Mar 22nd, 9:30 AM

Infant Mortality: A Community Engagement Model

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University of Massachusetts Medical School

Et al.

Worcester Healthy Baby Collaborative

Infant Mortality: A Community Engagement Model

8th Annual UMMS Community Engagement and Research Symposium

March 22, 2019

Sara Shields, Cathy Violette, Tasmina Hydery, and Heather Alker,

With special thanks to

Jennifer Moffitt, Alexis Travis, Elizabeth Meyer, Meghan Schmidt, Trevor Gagnet, Heather Lyn Haley and all the WHBC members

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Objectives

- History of WHBC
- Explain concepts of community engagement approach to public health through local examples
  - Nhiyra Ba
  - Community Healthy Baby Forum
- Future of WHBC

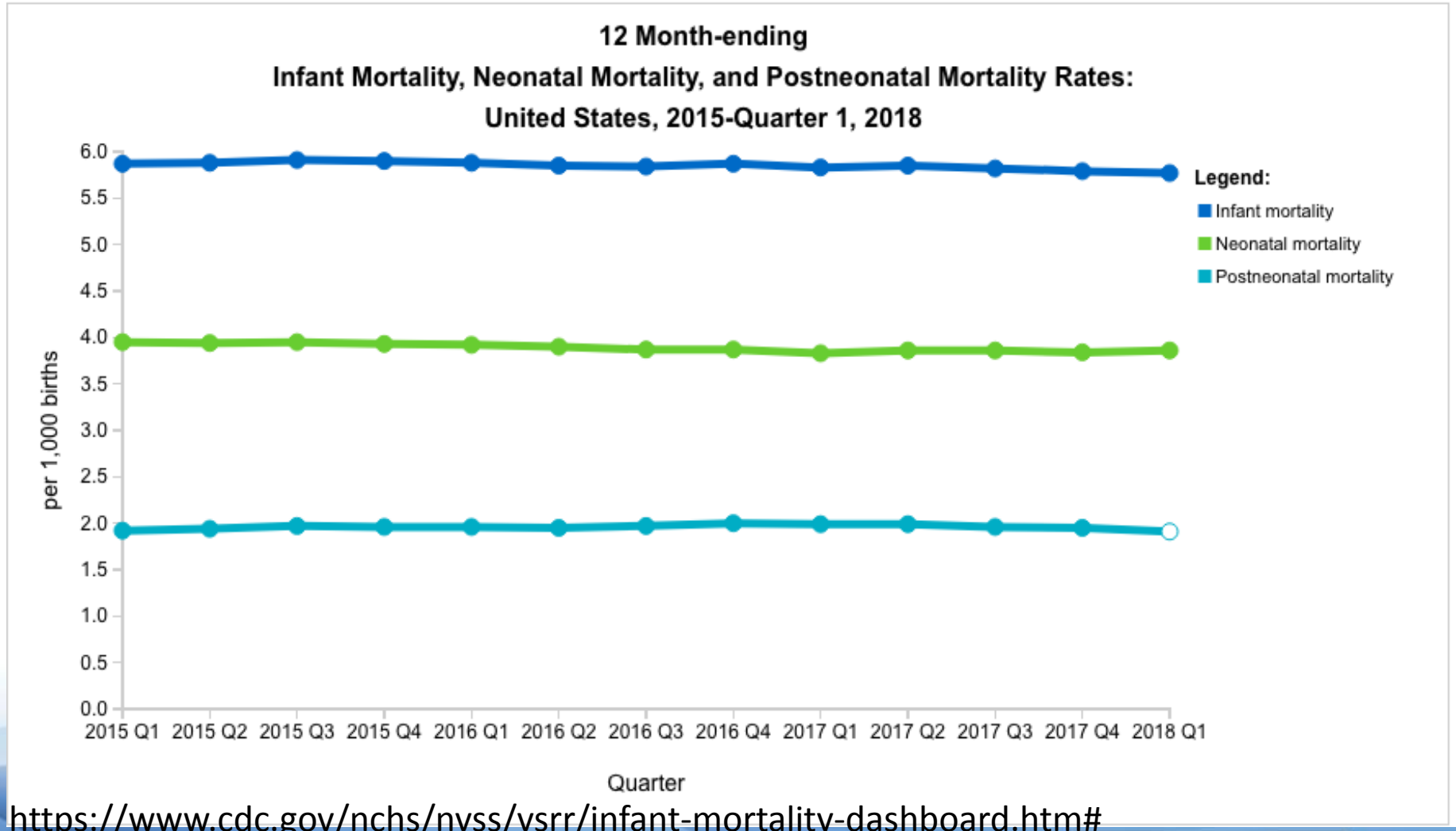
What is Infant Mortality?

- Ratio

$$\frac{\text{Deaths in infants under 1 year of age}}{\text{1000 live births}}$$

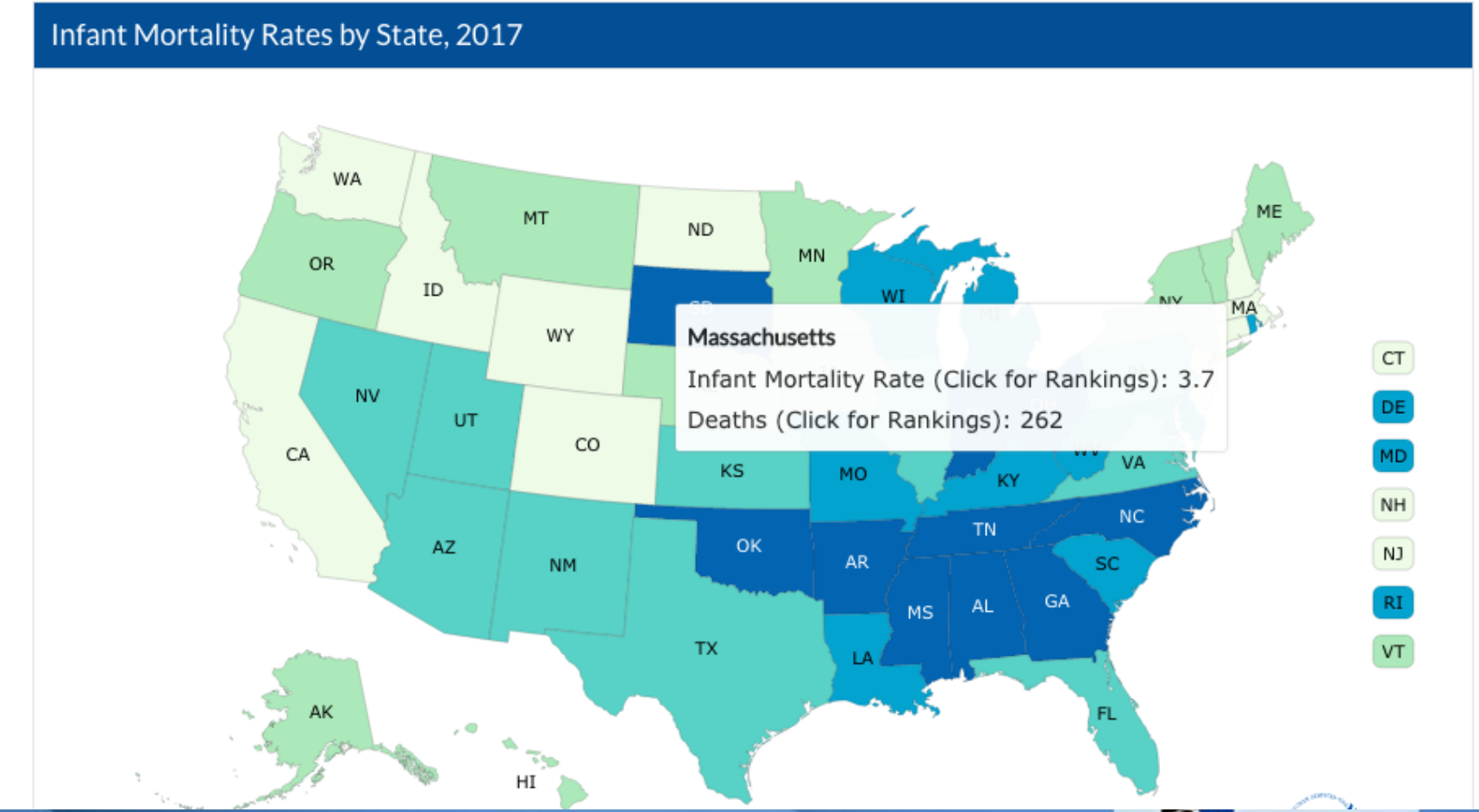
- Neonatal mortality: up to 28 days of life
  - 2/3 of infant deaths
  - Drivers: prematurity, birth defects, maternal health, access to care
- Post-neonatal mortality: 28-364 days of life
  - 1/3 of infant deaths
  - Drivers: sequelae of prematurity/birth defects; SUID/SIDS; infection; injury

Latest IM Data (CDC Provisional)



https://www.cdc.gov/nchs/nvss/vsrr/infant-mortality-dashboard.htm#

CDC: State 2017: MA has lowest IMR in nation at 3.7

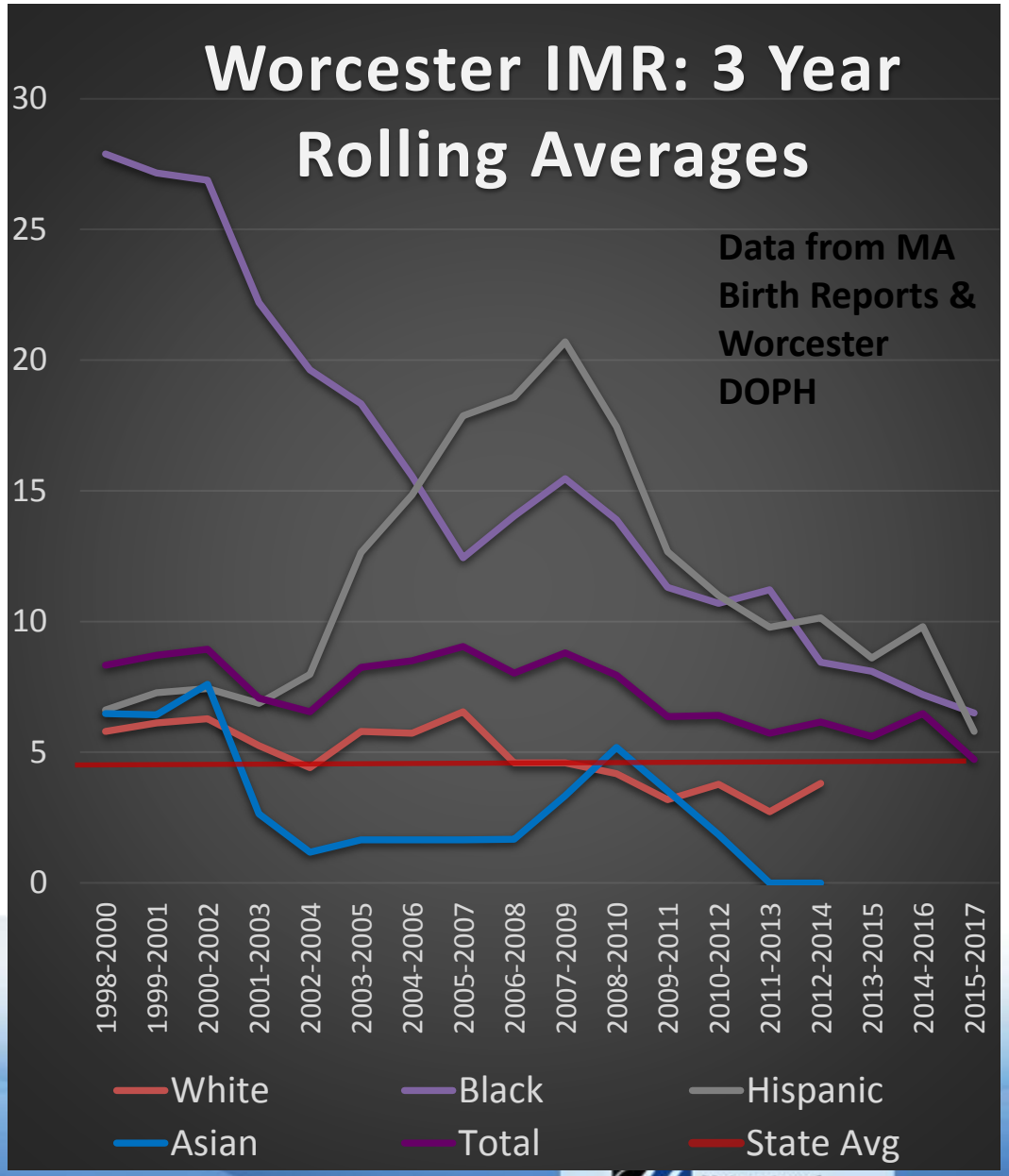


Worcester

- Worcester's infant mortality rate (IMR) remains higher than that of the state overall. Preliminary data suggests that from 2015 to 2017 Worcester had at a rate of 4.9 deaths per 1,000 live births.[3]

- Leading causes of IM in Worcester:
  - Prematurity, Congenital Anomalies, Other (Infection/ Complications), SIDS.
- Leading Cause of IM in United States:

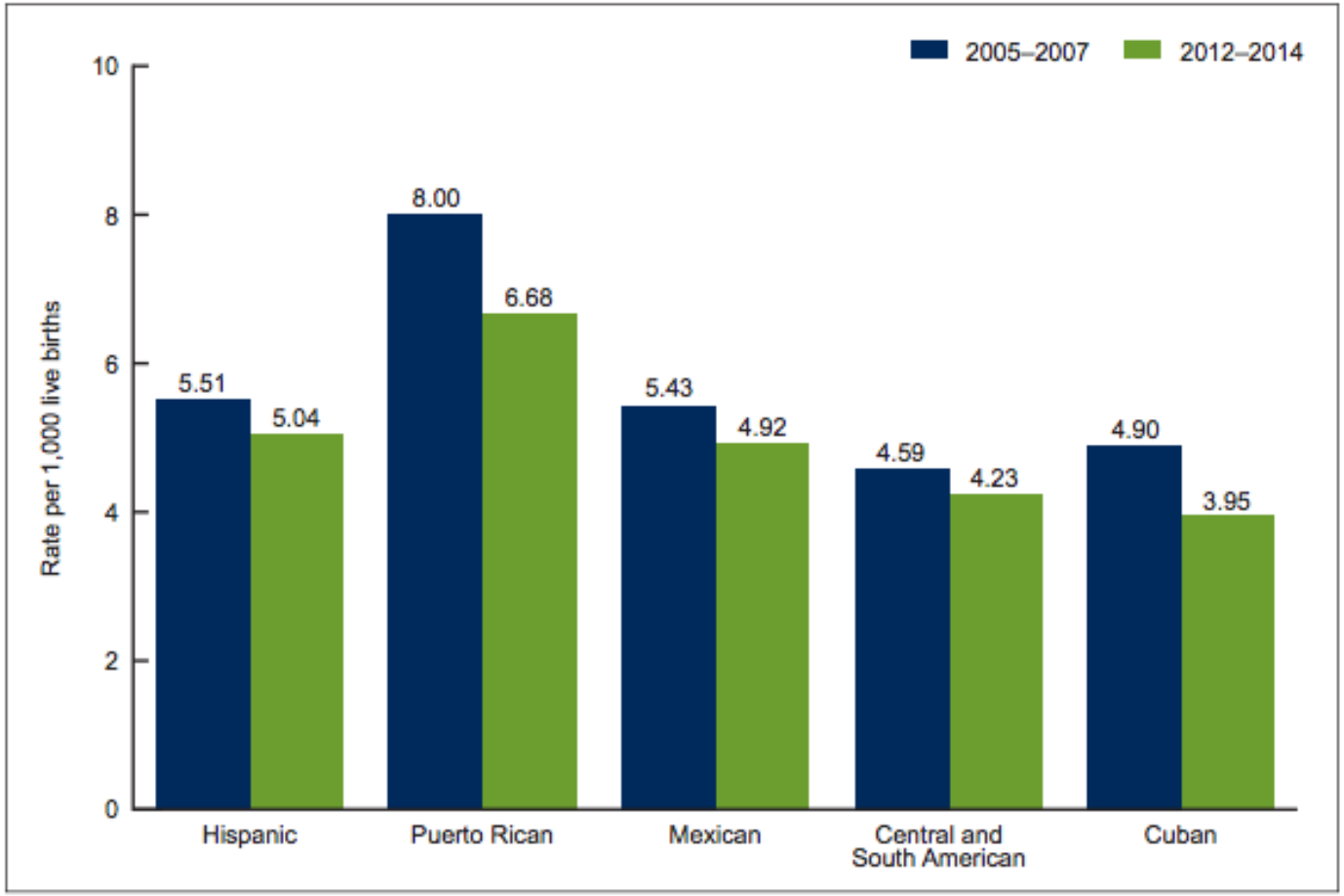
  Congenital Anomalies, Prematurity, SIDS, Complications, Accidents (CDC)



Infant mortality rates among Hispanic subgroups declined from 2005–2007 to 2012–2014.

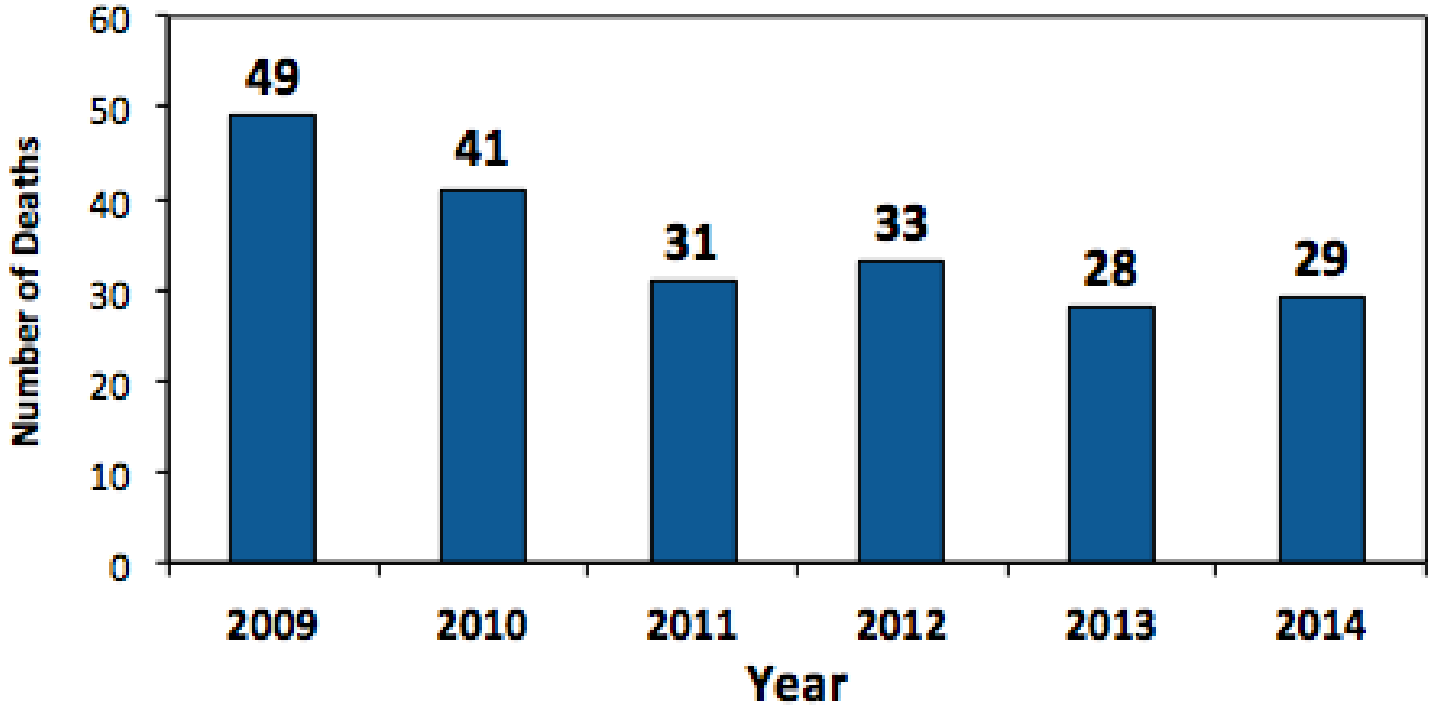
- The largest declines in the infant mortality rates among Hispanic subgroups from 2005–2007 to 2012–2014 were observed among infants of Cuban (19%) and Puerto Rican (17%) women (Figure 2).

Figure 2. Infant mortality rates, by Hispanic-origin subgroup of mother: United States, 2005–2007 to 2012–2014



NOTES: For each Hispanic-origin subgroup, the decline in the rate from 2005–2007 to 2012–2014 is statistically significant ($p < 0.05$). Access data table for Figure 2 at: https://www.cdc.gov/nchs/data/databriefs/db279_table.pdf#2.
SOURCE: NCHS, National Vital Statistics System.

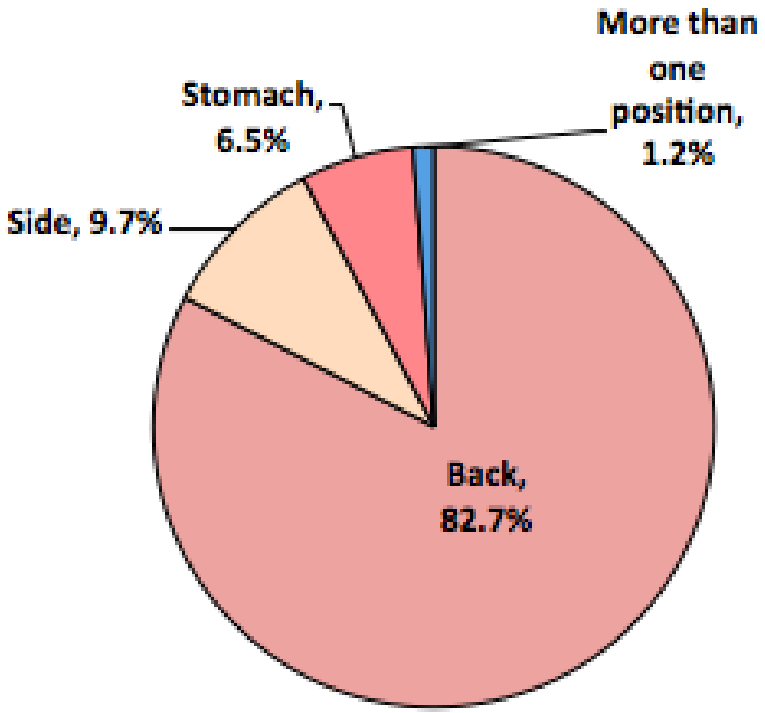
Sudden Unexpected Infant Deaths*, MA Infants, 2009–2014 (n=211)



Source: Registry of Vital Statistics, MDPH.

*SUID includes: SIDS, unintentional suffocation in bed, and undetermined causes

MA PRAMS Findings: "In which *one* position do you *most often* lay your baby down to sleep now?"



Percent placing infant to sleep on back by selected demographics	
Black non-Hispanic mothers	68.5%
Hispanic mothers	67.3%
Asian mothers	84.6%
White non-Hispanic mothers	89.5%

Source: MA Pregnancy Risk Assessment Monitoring System preliminary findings, 2013

Bed Sharing Frequency by Select Race/ Ethnicity, 2013

	Black NH	Asian NH	Hispanic	White NH
<1 time per week or never	27.5%	31.9%	38.7%	51.0%
1-4 times per week	13.2%	13.4%	10.3%	19.0%
5+ times per week or always	59.3%	54.7%	51.0%	30.0%

Source: MA Pregnancy Risk Assessment Monitoring System preliminary findings, 2013

Background

Worcester Infant Mortality Reduction Task Force (WIMRTF)

- Formed in the late 1990s
- Volunteer coalition of community programs, public health departments, and healthcare providers to address rising infant mortality rates (IMR), particularly in the African immigrant population.

WHSI 1998-2012

Worcester Healthy Start Initiative

- offered case management to Worcester's neediest pregnant women and families for up to two years' postpartum

WIMRTF and WHSI Co sponsored biannual community education seminars

Funding not renewed after June 2012

Education & Research

1) City Council Reports
2) Opinion pieces in T&G
3) Radio PSAs

WIMAP 2007

- Worcester Infant Mortality Assessment Project
  - Pilot study of all Black births, including interviews with mothers and SNP genetic analysis.
  - Data inconclusive

Ghana trip 2010

Research: Chart Audits

- Annual analysis of all infant deaths
- Dr Dale Magee (obstetrician)/ Dr Heather Alker
- Chart review of every infant death
  - SVH and Umass
  - Worcester residents
- Standardized abstraction
- Real-time data updates
- State data has partially caught up

- MOD collaboration c. 2010
- WHBC: name change 2012
  - Focus on education

- Adapting "Blessed Baby" curriculum→ Nhyira Ba
- **"by the community and for the community"**
- Linkages with local leaders
- Focus on health rather than "mortality"
- Created:
  - Culturally and linguistically appropriate social media sites
  - Educational pamphlets
  - videos about prenatal nutrition

By/for community

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Provider Video

https://www.youtube.com/user/NhyiraBaWorcesterMA

WHBC 2016 Focus

- Grant from the March of Dimes
- "Community Engagement Model" with Worcester's Hispanic community
- Networking (Adelante, business/health leaders)
- Health Fairs/Community Quilt
- Community Healthy Baby Forum 9/30/16
  - Asked attendees to "vote" on projects

Hispanic Infant Mortality: What Do We Know At This Point?

- Key Informant Interviews 2014
- Multiple social determinant vulnerabilities for Hispanic IM
  - Poverty
  - Low high school graduation rates
  - Domestic violence
  - Mental health issues across generations
  - High mobility (including in schools)
  - Single parenting

Worcester's Community Strengths*

1) Strong extended families
2) Faith based institutions
3) Strong social service agencies/community based organizations
4) Youth development organizations specific to Latino youth
5) Innovative schools
6) Institutions of higher learning with programs geared to Latinos
7) An active Spanish media
8) A community willingness to collaborate

*From key informant interviews 2014

Community Quilts

With special thanks to WHBC Vice Chair Cathy Violette, MSN, WHNP-BC, AWHC-RNC and her team of quilters

Community Healthy Baby Forum 9/30/16
Infant Mortality Awareness Day

PROCLAMATION

WHEREAS: Infant mortality refers to the death of a baby less than one year of age and is an important indicator of the health of a community; and

WHEREAS: The month of September has been designated Infant Mortality Awareness Month to raise public awareness and offer education about reducing infant mortality; and

WHEREAS: The City of Worcester is commited to improving the health and well-being of infants by raising awareness about the importance of infant mortality; and

WHEREAS: The infant mortality rate of Worcester averaged 5.9 deaths per 1,000 live births from 2011 to 2013 compared to the state average of 4.2 per 1,000 during the same period; and

WHEREAS: The average infant mortality rate of Worcester's Hispanic population is nearly four times that of the White population during the last several years, and the Worcester Healthy Baby Collaborative is dedicated to reducing these health disparities; and

WHEREAS: The Worcester Healthy Baby Collaborative is holding a Community Healthy Baby Forum to explore solutions to issues of infant mortality in the community.

NOW THEREFORE, I, Joseph M. Petty, Mayor of the City of Worcester do hereby proclaim September 30, 2016 as

"INFANT MORTALITY AWARENESS DAY"

in Worcester, and do urge all citizens to take steps in providing a healthy start to life for every newborn child.
Issued at Worcester on this 30th day of September, 2016

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Top Vote-Getter: Baby Boxes

Provide boxes with mattresses to provide a safe sleep space for newborn

Worcester Healthy Baby Collaborative

www.worcesterhealthybaby.org

UMMS/GSN: Population Health Clerkship

- 2 week immersion course for 2nd year medical students and NP students through the Dept. of FMCH
- Goal: introduce students to public health & to communities as a unit of care
- September Community Forum, March of Dimes, Population Health Equity

Student Next Steps/Longevity

- Interprofessionalism
- Burncoat Learning Community
- Summer Service-Learning Assistantship Program
- Mick Huppert Award

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WHBC Next Steps Overall

- Fetal and Infant Mortality Review (FIMR)
  - Hearing directly from the families; offering resources
- Ongoing real-time chart audits
  - City DPH epidemiologist
- Universal newborn home visiting (using EI?)
- Strengthening community connections
- Worcester's CHIP/CHA

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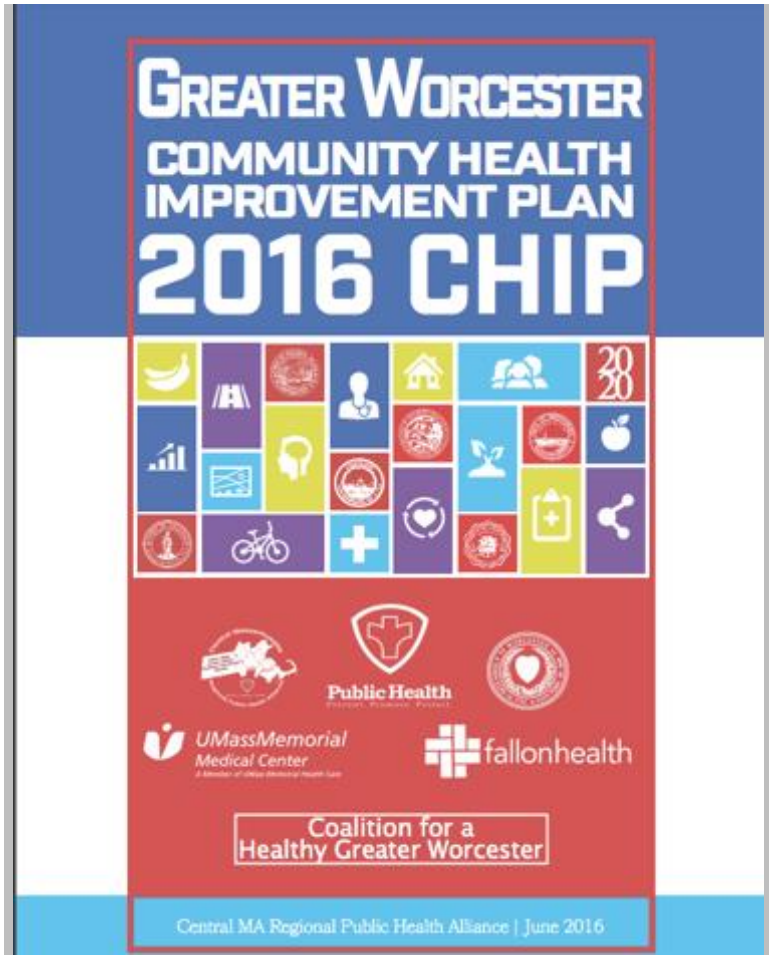


Worcester's CHIP & Infant Mortality

Access to Care. Aim: Create a well-coordinated, respectful, and culturally-responsive environment that encourages prevention of chronic disease, reduction of infant mortality, and access to quality comprehensive care for all. This priority area seeks to meet its aim by increasing the number of providers in the region, better coordinating services, and enhancing and expanding culturally responsive practices in clinical settings.

Priority Area: Access to Care

Aim: Create a well-coordinated, respectful, and culturally-responsive environment that encourages prevention of chronic disease, reduction of infant mortality, and access to quality comprehensive care for all.

Worcester Baby Box Initiative

March 22, 2019

Tasmina Hydery, PharmD, MBA, BCGP
Assistant Professor, Family Medicine and Community Health
Clinical Consultant Pharmacist, Commonwealth Medicine
Vice Chair, Worcester Healthy Baby Collaborative
Remillard Family Community Service Award Recipient

Objectives

- Provide background on sleep-related deaths
- Summarize American Academy of Pediatrics (AAP) guideline recommendations on safe sleep
- Discuss goals of Worcester Baby Box initiative
- Evaluate preliminary survey responses
- Review ongoing community distribution efforts and future goals

Infant Sleep-Related Death[1]

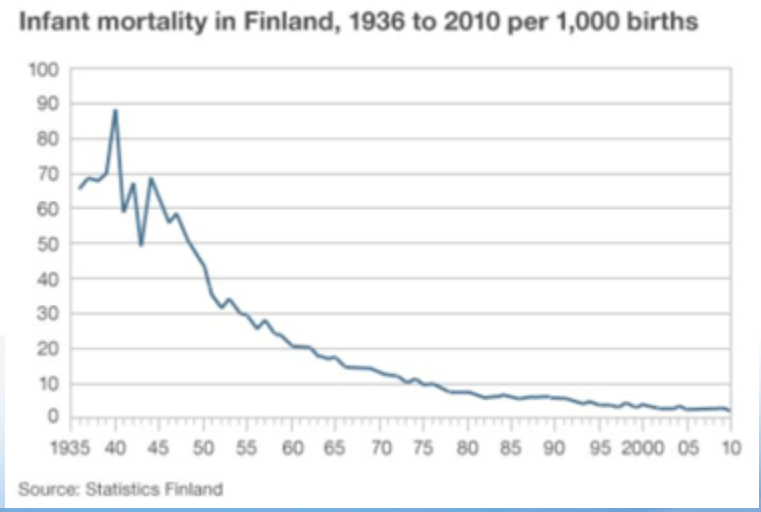
- 3,500 infants die annually in US from sleep-related deaths
  - Sudden Infant Death Syndrome (SIDS)
  - Ill-defined deaths
  - Accidental suffocation and strangulation in bed (ASSB)
- Infants deaths sharply decreased in 1990's and plateaued recently
- National data from 2015
  - 1 in 5 mothers placed baby on side or stomach
  - More than half of mothers reported bedsharing
  - 2 in 5 mothers reported using soft bedding

Consensus Guidelines[2]

Treatment Guideline	Recommendations for a Safe Sleep Environment
American Academy of Pediatrics (Oct 2016)	• Skin-to-skin care is recommended immediately following birth for at least an hour as soon as the mother is medically stable and awake. • Place the baby on back on a firm sleep surface with a tight-fitting sheet. • Avoid use of soft bedding, including crib bumpers, blankets, pillows and soft toys. • Breastfeeding is also recommended as adding protection against SIDS. After feeding, move the baby to his or her separate sleeping space in the parents' bedroom. • Room-sharing decreases the risk of SIDS by as much as 50 percent. • Offer a pacifier at naptime and bedtime. • Supervised, awake tummy time is recommended daily to facilitate development.

Across the Atlantic[3]

- Since the 1930's Finland's expectant mothers have been given a box and kit of clothes, sheets, and toys from the government
- Choice of the box or a cash grant ~140 euros
  - To qualify, the mother needed to have a prenatal visit prior to the 4th month of pregnancy
- Infant mortality rates improved



Efforts in the United States[4]

- SAFE-T program (Sleep Awareness Family Education at Temple)
  - Control group: standard nursing discharge instructions
  - Intervention group: received education from select group of nurses under direction of pediatrician, baby box with supplies, watched a 3-minute instructional video on the use of the baby box
- Follow-up interview
  - Reduced rate of bedsharing by 25% among intervention group in first eight days of life

Goals of Worcester Baby Box Initiative

- Create educational resources to meet Worcester's local needs
- Distribute free educational resources and baby boxes to 500 Worcester residents
- Promote interprofessional collaboration
- Teach medical and nursing students about grass roots community work
  - Population Health Clerkship
  - Summer Research Assistantship
- Ultimate goal of universal distribution

Community Partnerships

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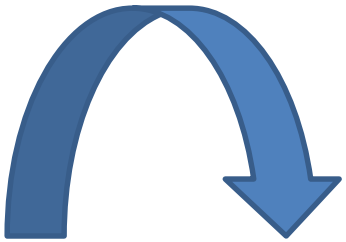
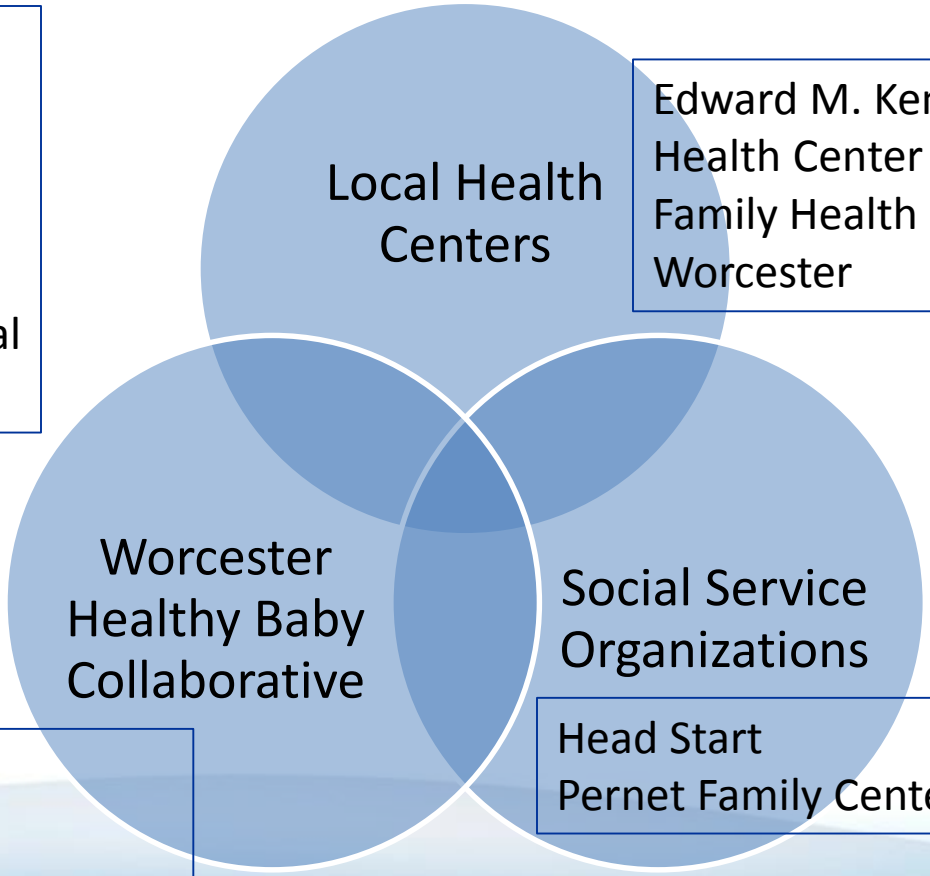
University of Massachusetts Memorial Medical Center



Mentorship:
Chair
Vice Chair
Subcommittee members



Edward M. Kennedy Health Center
Family Health Center of Worcester

Head Start
Pernet Family Center

What is The Process?

Provide information to expectant mothers at prenatal visit

Fill out consent form, pre-education survey and watch educational videos

Fill out post-education survey and take home supplemental educational materials, baby box, and supplies

Wait for the baby to arrive!

Anticipate follow-up communication from team 6 to 8 weeks post-due date

Survey Questions

- Pre-education survey and post-education survey
  - Demographics: age, race/ethnicity, primary language, highest level of education, due date
  - Health-related behaviors: smoking, substance use, postpartum depression, family planning, breastfeeding, bedsharing, room sharing
- Follow-up survey
  - Health-related behaviors: breastfeeding, bedsharing, room sharing
  - Free-response text regarding strengths and areas for improvement

Progress to Date

Spring 2017: Educational videos filmed and edited

Fall 2017: UMASS IRB determined project is quality evaluation

Winter 2017: Surveys and release waiver finalized

Spring 2018: Baby Box Company agrees to make donation

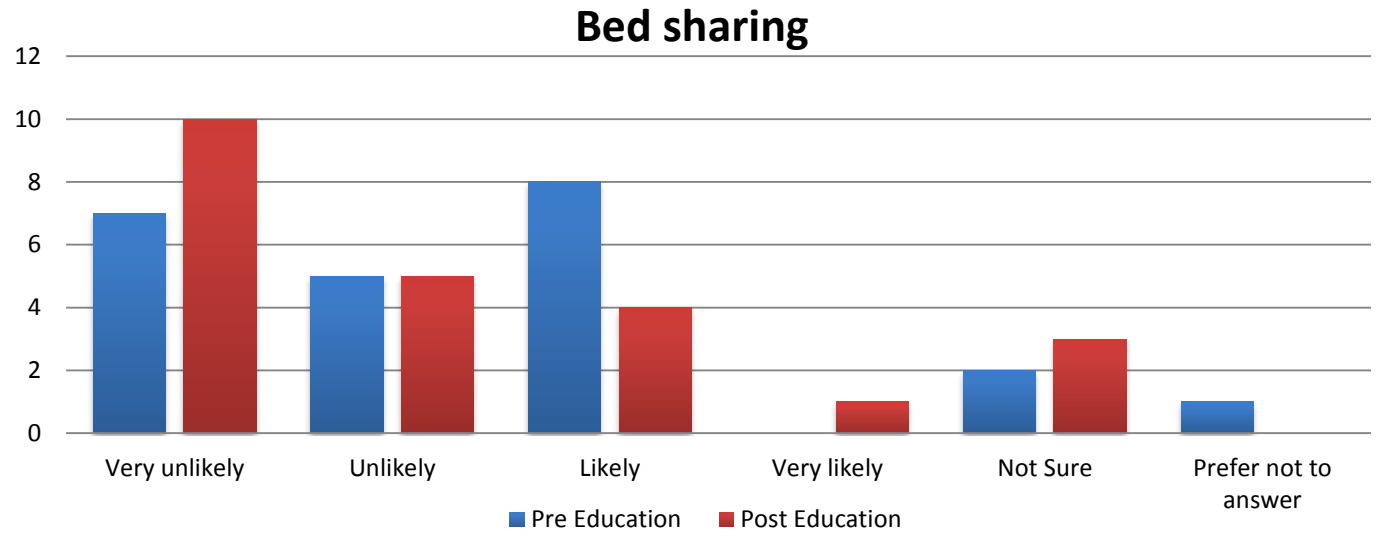
Ongoing: Distribution sites at local health centers and social service organizations

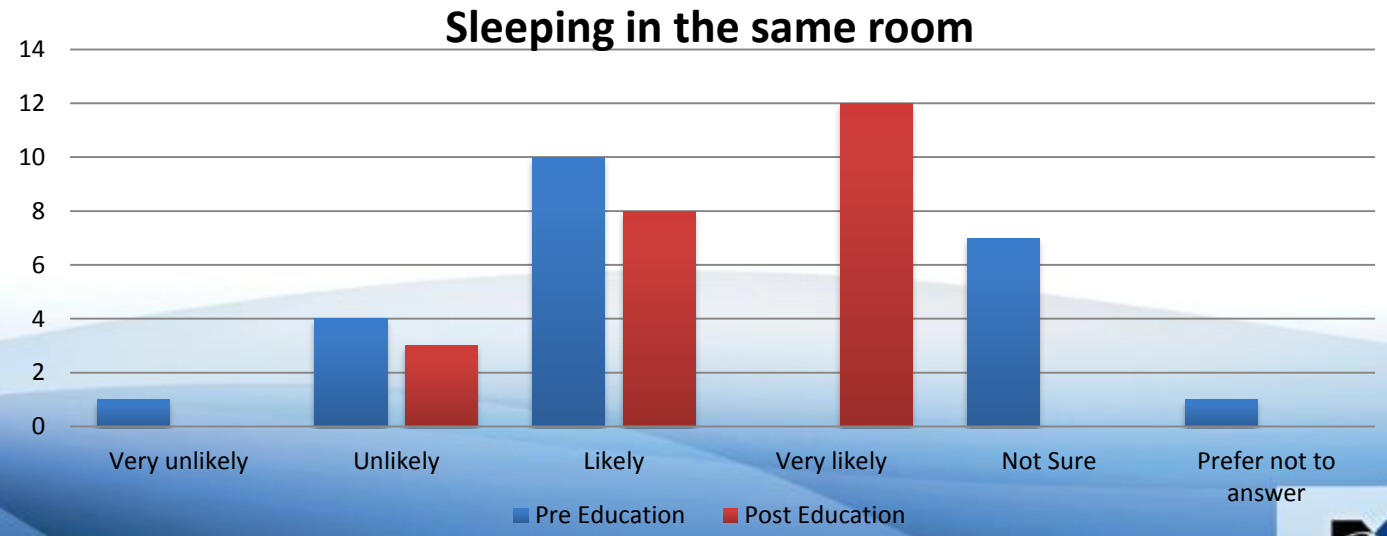
Formal distribution days held in June 2018, September 2018, and November 2018

Participation To-Date

- 38+ baby box recipients of diverse backgrounds
  - Race/ethnicity: White/non-Hispanic, Hispanic/Latino, Black, Asian/Pacific Islander, Inuit
  - Primary language: English, Arabic, Twi, Vietnamese, Spanish, Swahili
  - Education: some high school, high school graduate, some college, college graduate

Preliminary Data to September 2018 (N=23)





Growth and Sustainability[6,7]

- Translation of videos and educational materials to other local languages
- Establish relationships with more local health centers and social service organizations for distribution
- Massachusetts Senate approved budget amendment No. 507
  - Creates pilot program under DPH to provide free safe-sleep receptacles to new parents or guardians
  - Goal of legislation: bring expecting mothers closer with healthcare community to improve prenatal and postnatal care
- Apply for additional grant funding for ongoing support

Discussion/Conclusions

- Distribution of educational materials and baby boxes and student mentorship will be an ongoing effort
- The overarching goal of the Worcester Baby Box initiative is to engage with the community to further understand the disparities
- Contact worcesterbabybox@gmail.com if you're interested in serving on our subcommittee, or hosting a distribution day

References

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Questions

Thank you to Sara Shields, Cathy Violette, Heather-Lyn Haley, Emily Nuss, Eden Hen, Paul Rizzo, Ellie Meyer, Joanna Glanz, Vanessa Villamarin, Anne Covino, Amie Richard, and Karina Wallace for your contributions

Mapping Infant Mortality in Worcester: Updated Geocoding Results from the Worcester Healthy Baby Collaborative

March 20, 2019

Heather Alker MD MPH

Preventive Medicine Core Faculty, Umass Medical School Department of Family Medicine and Community Health

Thank you to Edward Peluso, Fin Mooney and Dr Yelena Ogneva-Himmelberger Clark University.

Disclaimer: Data from WHBC is considered Preliminary and for internal use only.

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Infant Mortality

- Primary causes:
  - Congenital anomalies, preterm birth and low birth weight, Sudden Infant Death Syndrome (SIDS), maternal pregnancy complications, and injuries. (CDC)
- Definition:
- **Stillbirth:** fetal death at 20 weeks or later OR 350+ gm.

VERSUS

- **Infant Death:** Death of an infant born with any sign of life. (~20+wks)

Neonatal 0-28 days

Post-neonatal 28 days- 1year

•Infant Mortality Rate reflects not only the infant and maternal health, but also the overall health of the community and state[1]

•This is because it has many social and behavioral factors

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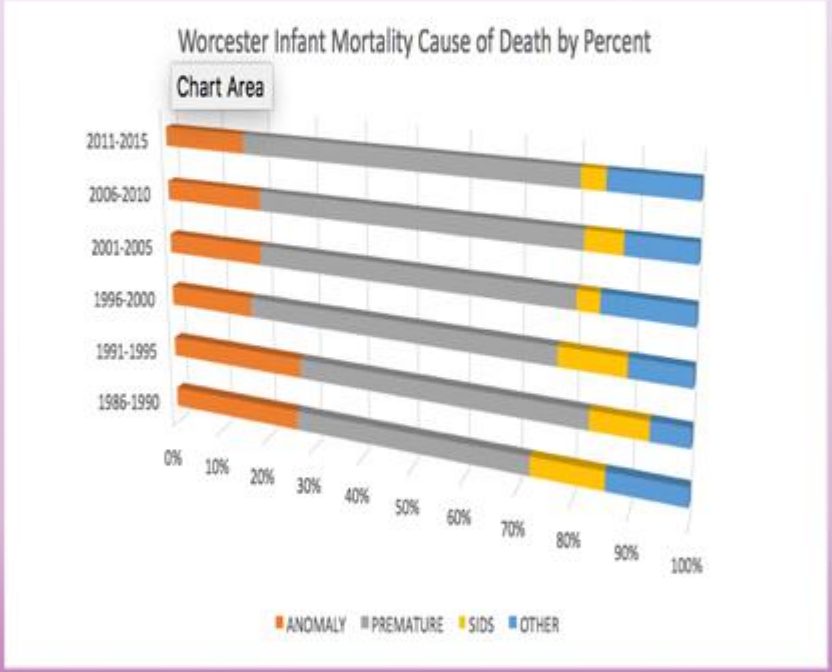
Cause of Infant Deaths in Worcester



YEAR	ANOMALY	PREMATURE	SIDS	OTHER	Total Deaths
1986-1990	26.70%	45.80%	13.30%	14.20%	120
1991-1995	27.60%	55.20%	10.30%	6.90%	116
1996-2000	17.40%	59.80%	12%	10.90%	92
2001-2005	19.80%	60.40%	4%	15.80%	101
2006-2010	19.80%	61.50%	6.60%	12.10%	91
2011-2015	16.70%	63.90%	4.20%	15.30%	72

GIS Mapping 1987-1997 Data

Mark Hayward Clark University

Figure 2. Infant deaths by Census Block location and select one-mile buffers

Figure 3. Population density map for the city of Worcester and infant death locations

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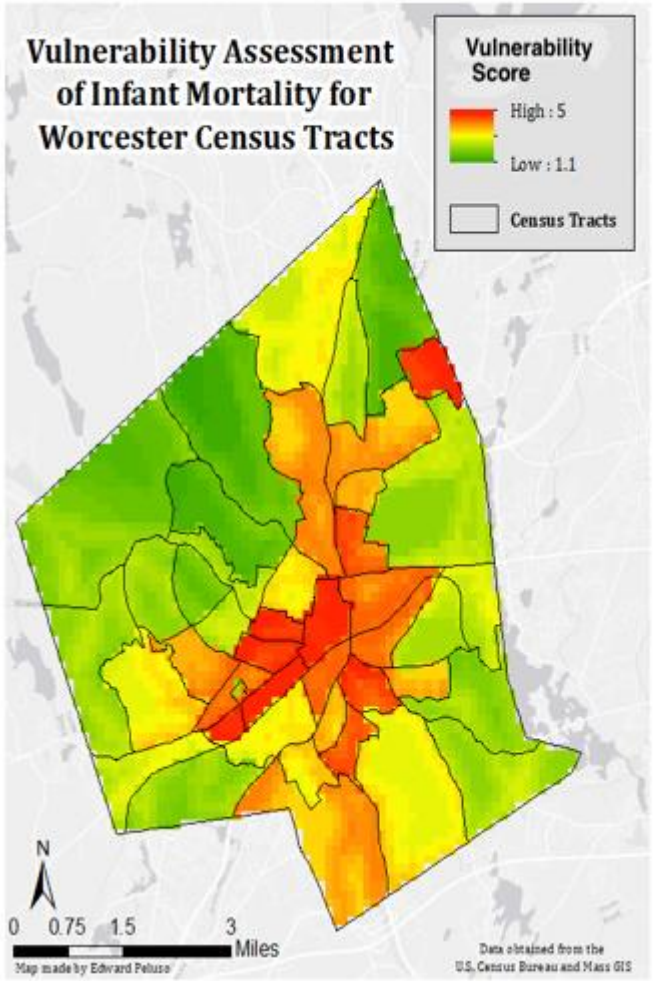
Research Objectives

- Determine the risk of infant mortality by **Census Tract** with vulnerability assessment.
- Map Infant Deaths in Worcester
- Statistically Compare Infant Deaths with the number of infant births in each Census Tract.
- Determine hotspots/areas of statistically significant clustering



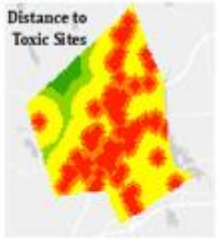
The Infant Mortality Vulnerability Score is based on a multi-criteria evaluation, combining census data on poverty rate, hispanic & black populations, distance to highways, and distance to sites of disposal of hazardous material. A score of 4-5 indicates high vulnerability, whereas a score of 1-2 indicates low vulnerability.

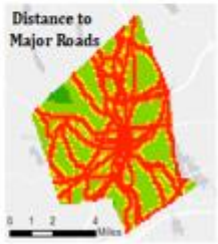
These values were determined by reclassifying data from the 2017 American Community Survey, and from Mass GIS.

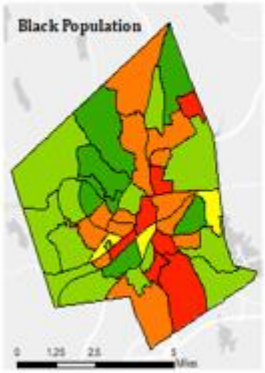
For poverty rates, a score of 4-5 was assigned to census tracts with a poverty rate of over 25%.

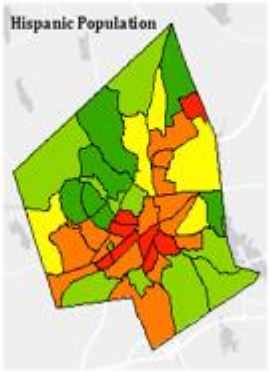
For Hispanic and Black populations, a score of 4-5 was assigned to census tracts with a population rate of over 15%.

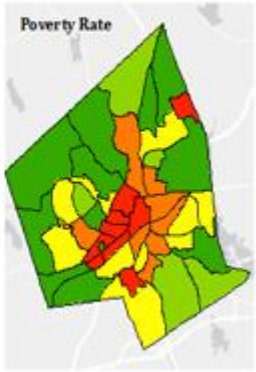
For distances to highways and sites of disposal of hazardous material, a score of 4-5 was assigned areas within 1000 ft of proximity.



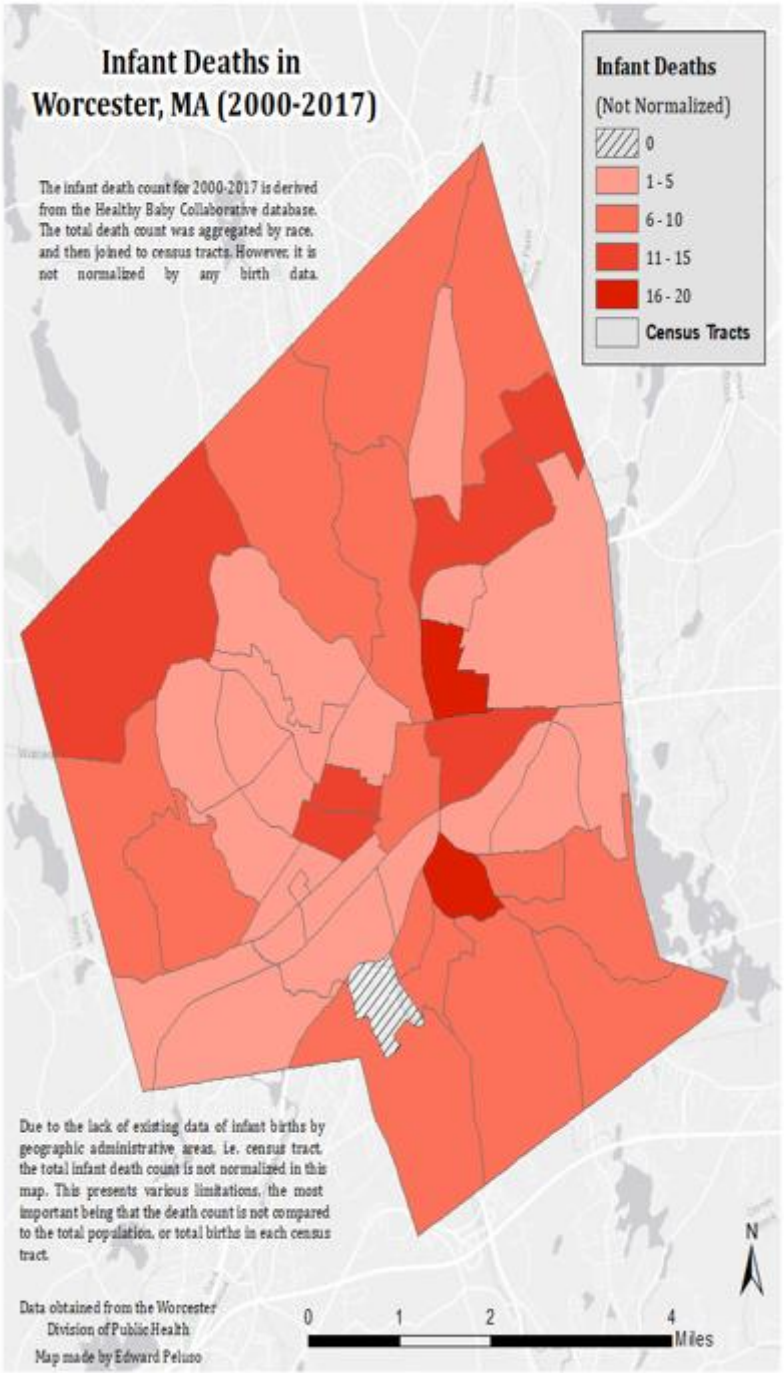








Vulnerability Assessment



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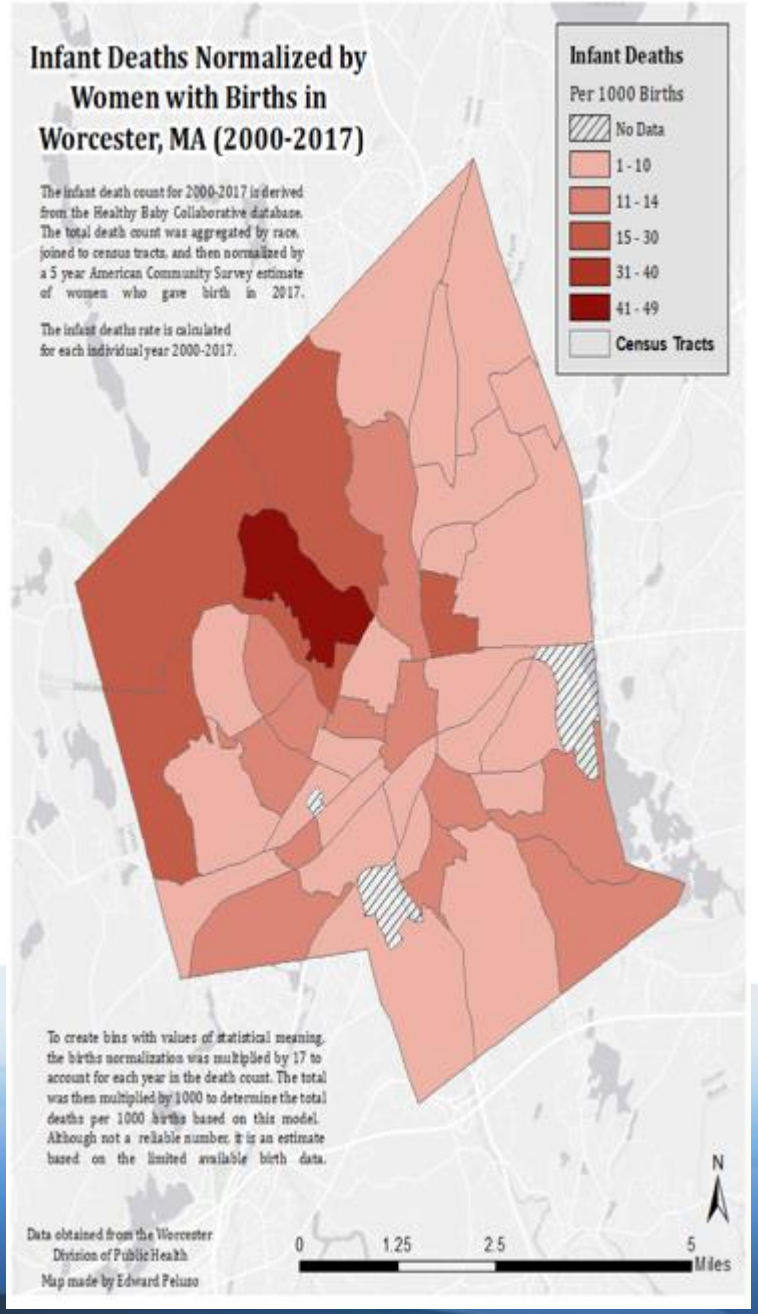

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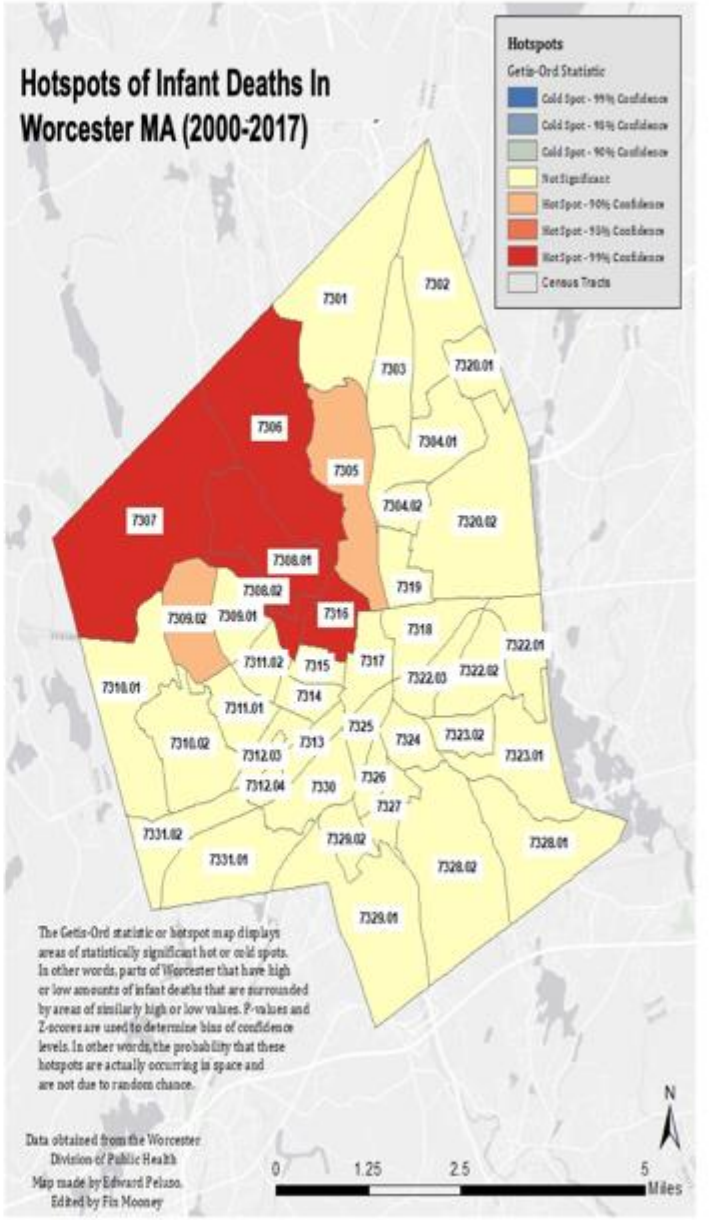
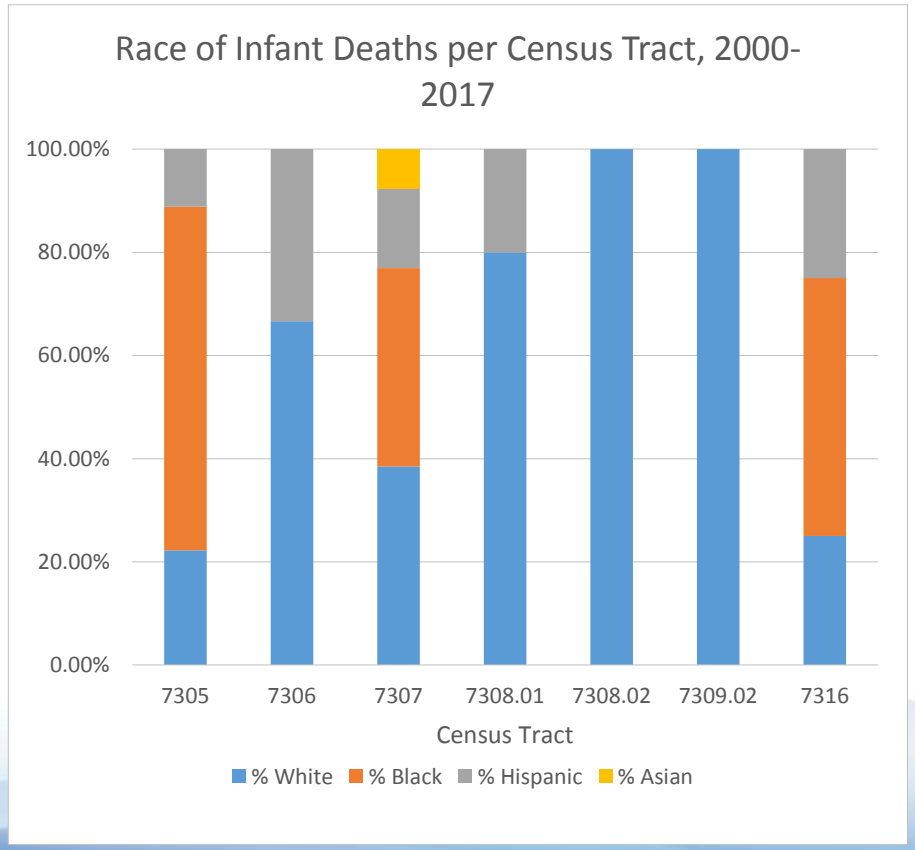
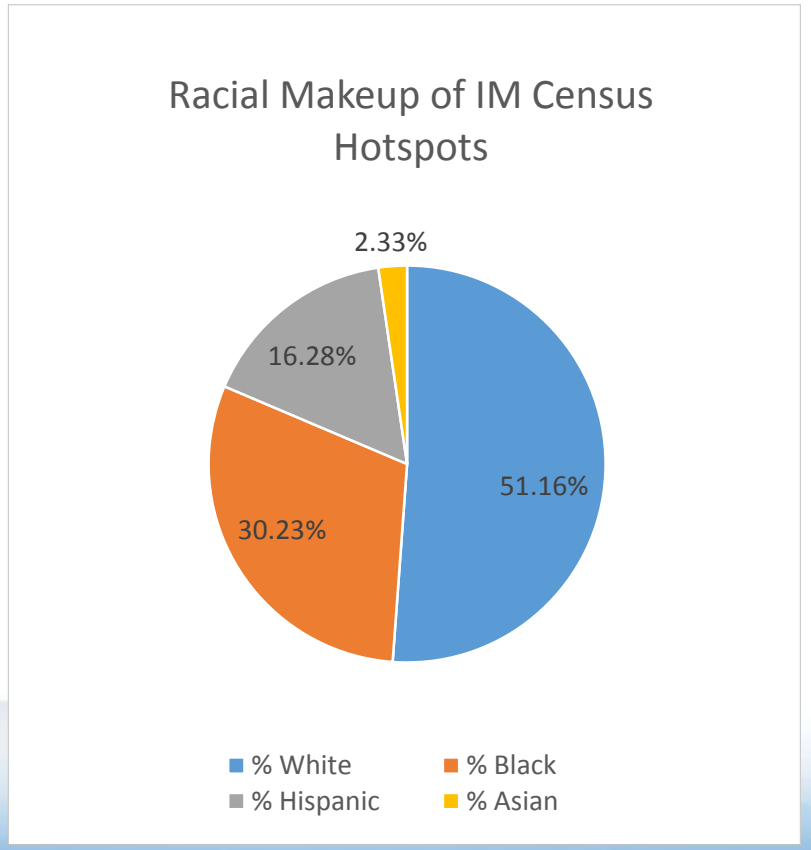
Hotspots[4]

Census Tract	Encompassing/Surrounding Neighborhood
7308.01	Salisbury Street
7308.02	Newton Square
7306	Forest Grove
7307	Salisbury Street
7316	Newton Square/Piedmont
7305	Indian Lake East
7309.02	Newton Square/Beaver Brook

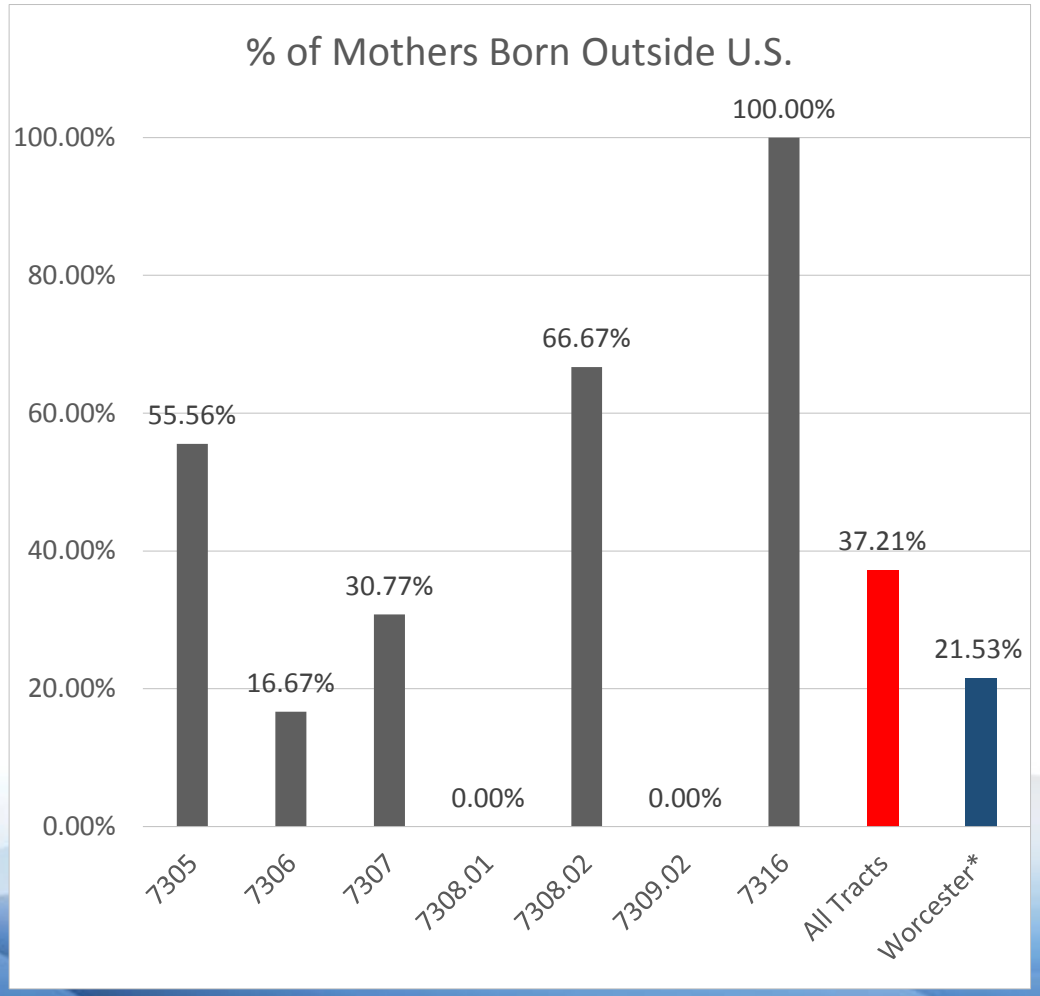


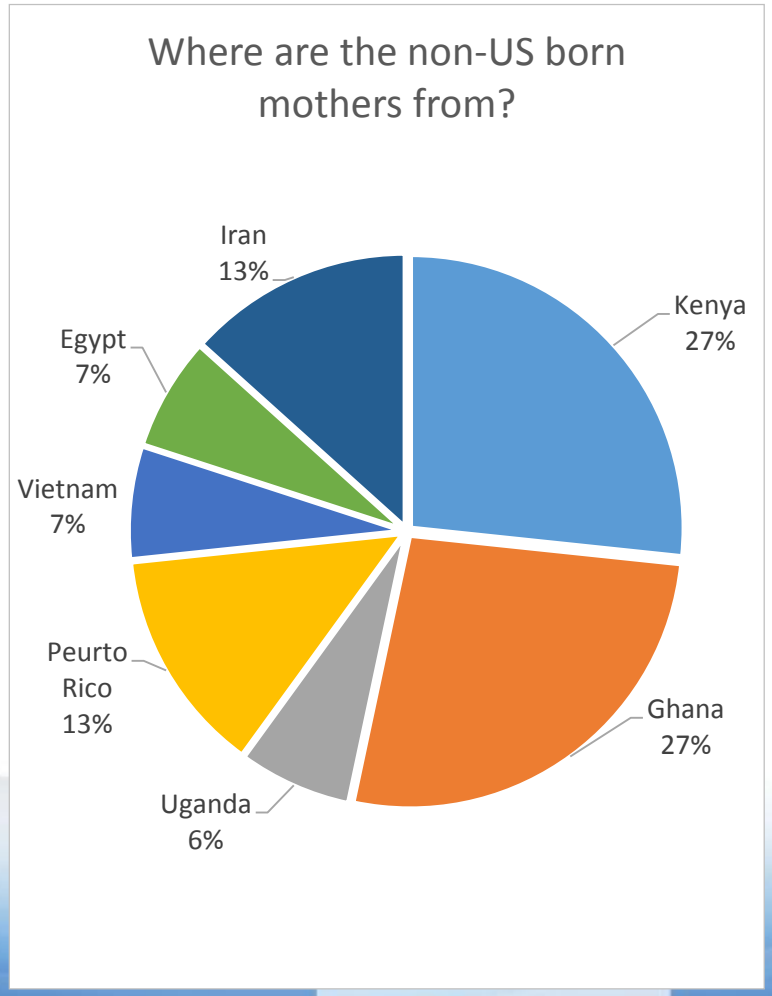
Inside the Hotspots: Race





Inside the Hotspots: Born Outside US





*data from ACS 5-year estimate (2012-2016)

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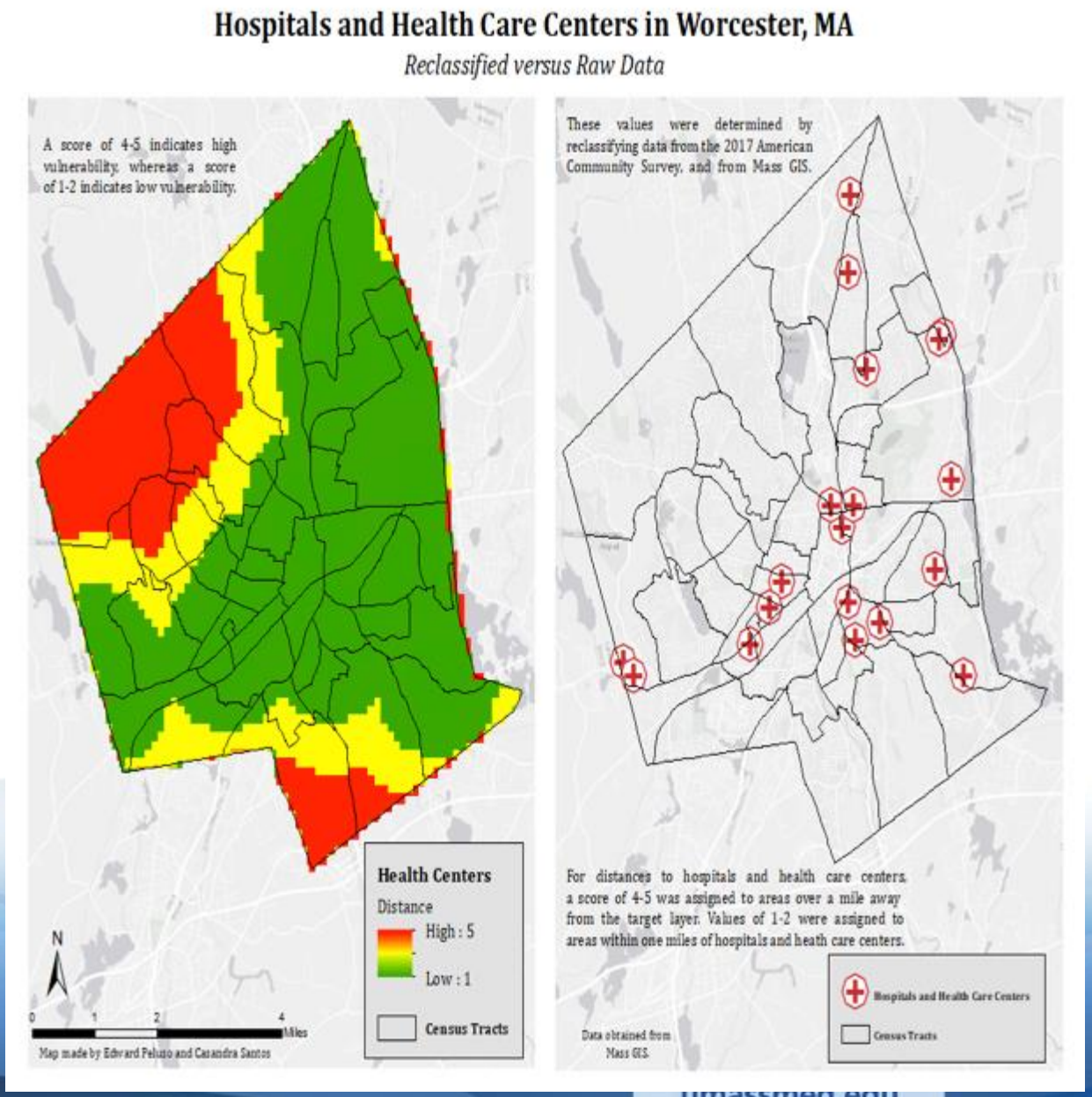
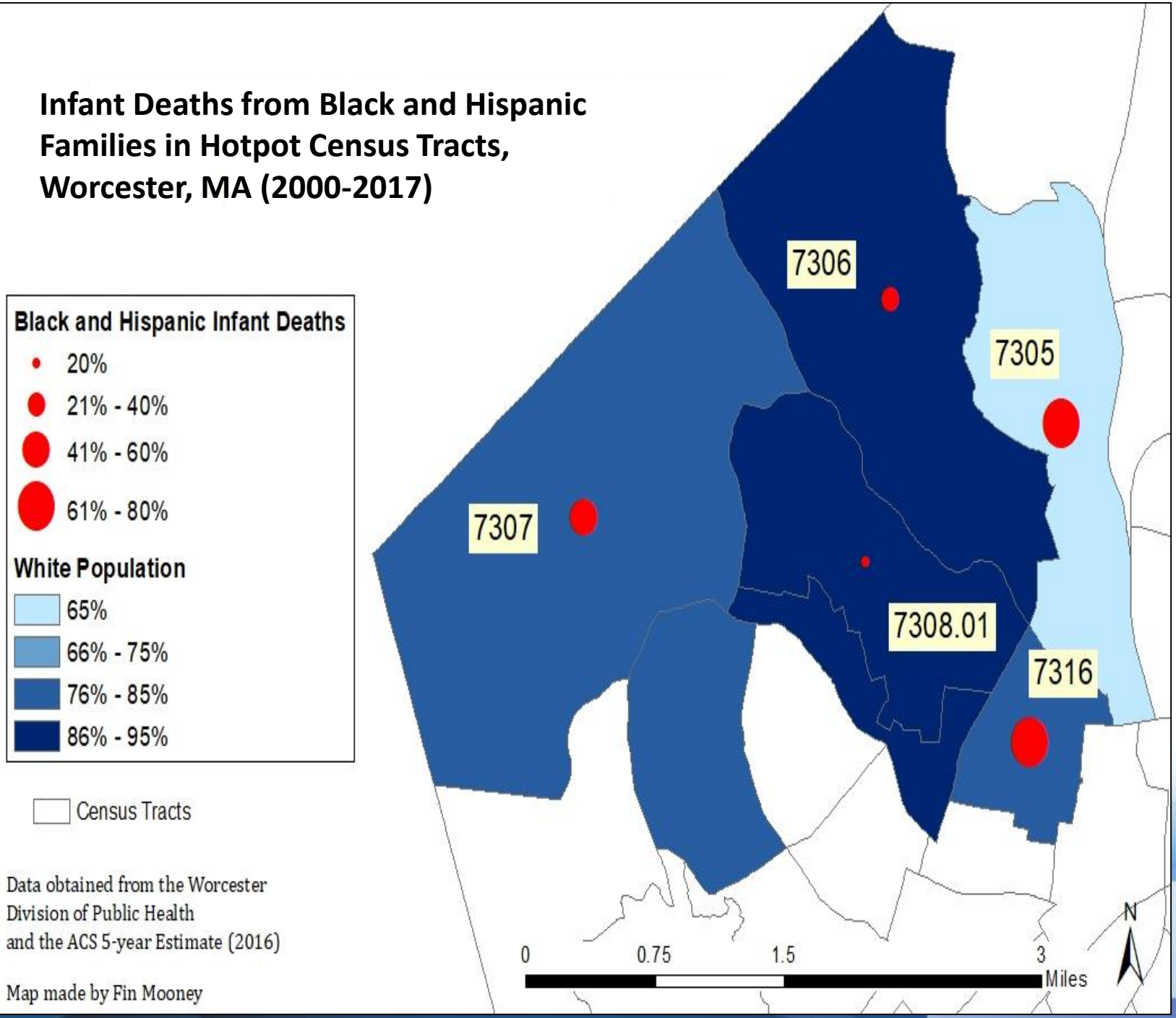
Inside the Hotspots: Accessibility

Prenatal Visits During Pregnancy

	Hotspots	Neutral/Coldspots
Avg. # Prenatal Visits:	**6.08**	**7.25**



Infant Deaths from Black and Hispanic Families in Hotpot Census Tracts, Worcester, MA (2000-2017)



Data obtained from the Worcester Division of Public Health and the ACS 5-year Estimate (2016)

Map made by Fin Mooney

Inside the Hotspots:

Infant Deaths Compared to Size of Black and Hispanic Populations in Hotspot Census Tracts

Census Tract	% of Black Infant Deaths	% of Population Black	% of Hispanic Infant Deaths	% of Population Hispanic
7305	66.7%	21.1%	11.1%	13.6%
7306	0.0%	8.8%	33.3%	5.5%
7307	38.5%	12.6%	15.4%	11.3%
7308.01	0.0%	3.2%	20.0%	3.6%
7308.02	0.0%	4.8%	0.0%	9.8%
7309.02	0.0%	13.5%	0.0%	4.4%
7316	50.0%	12.7%	25.0%	7.6%

Conclusions

- Hotspot census tracts:
  - Relatively unpopulated/rural part of the city.
  - Away from hospitals and health clinics.
- High percentage of infant deaths from Black and Hispanic families in mostly white areas--why?
  - ?living away from Black and Hispanic communities.
  - This agrees with the Ohio (2017) paper
  - Immigrant families also over represented (Moms born outside US)
- We need qualitative data!
  - Interviews with affected mothers and families
    - Do they feel isolated or unable to access health care and doctors?

Future Research

- What hospitals/health clinics are these mothers visiting?
  - Are the hospitals/clinics welcoming for ethnic and racial minorities? Is transportation an issue?
- Do women feel safe at home, do they feel isolated?
- What do the mothers believe is the reason for their infant's death?
- Where are the Latino, Black and Immigrant families concentrated within the census tracts?
- Where are Preterm Births concentrated?

- WHBC Strategic Planning goals include a "deeper dive" through a further look at the data for infant mortality and the drivers of infant mortality.

Limitations

- Not completely sure that Black and Hispanic families have higher infant mortality rates in these census tracts because of “isolation”
  - ❑ Unable to calculate each racial group's IMR per census tract.
  - ❑ Working with **small numbers**
  - ❑ Birth attendant might have recorded a fetal death as an infant death, and vice versa.
  - ❑ Data from chart review is subjective eg. The mothers were recorded as either having “inadequate”, “adequate”, or “sufficient” care during pregnancy by a researcher/doctor.

Take away…

1. Qualitative and quantitative analyses should run alongside each other
2. The state government data is processed slowly.
   - Late release of birth reports, not making census tract data available, inefficient and unreliable practices of recording health data.
3. Infant mortality in Worcester has significantly decreased!
   - We’re doing something right

References

1. Chen, Alice, Emily Oster, and Heidi Williams (2016). “Why Is Infant Mortality Higher in the United States Than in Europe?” *American Economic Journal. Economic Policy* 8.2: 89–124.
2. “Infant Mortality.” Worcester Healthy Baby Collaborative, 21 June 2018, www.worcesterhealthybaby.org/what-is-infant-mortality.
3. Santos, Casandra, and Edward Peluso. “A Vulnerability Assessment of Infant Mortality in Worcester, MA.” PowerPoint Presentation. 30 Apr. 2018
4. Fin Mooney. “Infant Mortality in Worcester: Where is it concentrated?” Worcester DPH. August 8, 2018.
5. Infant Mortality Research Partnership. “Reducing Infant Mortality in Ohio: Individuals, Communities, Systems, and Interventions.” Ohio Colleges of Medicine Government Resource Center, June 2017.

Questions?

A Baby's Health
Is A City's Wealth

– Dr. Leonard Morse, former Commissioner of Public Health, Worcester

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