



# DATA AND RESEARCH TO ACTION WORKGROUP

SACIM June 17-18, 2020 Meeting

**DRAW** Workgroup Report + Breakout Summation

SACIM Member - Magda Peck ScD, Co-Lead



# DATA AND RESEARCH TO ACTION (DRAW)

- **INITIAL CORE SACIM PARTICIPANTS:** Jeanne Conroy, Janelle Palacios, Danielle Ely, Cheryl Broussard, Magda Peck, Ed Ehlinger
- **DEVELOPED ORGANIZATIONAL “PRAXIS”**
- **IDENTIFIED ISSUES, GAPS, AND OPPORTUNITIES IN DATA AND RESEARCH SPECIFIC TO COVID-19 PANDEMIC**

# DATA AND RESEARCH TO ACTION (DRAW)

Initiated in 2020, the *Data and Research to Action Workgroup* serves to assure that SACIM's ongoing deliberations and decision-making for producing strategic policy recommendations for preventing maternal and infant mortality and promoting health equity, are based on available evidence and science that are credible and reliable, timely and relevant.

# **DRAW Consultation 1:** Specific to COVID-19

- 1. How (well) are existing and emerging data systems and sources informing us about women and infants' health risks and outcomes before, during, between and beyond pregnancy, amidst this pandemic?*
- 2. What major gaps and/or deficiencies in maternal and infant health data and surveillance systems have been exposed and/or exacerbated by the pandemic - including amplified racial disparities?*
- 3. How can data and surveillance from related sectors help us examine the impact of health care and underlying socio-economic forces on maternal and infant health outcomes during the pandemic...and recovery?*
- 4. What changes should we recommend now for strategic improvements?*

# **DRAW Consultation 2:**

## **For Preventing Maternal and Infant Mortality Overall**

**A. *What are the major gaps and/or deficiencies in data, surveillance and research methods, capacity-building, and/or systems that SACIM should address*** with potential recommendations for improvements, in the next 6 – 12 months?

**B. *What new or emerging quantitative and/or qualitative data and research\*\* should be elevated to inform the work of SACIM, in the next 6 – 12 months?*** (\*\*related to maternal, fetal and infant morbidity and mortality, from public health, health care *and* related economic and social policy sectors, e.g. housing, food security, child care, economic development, justice, education, business).

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## Breakout Group 2 @ SACIM - June 17, 2020

- **10+ PARTICIPANTS:** SACIM: \*Jeanne Conroy, \*Paul Wise, \*Magda Peck; Danielle Ely, Cheryl Broussard, Wanda Barfield, Maria Carlos; **GUESTS:** Carol Gilbert, Kate Lewandowski, Ellen Tilden; **STAFF:** Ada Determan
- **AGENDA:** Consultation specific to COVID-19 and beyond: *generate robust ideas, input, recommendations*

## DATA ISSUES AND OPPORTUNITIES

# Put Foundations and Frameworks, First

1. Stay grounded by **health equity**, committed to anti-racism
2. Set SACIM's **framework(s)**: consider human rights, reproductive justice, birth equity, pregnancy well-being
3. Be informed by, and learn from, (**MCH) history** - especially after national crises; seize opportunities for innovation (e.g. Zika), and *transformative systems change*
4. SACIM may help '**bridge**' **maternal/women's health and infant/child health** through data, for unified advocacy voice
5. Foster strategic **cross-sector** collaboration and trans-disciplinary research, essential to address upstream SDOH; *maternal and infant mortality may not be at center*

# **GAPS, LIMITATIONS** IN PERINATAL DATA SYSTEMS, ...*exacerbated* by COVID-19 pandemic

- **LOW CAPACITY.** Under-resourced and overstretched conditions + limited capacity to generate timely birth, hospital, other data, to inform maternal/infant morbidity, mortality
- **INCOMPLETE.** Missing on race, ethnicity, age, gender, pregnancy status, and more
- **NOT UNIFORM.** No unique identifiers to link data across systems, sectors; not universal
- **HARD SOURCES.** Reliance on facilities/institutional data: billing vs patient care information
- **TIMELINESS.** Slow (though improving) 'wheels' of governmental data

# **GAPS, LIMITATIONS** IN PERINATAL-RELATED DATA SYSTEMS, exacerbated by COVID-19 (2)

- Unmeasured, unavailable, uneven **data on Racism**
- Limited Data about **special populations**: e.g. incarcerated, undocumented, IPV risk, housing crowding/insecurity - homeless or shelter-based...
- **Silos, Inter-operability**: unlinked data or systems, across disciplines and sectors: economic, housing, criminal justice, education, food/nutrition;

# *YES, AND...* OPPORTUNITIES FOR **INNOVATION** TO STRENGTHEN DATA SYSTEMS AND CAPACITY

- Learn from, adapt innovative data & **trans-surveillance approaches in prior crises: Zika in PR, Opioids**
- Explore, leverage **Social Media** platforms
- Build on **lessons learned in MMRC's**
- Identify and **augment surveillance** (e.g. PRAMS linkages) and **emerging registries** (PRIORITY – Pregnancy Coronavirus Outcomes, UCSF) systems
- **Better use data we have**; more not always better

*AND, AND...* “Build cross-disciplinary bridges to create a common wisdom.” (P Wise)

- Longstanding, splintered and centrifugal forces at work...
- **Design architecture** to build new interactions with other sectors of greatest concern, actively, with purpose...
- Be thoughtful, creative: Which are data sets, linkages are needed to **tell the story** that is data-based and compelling?

# DRAW: PARTING ADVICE:

***Don't waste a crisis:*** seize uninvited opportunities in Covid-19 to change frameworks and narratives, build bridges, lift up our life course framework and lessons learned about racism from maternal and infant mortality work, strengthen data capacity, foster innovation.

**CLOSING 'PULSE':** momentum, creativity, innovation, interoperability, opportunity, strategy, collective wisdom