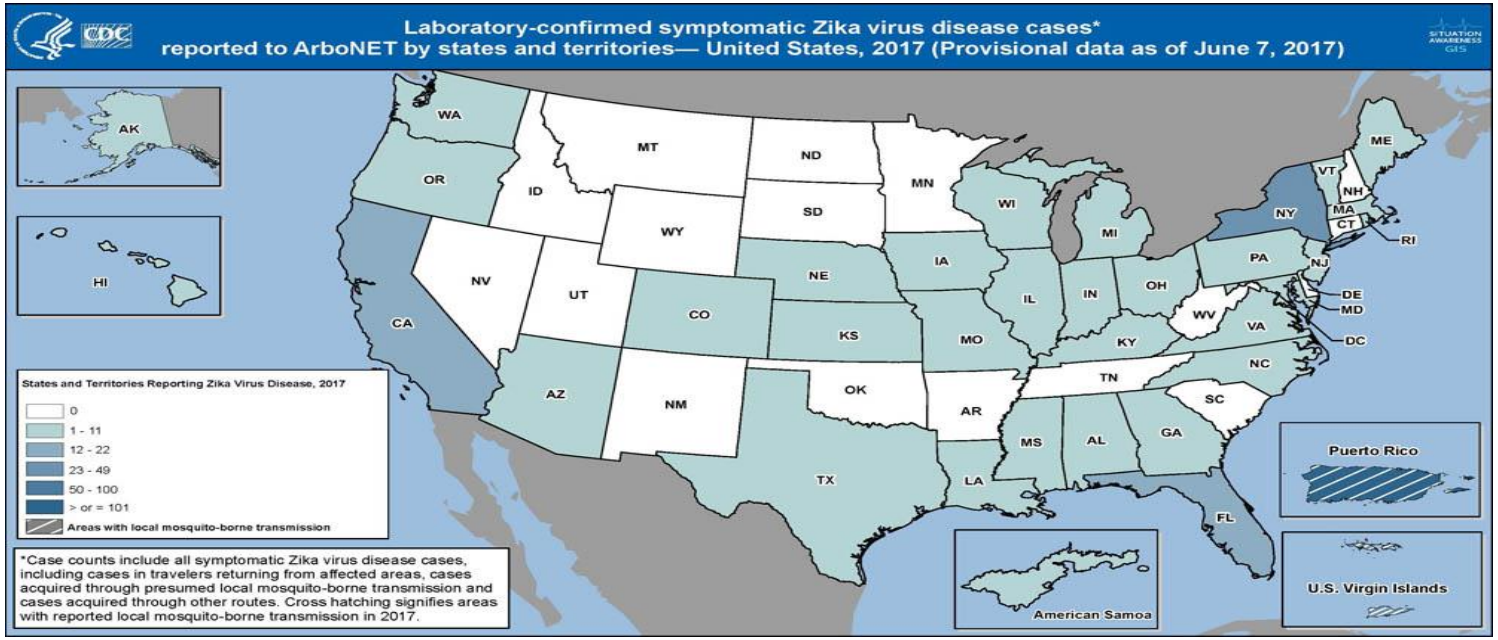
Timeline

- First human case in 1952 in Uganda
- 2 epidemics: 2007 and 2013 – 2014
- First Florida case –January 19, 2016
- First Zika related microcephaly baby born in Florida – June 28, 2016
- Free Zika testing started for all pregnant women – August 3, 2016



Cases of Zika in the U.S.

- **125 Zika virus disease cases reported in 2017**
  - 124 travel-related cases
  - 1 sexual /laboratory/blood borne transmission



https://www.cdc.gov/zika/geo/united-states.html

Florida: Gateway into the U.S.

- South Florida presents a unique challenge because of the constant flux of individuals
- Come from areas endemic with Zika
- Many have businesses outside the country but reside inside the U.S. and travel constantly
- Culture plays a significant role in delivering healthcare

"Florida has been the gate of entrance of Zika because of immigration, how close we are to the endemic areas, the high immigrant population, the conditions in terms of having the vector…. We must protect Florida."

- Infectious Disease Specialist

Carnaval Miami 2017

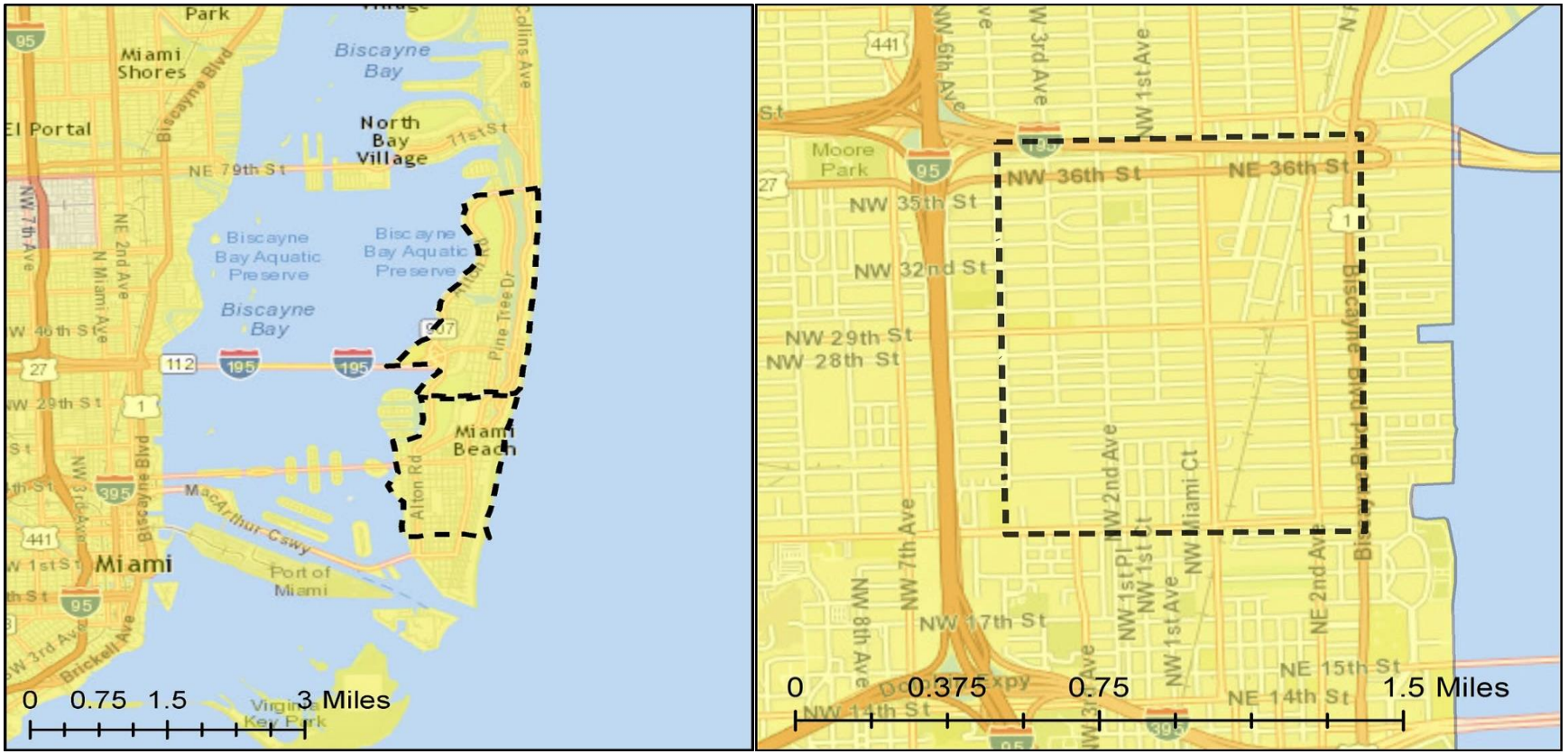
Zika in Florida (May, 2017)

Infection Type	2016	2017
Travel – related	1,122	55
Locally acquired	285	4
Undetermined	49	12
Total	*1,456*	*71*
Pregnant women with lab-evidence of Zika	299	48

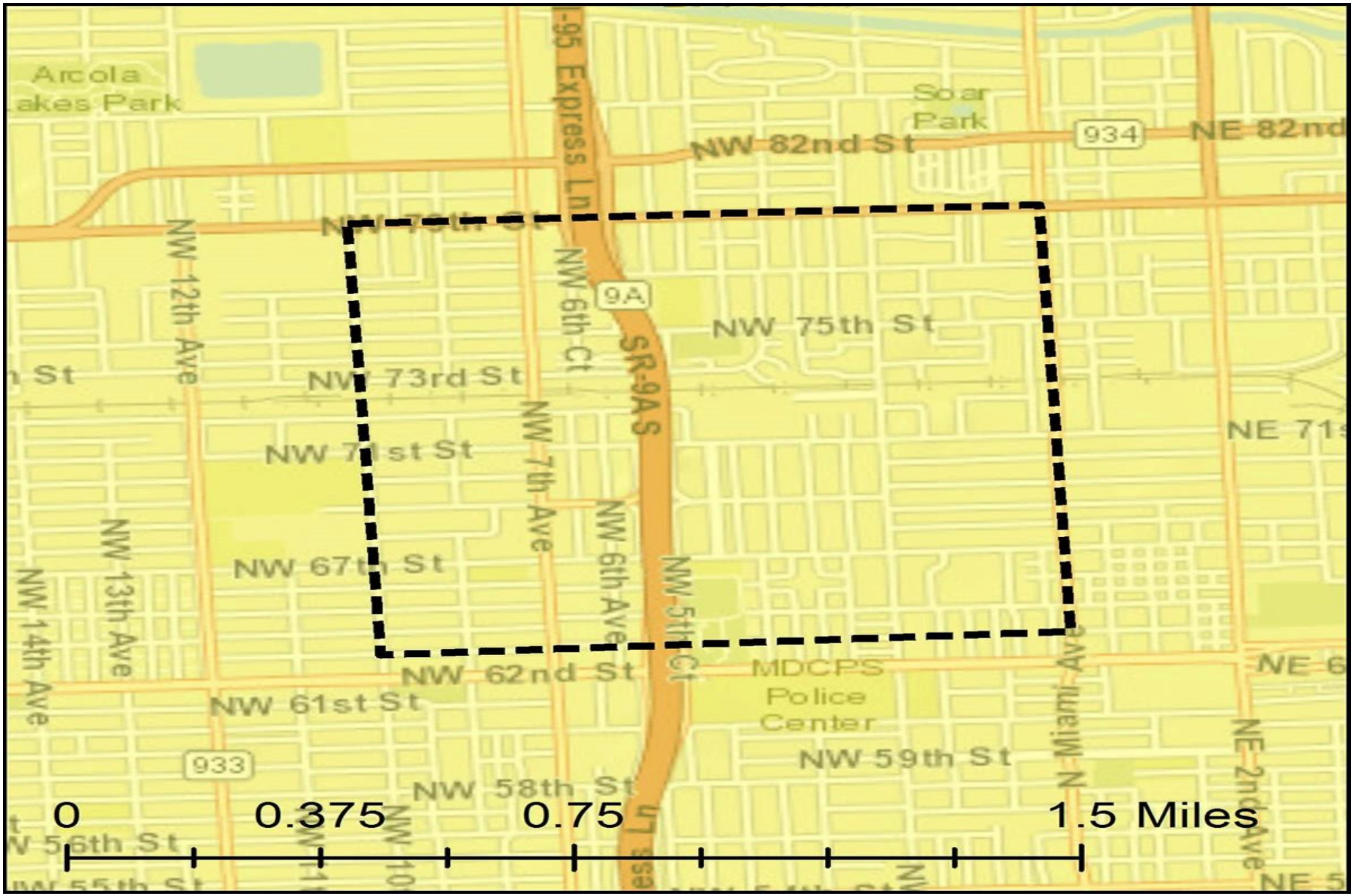
http://www.floridahealth.gov/diseases-and-conditions/zika-virus/ May 24, 2017

Areas in Florida Most Impacted by Zika

- Miami Dade County –Little River, South Beach, North Beach and Wynwood

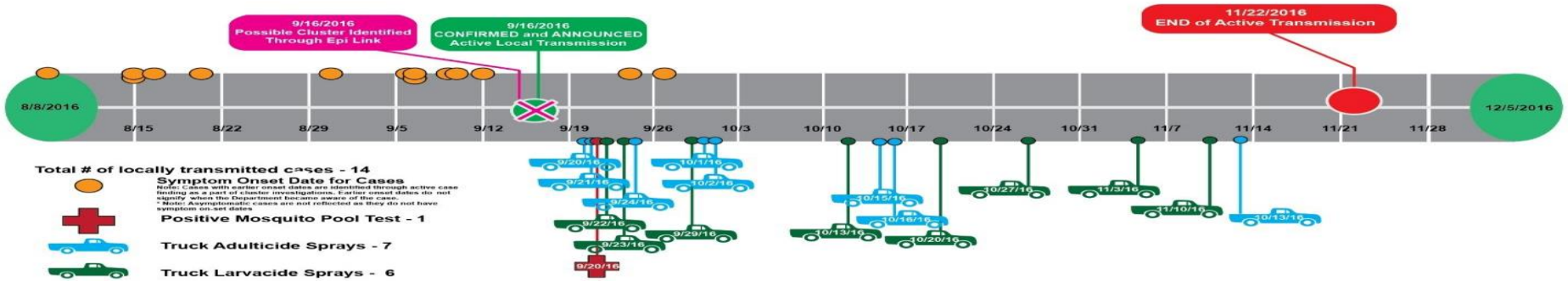


https://www.cdc.gov/zika/intheus/florida-maps.html



https://www.cdc.gov/zika/intheus/florida-maps.html

North Miami Beach Zika Activities Timeline



Total # of locally transmitted cases - 14

Symptom Onset Date for Cases

Note: Cases with earlier onset dates are identified through active case finding as part of cluster investigations. Earlier onset dates do not signify when the Department became aware of the cases.
* Note: Asymptomatic cases are not reflected as they do not have symptom on-set dates

Positive Mosquito Pool Test - 1

Truck Adulticide Sprays - 7

Truck Larvacide Sprays - 6

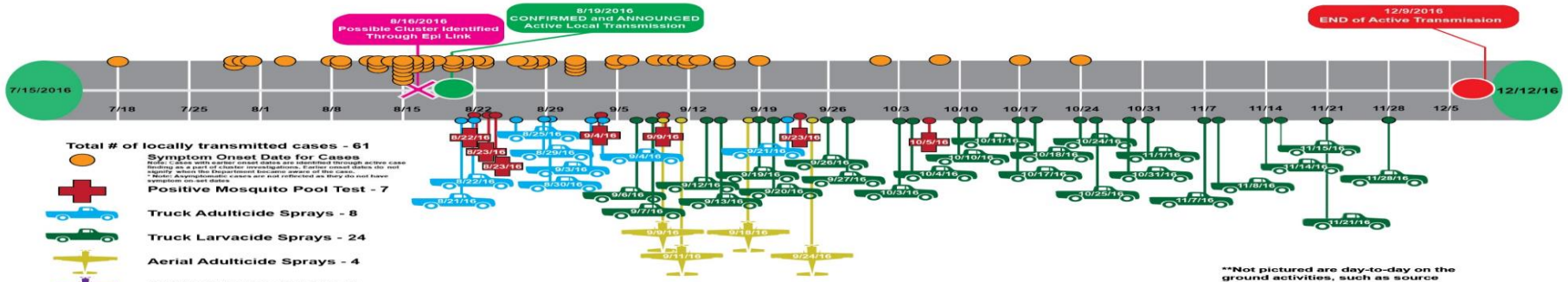
Aerial Adulticide Sprays - 0

Aerial Larvacide Sprays - 0

**Not pictured are day-to-day on the ground activities, such as source reduction and backpack spraying.

**Graph illustrates the most recent information received detailing mosquito control efforts in Miami Beach.

South Miami Beach Zika Activities Timeline



Total # of locally transmitted cases - 61

Symptom Onset Date for Cases

Note: Cases with earlier onset dates are identified through active case finding as part of cluster investigations. Earlier onset dates do not signify when the Department became aware of the cases.
* Note: Asymptomatic cases are not reflected as they do not have symptom on-set dates

Positive Mosquito Pool Test - 7

Truck Adulticide Sprays - 8

Truck Larvacide Sprays - 24

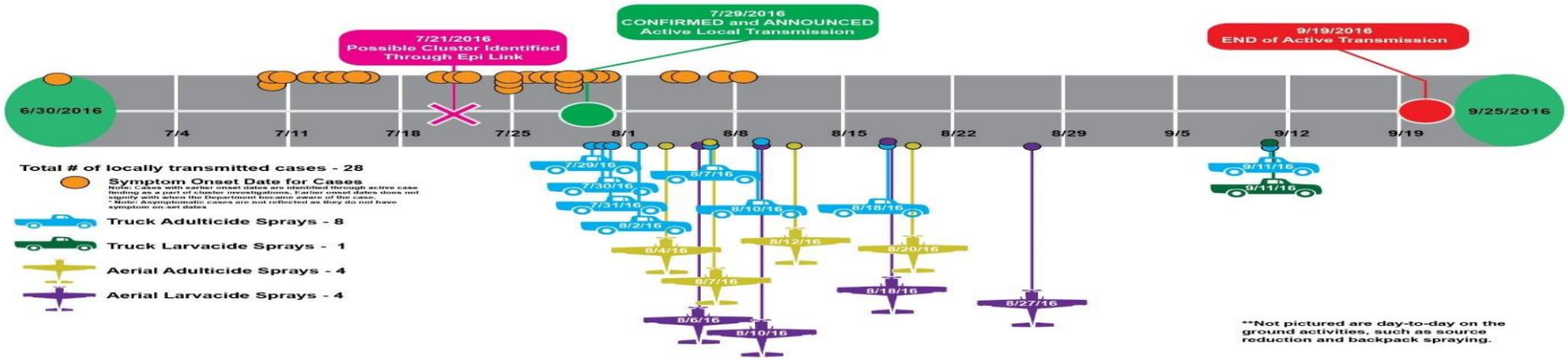
Aerial Adulticide Sprays - 4

Aerial Larvacide Sprays - 0

**Not pictured are day-to-day on the ground activities, such as source reduction and backpack spraying.

**Graph illustrates the most recent information received detailing mosquito control efforts in Miami Beach.

Wynwood Zika Activities Timeline



Total # of locally transmitted cases - 28

Symptom Onset Date for Cases

Note: Cases with earlier onset dates are identified through active case finding as part of cluster investigations. Earlier onset dates does not signify when the Department became aware of the cases.
* Note: Asymptomatic cases are not reflected as they do not have symptom on-set dates

Truck Adulticide Sprays - 8

Truck Larvacide Sprays - 1

Aerial Adulticide Sprays - 4

Aerial Larvacide Sprays - 4

**Not pictured are day-to-day on the ground activities, such as source reduction and backpack spraying.

Evaluating Systems of Care for Zika Response in Florida through Journey Mapping

What is Journey Mapping?

- A qualitative approach to understanding the experience of an individual
- Based in consumer research
- Growing association of journey mapping in research protocols outside of the consumer research sector (e.g. health care, social services)

WALKING IN THEIR SHOES

Stages of Journey Mapping

Select the population of interest
Segmentation is used to assess the customer experience
i.e., areas of satisfaction or needing improvement

Find out as much as you can about the customer!
Methods:
Focus groups
Interviews
"Mystery shopping"
Assess relevant services

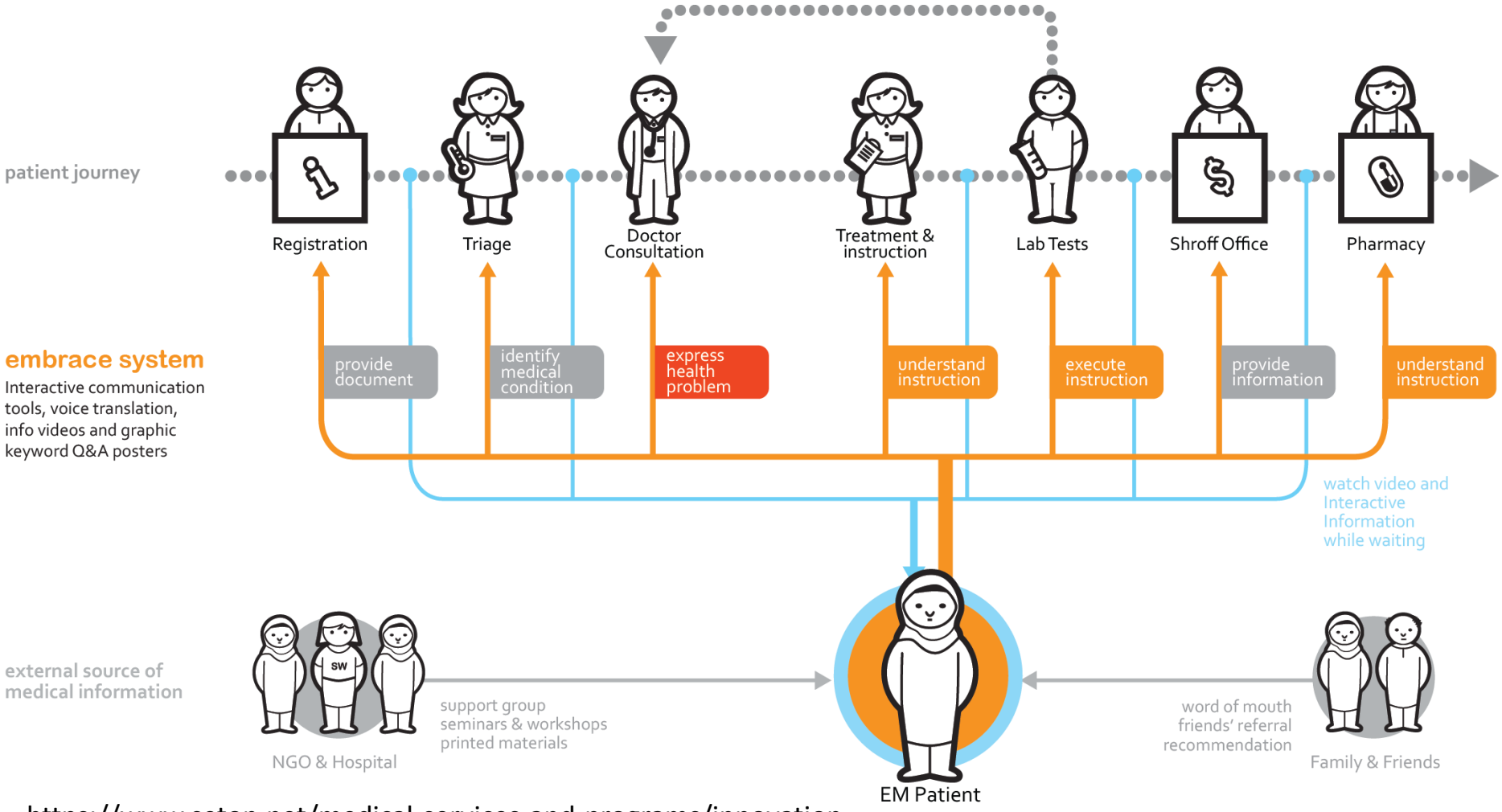
Components:
1. Touchpoints
2. Participant
   - Personas
   - Emotions
   - Thoughts
   - Positive Aspects
   - Negative Aspects
3. Analyses
4. Visualization

See next Slide for examples

Use information to improve services
e.g., Cutting out unnecessary steps, improving communication, Staff training, etc.
Enhance the overall experience

- What measures will be used?
- How well did the Journey Map process work?
- Did the changes improve the experiences of the targeted population?
- What continues to need work?

An Example



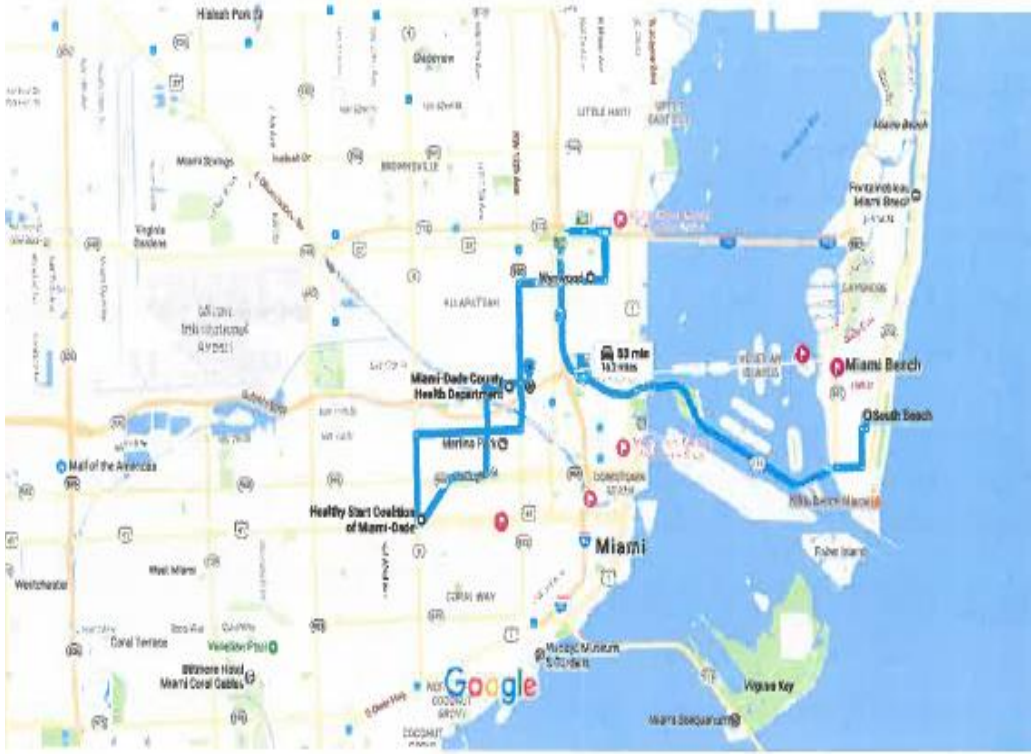
https://www.seton.net/medical-services-and-programs/innovation

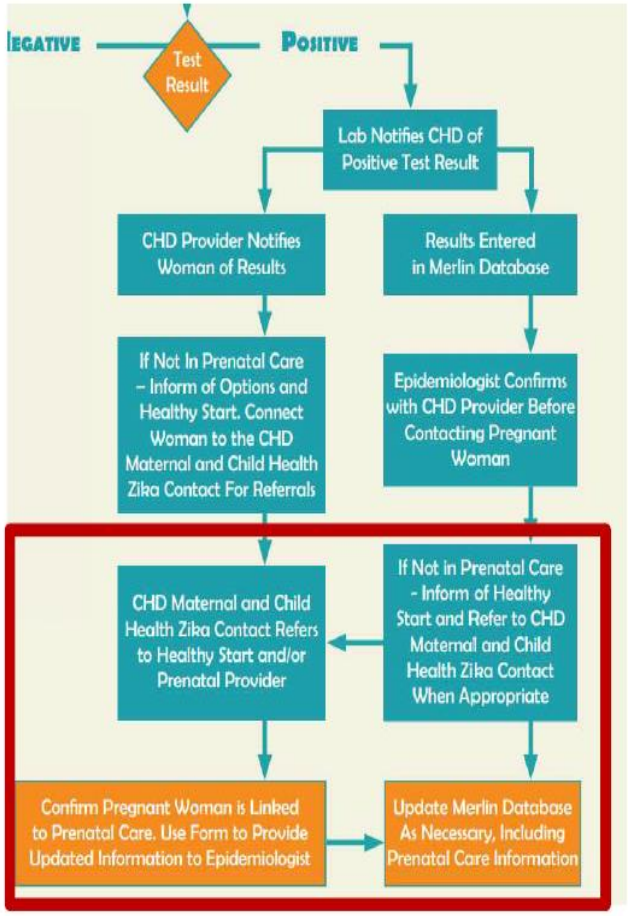
Another Example

What Journey Mapping Can Illustrate

- Persona
  - Motivations
  - Expectations
- Thoughts and Emotions
- Touchpoints
- Facilitators and Barriers

Mapping the System of Care for Families of Infants Impacted by Zika Virus





Florida's Public Health Response

On February 3rd, 2016 the Governor of Florida declared a public health emergency, which activated the Florida Department of Health's Incident Command System.

The coordinated response within DOH includes:

- **Epidemiologists** from the arbovirus and infectious disease surveillance programs, who provide leadership, clinical expertise, and experience directing public health investigations including data collection, case identification, analysis, report preparation, and dissemination of information to numerous stakeholders. In addition, epidemiology staff notify hospitals and health care practitioners about disease reporting requirements, clinical guidelines, and prevention opportunities.
- **County Health Department** epidemiologists, who conduct public health investigations, provide clinical guidance to health care practitioners, and educate the general public about Zika virus.
- (**Florida's state public health laboratory** staff, who develop guidance on sample collection, perform laboratory tests, and report test results to state and local epidemiologists.

Florida's Public Health Response

On February 3rd, 2016 the Governor of Florida declared a public health emergency, which activated the Florida Department of Health's Incident Command System.

The coordinated response within DOH includes:

- **Florida's Birth Defects Registry** (FBDR) staff, who provide technical guidance, historical trends in prevalence, clinical expertise, and identification and abstraction of birth defect cases possibly linked to Zika virus.
- **Maternal & Child Health** (MCH) programs, including federal and state Healthy Start Coalitions, for educational outreach to health care practitioners and programs serving women of childbearing age.
- **Disease Intervention Specialists** (DIS), who offer assistance with sexually transmitted Zika virus cases by conducting sex partner interviews and epidemiological case mapping and help develop outreach tools.
- **Communications** staff, who develop and distribute public health messages about Zika virus to health care practitioners and the general public in appropriate languages and media formats (posters, social media, etc.).

Awareness

- CDC Guidance
- Media
- Public Perception

Prevention

- Wear long sleeve shirts, pants, and hats
- Use effective insect repellants
- Get rid of stagnant water
- Use condoms, even if pregnant

For Expecting Mothers

Zika Prevention Kit for Pregnant Women

A - Permethrin spray repellent for treating clothing

B - Treatment tabs for preventing mosquitoes from breeding in standing water

C - EPA-registered insect repellent

D - Condoms to prevent sexual transmission of Zika

E - Mosquito bed net

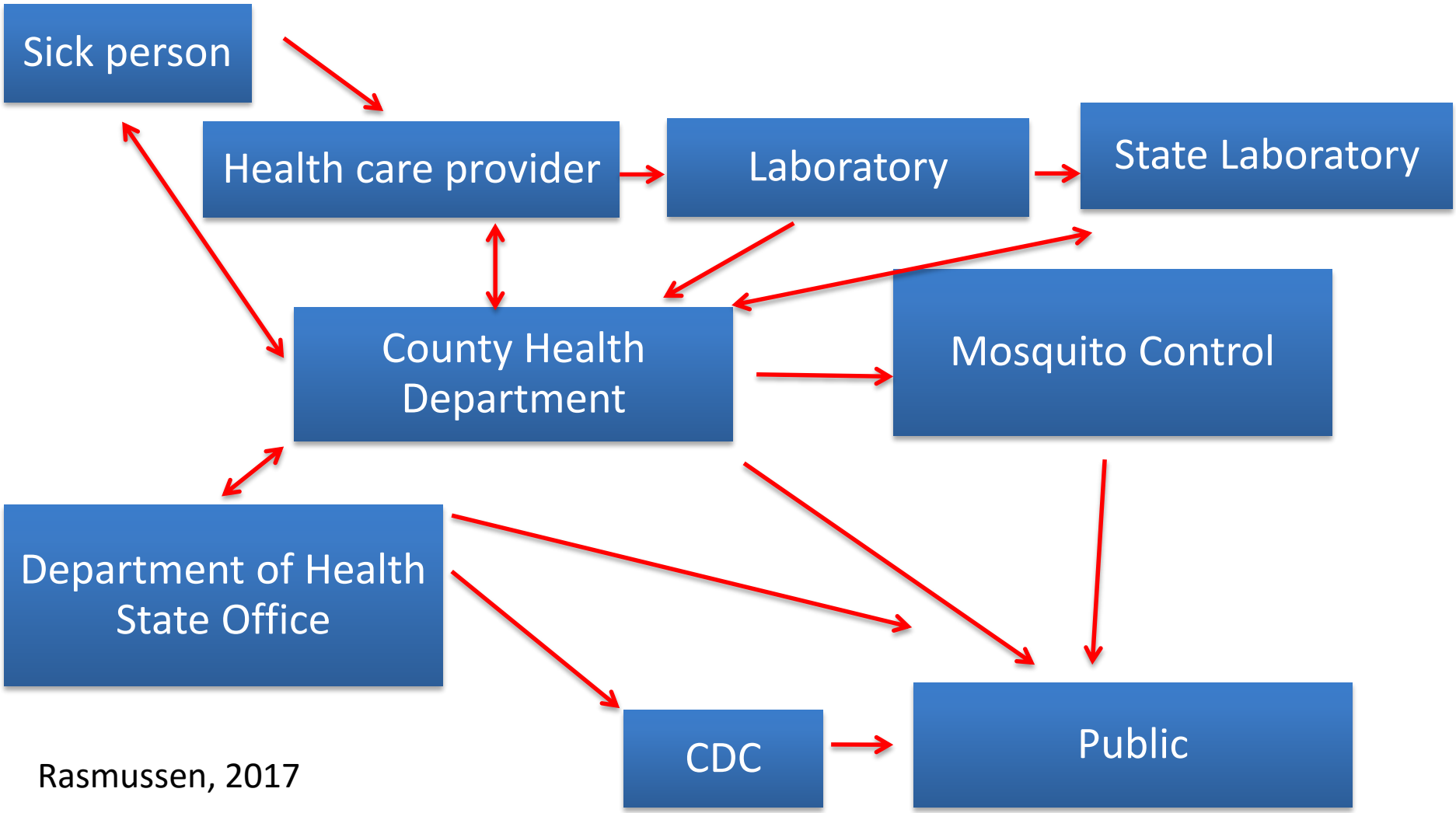
F - Educational materials in English and Spanish

Prevention

"We were distributing condoms. We were distributing and encouraging the use of repellents, long-sleeved clothing; we were doing a lot of education right from the very beginning on prevention." - Healthy Start Coalition

"The Zika kits, probably 100 and we served well over a thousand women in – I'm sure more - in the last six, seven months so they had been providing us with like I said a household repellent. It has condoms. It's a diaper bag. It also has the education for the Department of Health with the [message] and CDC guidelines so that has really helped us give the message." – Case Manager

Zika Case Investigation



Rasmussen, 2017

Key Partners for Department of Health

- Media
- FL Department of Health
- Mosquito Control
- Jackson Memorial Hospital
- OBGYN
- Healthy Start Coalition- case managers
- Research
- Pediatrics/ Early Steps

"At the beginning of the process there was a lot of news coverage very, very extensively and so a lot of women would hear that the Department of Health was conducting free testing…"
- Case Manger

"They are supposed to address and offer the women Healthy Start case management"
- Healthy Start Coalition

Zika Specialists

Private OBGYN/ Hospital

If Zika positive

- Jackson Memorial
- University of Miami
- Nicklaus hospital (Children's hospital)

Healthy Start Case Manager

After the birth of infant

Early Steps

"...when that first patient who had a locally acquired Zika was here literally every health officer was here with her... " – OB/GYN

Mosquito Control

- Mosquito populations controlled by larvacide or adulticide treatments
  - Ground based spray
  - Aerial spray
  - Proactive intervention:
    - Traps
    - Zika lab results investigation

- Concerned citizens
  - The amount of insecticide used is very minimal
  - Done during the nighttime
- One of the best control programs in the world!
  - Creates a trickle affect: “Florida can be the area where the virus anchors”- Infectious Disease Specialist

Key Partners for Mosquito Control

- Public works

"If you have one tire in your backyard that you forgot, it fills up with water; it could supply mosquitoes for the whole block."

"Mosquito control falls under public works, not under public health."

"I mean, this is Epidemiology 100 – reduce the vector, reduce the risk."

"We have the best GIS mapping system around. We use satellite imagery all we can."

- Infectious Disease Researcher

Current Healthcare System

- Addressing Zika in pregnant women is dependent upon:
  - Pregnant woman choosing to get tested
  - Pregnant women who are positive, agree to switch their OB to a specialist

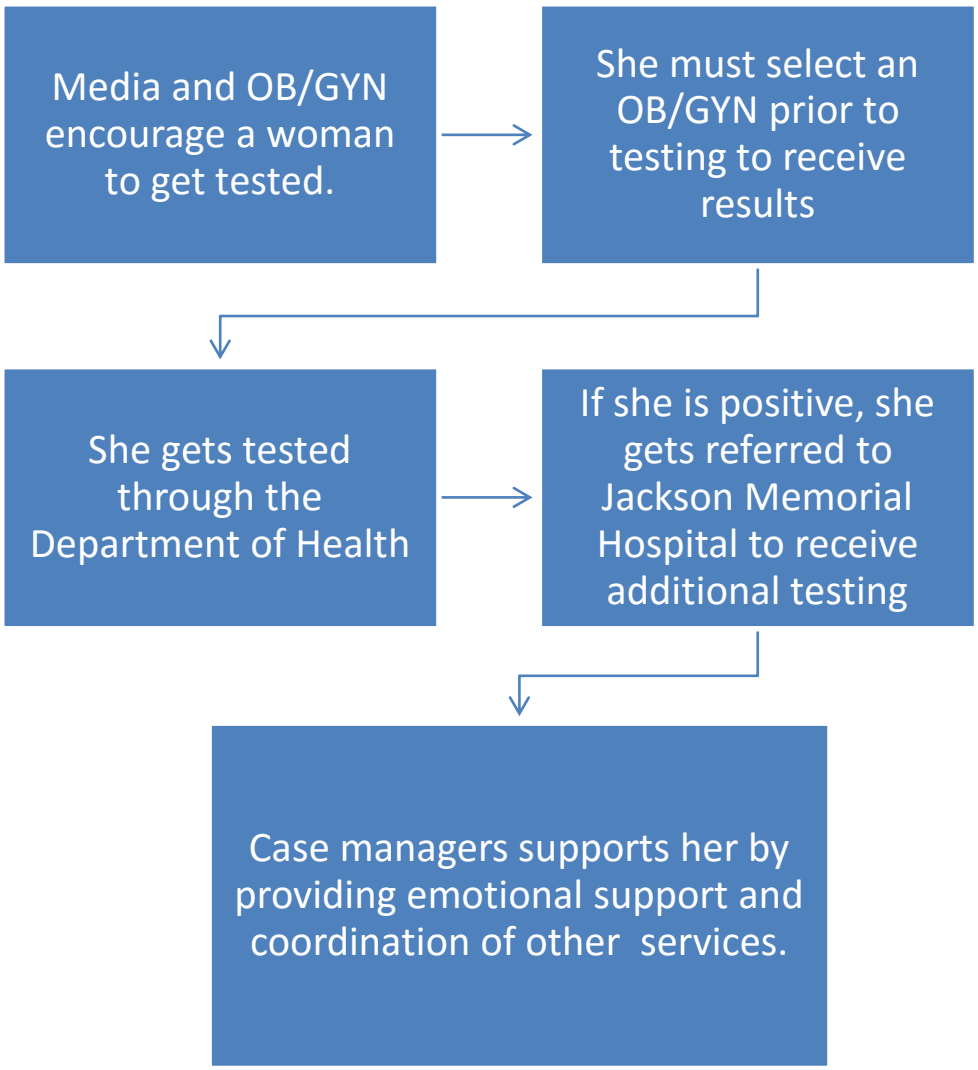
Role of Obstetrician

- Local Health Clinics
  - CDC Testing Guidelines of 1st and 2nd trimester testing, but many receive care in the 3rd trimester
  - Many patients fly in from Central and South America for obstetric care

Role of Healthy Start Coalition

- Communication Channels
- During the outbreak case managers were stationed at local clinics
- With the success of control, they are back at the central office
- Home Visits

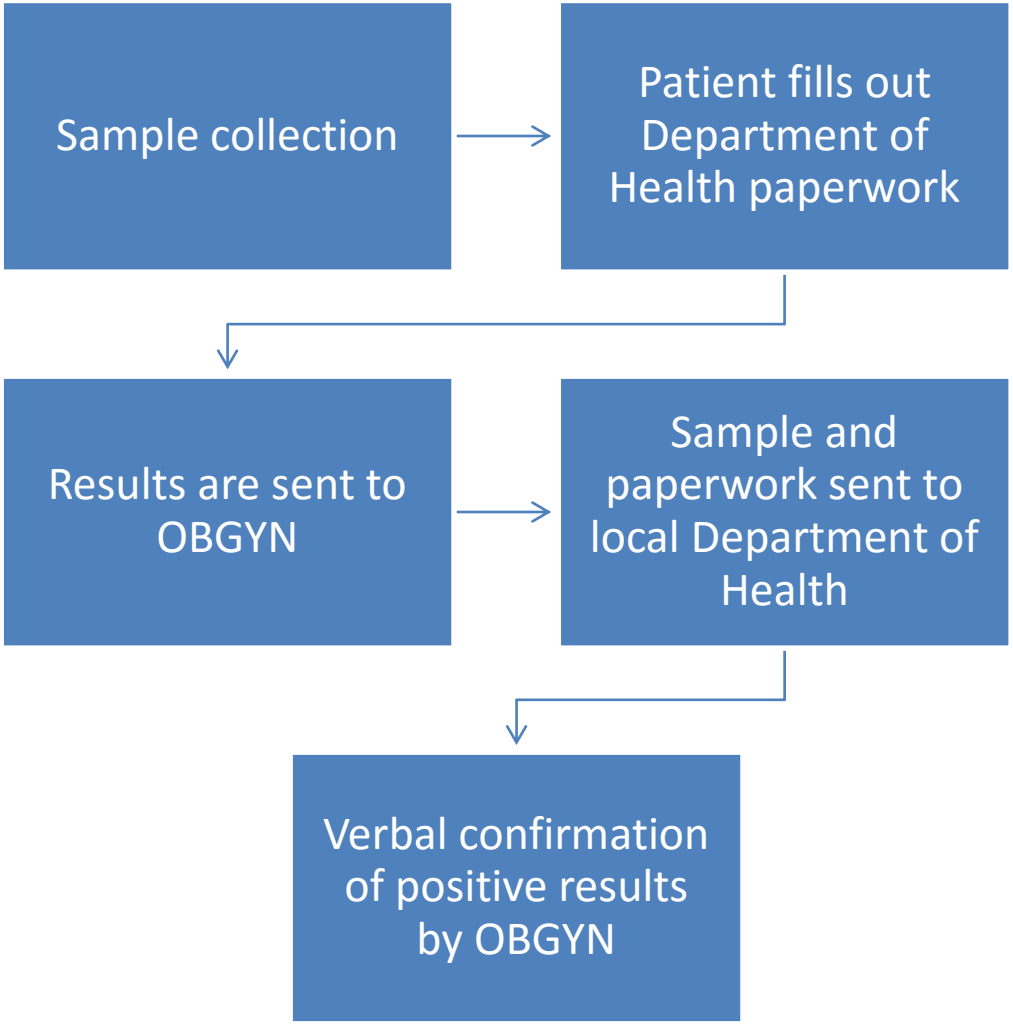
System for Prenatal Testing



"Well, the clinic was very, very adamant that they would not serve a mother that had not selected an OB-GYN…They need to share the results via physician and if they didn't have a physician, they were encouraged to identify a physician and come back for testing." - Case Manager

"They feel a little bit better because they know, at least they have an idea who they can call if they have any question and they're not struggling and they can call somebody."
- Case Manager

Prenatal Testing



"If it's positive, you can't just put it in a computer and hope someone sees it. There has to be a verbal confirmation from the ordering doctor." – OB/GYN

Zika Testing

- Immunoglobulins
  - Cross reactivity with other Flaviviruses (yellow fever, dengue, chikungunya) makes these tests unreliable
  - More specific testing developed in the future can allow for longer laboratory testing window
- Real Time PCR
  - Short amount of time for Lab confirmation tests
  - Results can take up to 3 weeks to be returned to provider

https://www.cdc.gov/zika/hc-providers/types-of-tests.html

Infant Diagnosis

- Pediatric Testing
  - Initial screenings should be performed within 2 days of birth
  - The CDC recommends the following exams be administer to all infants suspected of being affected by Zika Virus:
    - Comprehensive physical exam
    - A neurologic assessment
    - Postnatal head ultrasound
    - Standard newborn hearing screen before hospital discharge
    - Zika virus laboratory testing
- Continue to monitor developmental milestones and participating in pediatric visits

https://www.cdc.gov/zika/hc-providers/infants-children/evaluation-testing.html

Follow Up Care

Outpatient Management Checklist**	2 weeks	1 month	2 months	3 months	4-6 months	9 months	12 months
Infant with abnormalities consistent with congenital Zika syndrome† and laboratory evidence of Zika virus infection*	☐Thyroid screen (TSH & T4)	☐Neuro exam	☐Neuro exam	☐Thyroid screen (TSH & T4) ☐Ophthalmology exam	☐Repeat audiology evaluation (ABR)		
	☐Routine preventive health care including monitoring of feeding and growth ☐Routine and congenital infection-specific anticipatory guidance ☐Referral to specialists, including evaluation of other causes of congenital anomalies as needed ☐Referral to early intervention services (See Page 3, Checklist 2)						
Infant with abnormalities consistent with congenital Zika syndrome† and negative for Zika virus infection	☐Continue to evaluate for other causes of congenital anomalies ☐Further management as clinically indicated						
Infant with no abnormalities consistent with congenital Zika syndrome† and laboratory evidence of Zika virus infection*	☐Ophthalmology exam ☐ABR				☐Consider repeat ABR	☐Behavioral audiology evaluation if ABR not done at 4-6 months	
	☐Monitoring of growth parameters (HC, weight, and height), developmental monitoring by caregivers and health care providers, and age-appropriate developmental screening at well-child visits (See Page 3, Checklist 3)						
Infant with no abnormalities consistent with congenital Zika syndrome† and negative for Zika virus infection	☐Monitoring of growth parameters (HC, weight, and height), developmental monitoring by caregivers and health care providers, and age-appropriate developmental screening at well-child visits						

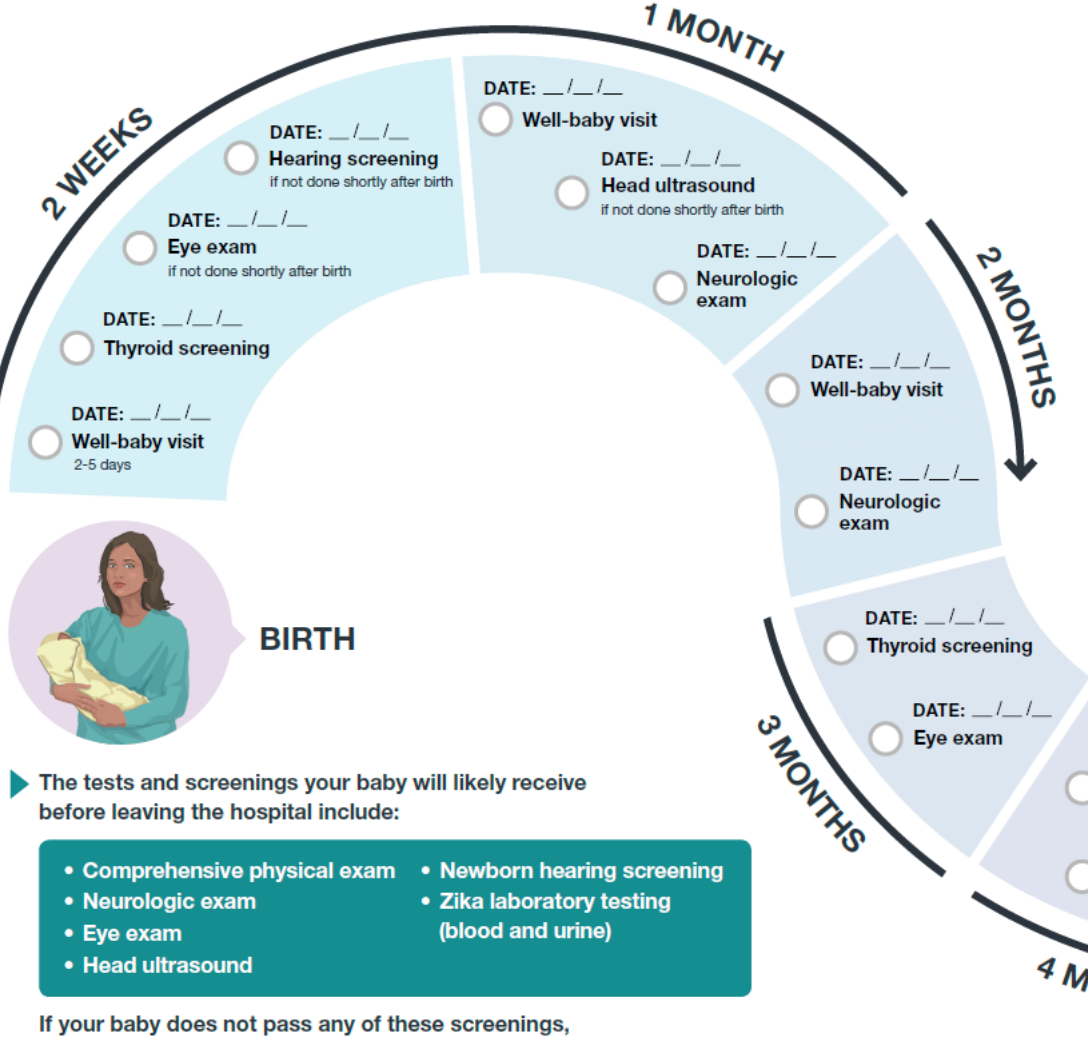
https://www.cdc.gov/zika/pdfs/pediatric-evaluation-follow-up-tool.pdf

ROADMAP FOR PARENTS OF BABIES WITH CONGENITAL ZIKA SYNDROME

This document should be used as a guide to discuss the screening and testing your baby may receive with his or her primary care provider. Each baby is different, and it is possible that your baby may need more tests or fewer tests.

Follow the roadmap to ☑ check off each recommended doctor's visit for the first year of follow up.

- **Routine well-baby visits** include an exam of how your baby is growing and developing, routine immunizations, guidance about what you might expect, and support for mental and social well-being. You also might be referred to a developmental specialist and early intervention services.
- **Talk to your baby's primary care provider about establishing a medical home for your baby.** A medical home is not a place. It is an approach to healthcare that makes sure your baby gets the best, most appropriate services.



- **The tests and screenings your baby will likely receive before leaving the hospital include:**

  - Comprehensive physical exam
  - Neurologic exam
  - Eye exam
  - Head ultrasound
  - Newborn hearing screening
  - Zika laboratory testing (blood and urine)

If your baby does not pass any of these screenings, you may be referred for additional follow-up.

https://www.cdc.gov/zika/parents/care-for-babies-with-congenital-zika.html

Support Your Baby

- If you suspect your baby was infected with the Zika virus:
  - Work with your baby's doctor
  - Keep all appointments
  - Track developmental progress
  - Contact Early Intervention Services
  - Ask Questions!

https://www.cdc.gov/zika/healtheffects/birth_defects.html

Family Support

- Mental Health
- Health Insurance
- Waiting for test results

So What Do We Do Next?

Strengths

- Good relationship with different healthcare providers and FDOH
- Experienced case managers
- Co location
- Faster testing process

Challenges

- Public Education
- Zika awareness
- Public not using/knowing of available resources
- Funding
- Stigma
- Confirmatory test still takes months

Gaps in Communication

- Communication between physicians and patients must get better
  - There are people falling through the cracks
- Educational issue
  - Trying to educate the parent about potential effects that are scary
  - Must connect with them early on so they know what the issues are
- Denial
  - Too many mothers do not return because they believe the baby appears fine
  - Doctors sometimes say…

"Just wait. He'll out grow it."
- Immunologist

Concerns

- There are not enough people being tested
  - Not all hospitals are testing on site
  - Causes missed opportunities for prenatal care and the avoidance of perinatal transmission
- Little knowledge about male transmission
  - Important to understand because men often travel more often than women
- Some women are refusing testing
  - Denial

Concerns

- Giving birth at local hospitals
  - Many local hospitals are not equipped to evaluate and care for infants born to Zika positive mothers
  - Mothers and babies are receiving care in different locations
- Many uninsured women are lost to follow-up

Concerns

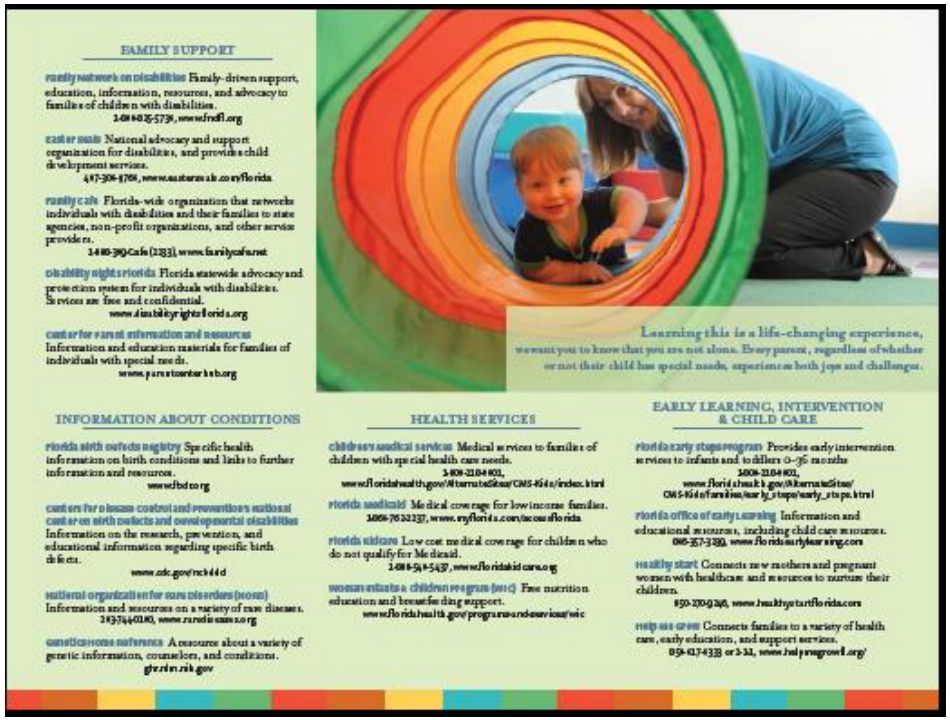
- There is no good diagnostic test that checks for exposure
  - The current system is reliant on people getting tested and the proper identification of those cases
- There is no constant surveillance for Zika and mosquitos are not routinely tested
  - Due to high costs
  - Forces us to rely on healthcare providers to screen patients and report

Potential Solutions

- Clinical trials – University of Miami
- System on how to curb the Zika Epidemic
  - Initiated a program in Hillsborough County schools to make mosquito the surveillance tool
  - Mosquito control

"we start enrolling the mom..., [providing] compensation for travel and time and neurocognitive development, neuro imaging, neurology, ear, nose, throat – so basically above and beyond what the CDC is recommending for three years both in an investigation capacity and recognition that most patients can't afford all of this" – OB/GYN

Health Resources Brochure



Thank you!

For more information:

Jennifer Marshall, PhD, CPH

Assistant Professor

University of South Florida College of Public Health, Department of Community & Family Health

(813) 396-2672

jmarshal@health.usf.edu

Introduction

- Population-based Birth Defects Surveillance and Utilization of Surveillance Data By Public Health Programs In Florida
  - Aim 1: Population-based Birth Defects Surveillance System: Ascertainment, Analysis, and Evaluation
  - Aim 2: Use of Surveillance Data for Prevention Activities
  - Aim 3: Use of Surveillance Data for Improving Access to Health Services and Early Intervention Programs