Care for Chagas Disease:
the Strong Hearts Project
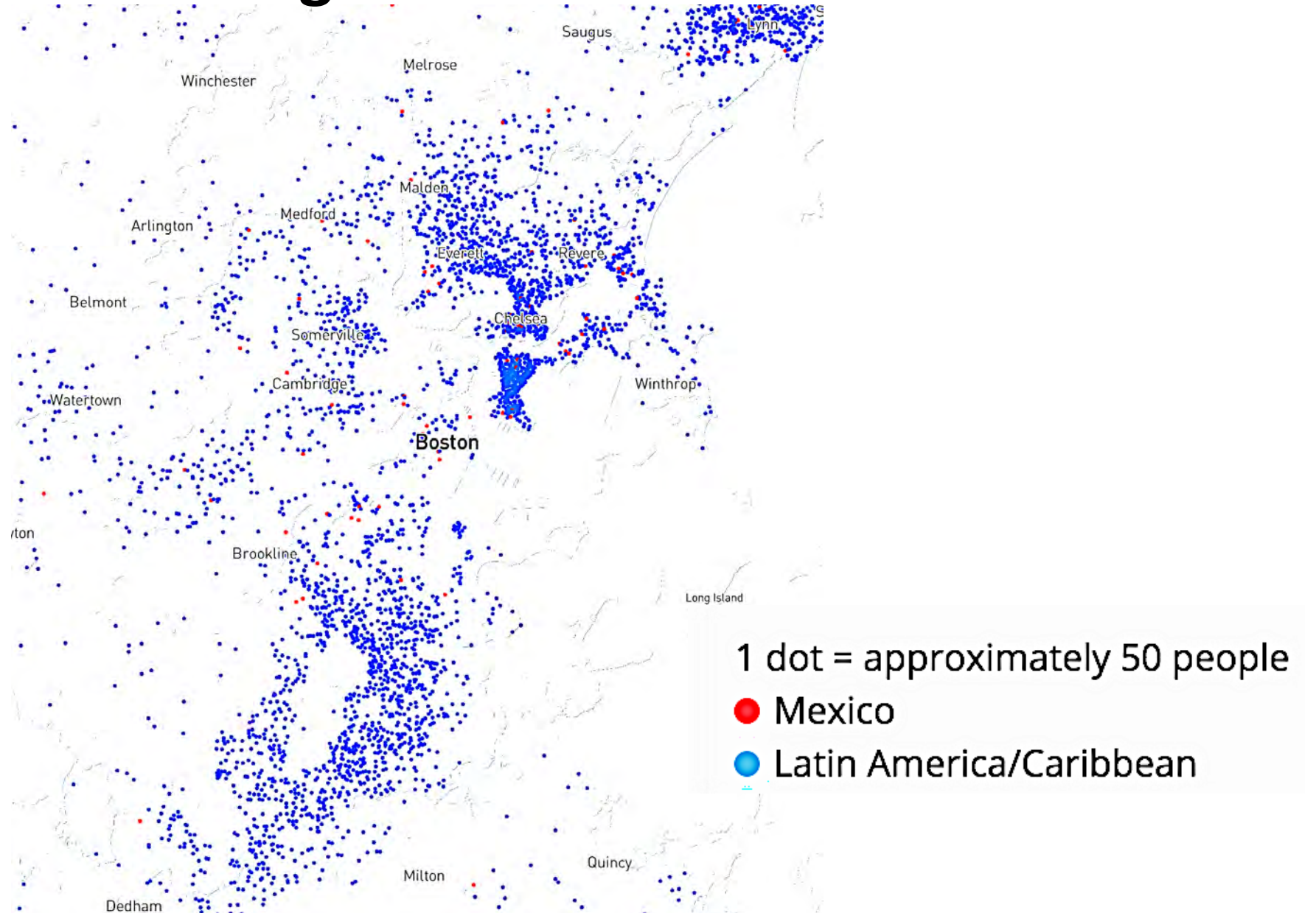

Julia Koehler, MD
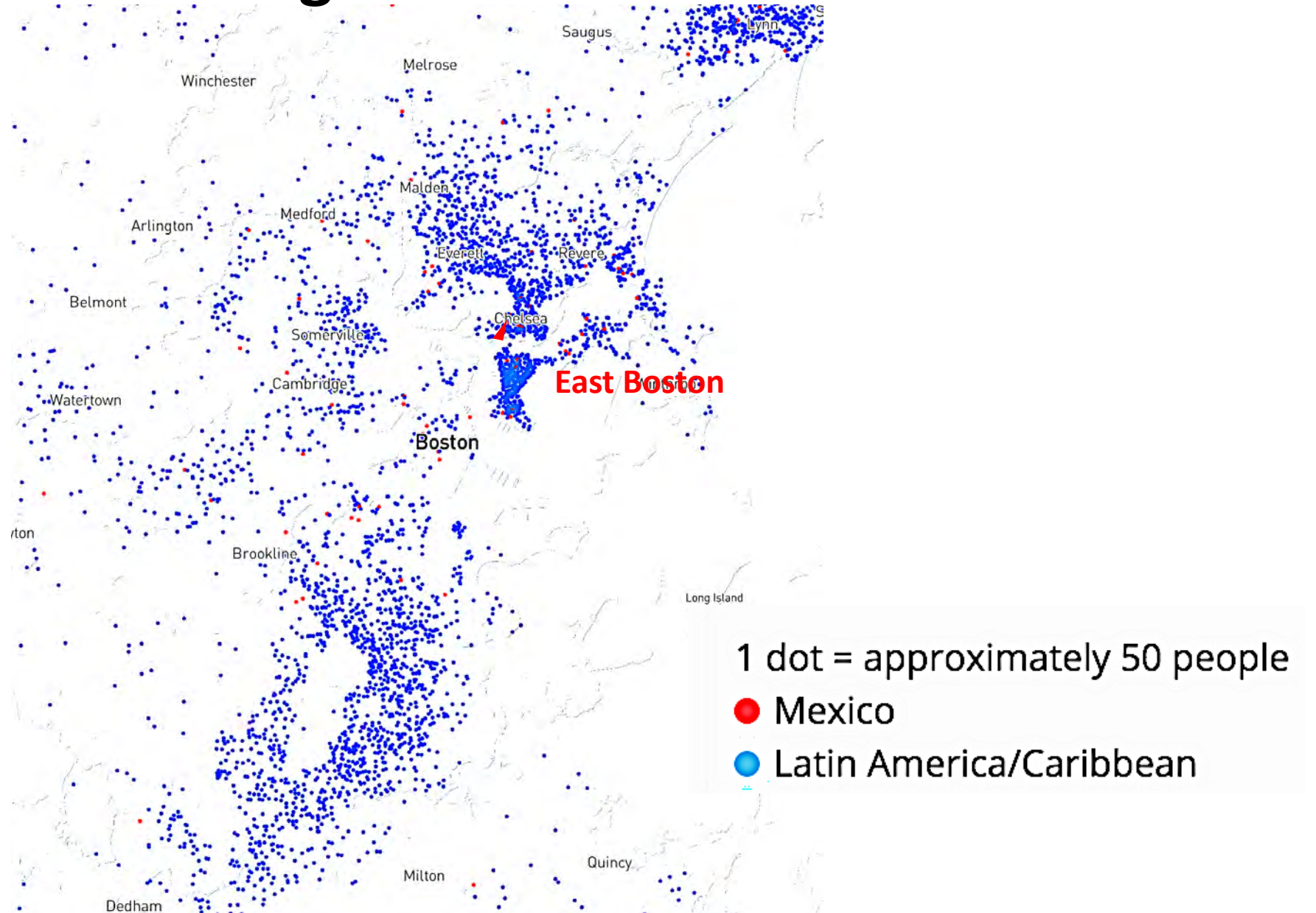**Boston Children's Hospital and Harvard Medical School**
5/19/2021

Latino immigrants in the Boston area

1 dot = approximately 50 people
- 🔴 Mexico
- 🔵 Latin America/Caribbean

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East Boston

East Boston Community- Santisimo Redentor

The Strong Hearts Project

Application to Boston Children's Hospital IRB, August 2016

Specific Aims

1. To increase awareness of Chagas disease among healthcare providers in Massachusetts serving communities at highest risk.

2. To educate affected communities on Chagas disease in order to motivate at-risk individuals to obtain screening and to pursue follow-up.

3. To establish appropriate screening and treatment for Chagas disease for high-risk populations in Massachusetts.

4. To augment available information about the epidemiology of Chagas disease in Massachusetts that may be used to direct policies on screening and treatment, and estimate the success of efforts towards aims 1-3 over time.

The Initial EBNHC Strong Hearts Team: they made the path by walking.

Juan Huanuco, MD

Jill Davis, RN

The Current EBNHC Strong Hearts Team: making the road.

Juan Huanuco, MD   **Jaime Gallegos Salazar, MD**   **Jim Gomes, MSW**

Steps to begin diagnosing:

1. Repeated information sessions in all 4 clinical departments of East Boston Neighborhood Health Center (Jen Manne-Goehler and Julia Koehler).

2. Arrange with on-site laboratory to split serum samples and hold aliquots until screening test returns (Juan Huanuco).

3. Arrange with IT staff to include patients' country of origin in medical record (Juan Huanuco).

4. Generate plan for the screening process and convince the health center Patient Care Committee over 2 meetings and eventually the health center Board (Juan Huanuco and Julia Koehler).

5. Identify ID specialists who would commit to seeing referred Chagas patients in a timely manner (Elizabeth Barnett and Julia Koehler).

Steps to continue diagnosing:

1. Community education in occupational health and ESL classes, community organizations, soup kitchen, churches (Julia Koehler).

2. Follow all positive screening samples and fill out CDC form and order serum sent to CDC (Juan Huanuco, Jill Davis, Jaime Gallegos Salazar).

3. Periodically pull results from health center electronic record system (Jill Davis) for analysis (Jen Manne-Goehler and Jill Davis).

4. Ensure that a care navigator can support patients' ability to attend clinic visits and support them with other needs (Julia Koehler).

5. Care navigation (Katie Collins and Jim Gomes).

Diagnoses through Strong Hearts
3/24/2017 - 4/14/2021

8,879 screening tests sent

82 patients diagnosed

"Nuts and Bolts" of a diagnosing program in a medical facility:

1. Educate clinicians to screen.

2. Provide information of country of origin in medical record.

3. Ensure confirmatory testing: can split the screening sample and save an aliquot, or have patients return. Latter option is easier with Quest using the higher-specificity Wiener ELISA.

4. Establish who monitors results coming from CDC and who refers to specialty care.

5. Care navigation. Ethics of diagnosing if care is not ensured?

Formula for success: (m x r)/b

Clinician Motivation x Resources/Barriers

Motivation:

1. altruism, wish to save lives, opposition to racism and to devaluation of specific human beings.

2. personal advancement e.g. publications, grants, career advancement, name recognition.

Resources:

1. support from institutional leadership.

2. intra-institutional guidelines, until general guidelines are adopted.

3. funding for staff.

Strong Hearts variables in (m x r)/b:

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3. funding for staff: intermittent funding for care navigator.

Food for thought and for investigation:

Clinician Motivation x Resources/Barriers

1. altruism: literature about innate preferences (caring about others) versus external incentives (wishing to be seen as caring) that can synergize to create an effective community consensus. Example: mask wearing.

2. personal advancement: may be effective.

Literature about contrary effect of financial incentives.

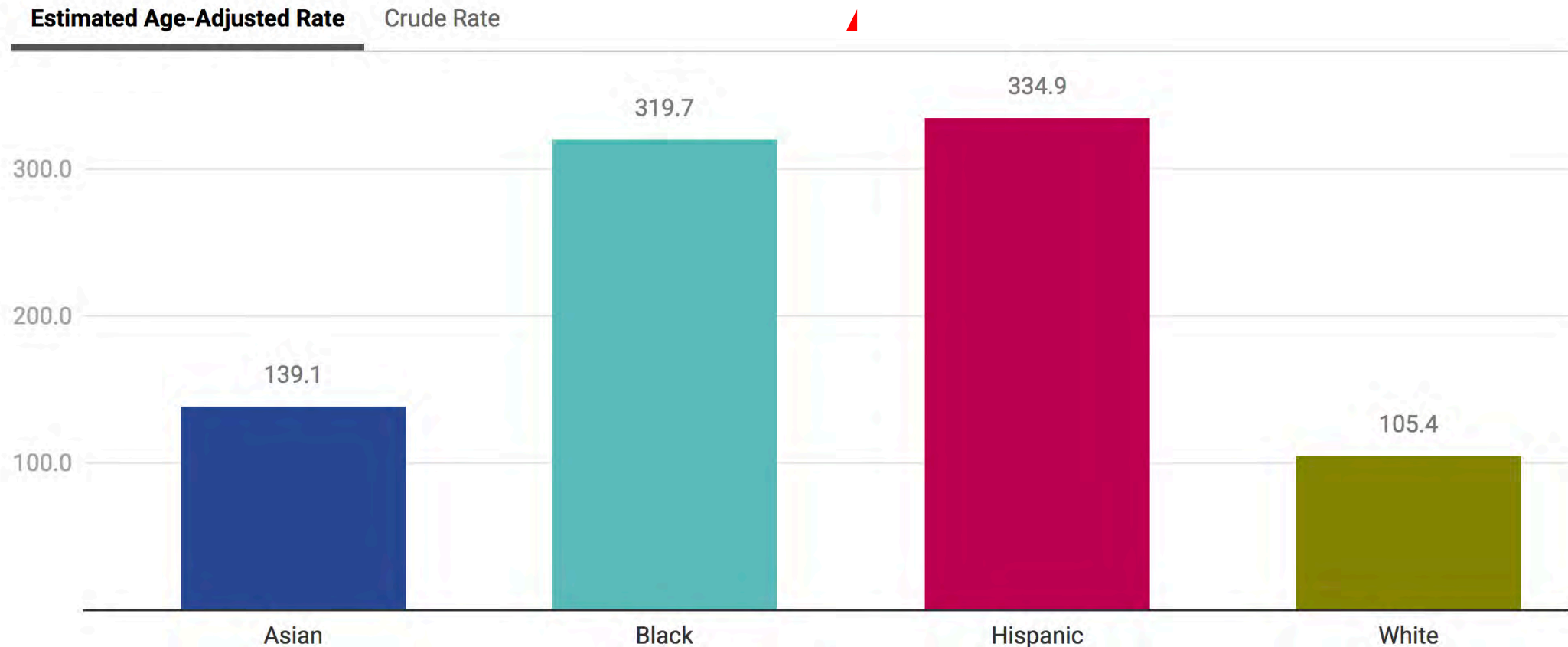# Clinician Motivation x Resources/Barriers

Barriers:

1. burdensome diagnostic procedure.

2. overburdened clinical staff.

3. medical system disinterest e.g.:

- failing referral systems.

- no consideration of language barriers.

- refusal to initiate care without insurance.

4. societal e.g.:

- patients' inability to attend medical appointments during working hours.

- lack of insurance.

- fear of immigration enforcement.

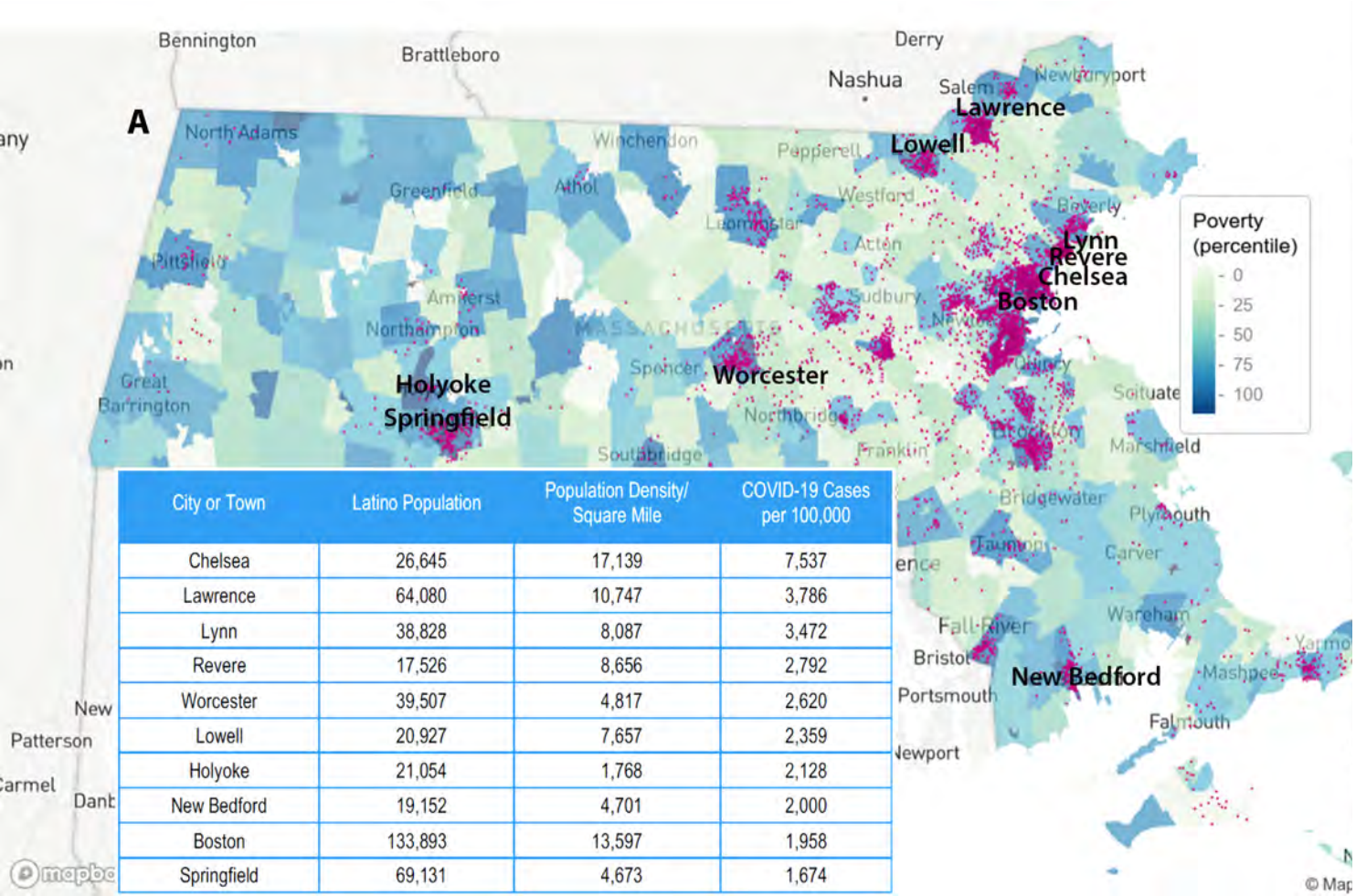- discomfort and fear of mistreatment in medical settings.

Age-adjusted COVID death rates are threefold higher for Latino and Black residents than for white residents of Massachusetts.

Crude versus Age-Adjusted Mortality Rates by Race and Ethnicity per 100,000 people in Massachusetts as of August 11th, 2020
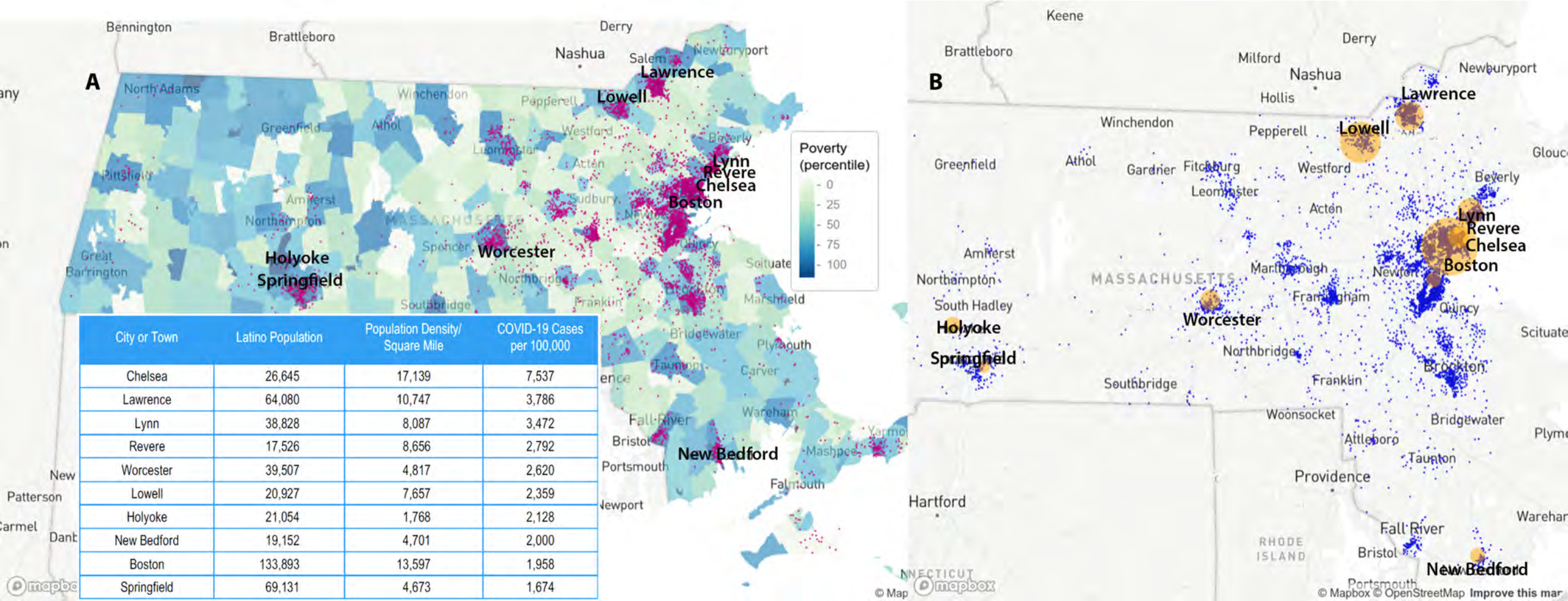
Estimated Age-Adjusted Rate   Crude Rate

Asian	139.1
Black	319.7
Hispanic	334.9
White	105.4

COVID-19 illness and death among those who are paid the least and discriminated the most.

City or Town	Latino Population	Population Density/Square Mile	COVID-19 Cases per 100,000
Chelsea	26,645	17,139	7,537
Lawrence	64,080	10,747	3,786
Lynn	38,828	8,087	3,472
Revere	17,526	8,656	2,792
Worcester	39,507	4,817	2,620
Lowell	20,927	7,657	2,359
Holyoke	21,054	1,768	2,128
New Bedford	19,152	4,701	2,000
Boston	133,893	13,597	1,958
Springfield	69,131	4,673	1,674

Latino immigrant populations, A. poverty and B. COVID-19 hotspots overlap. Each pink dot represents 50 Latino immigrants. Data from August 2020.

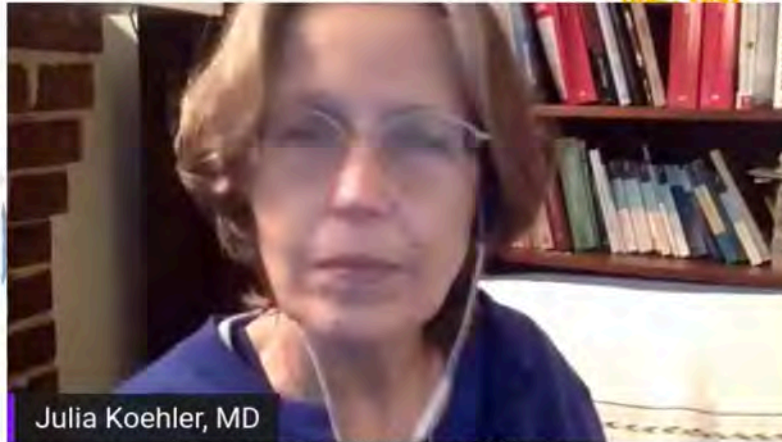# COVID-19 illness and death among those who are paid the least and discriminated the most.

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Latino immigrant populations, A. poverty and B. COVID-19 hotspots overlap. Each dot (A, pink; B, blue) represents 50 Latino immigrants. B. Size of yellow circles represents COVID-19 cases per 100,000 residents of the towns with highest number of COVID-19 cases per population. Data from August 2020.

Information: 100 posters in East Boston & Chelsea (Jim Gomes, Vanessa Pineda). Youtube videos (Vanessa P., Jim G., others). Doorknocking in Chelsea x9 weeks & dozens of information sessions with immigrant organizations over Facebook live with ~30,000 total views (Julia K.).

Concrete support for Chagas disease patients (Jim Gomes):

- Grocery store gift cards for $75, $50 and $50 sent sequentially to the patients.

- Help with food aid sign-up and with applying for rental assistance.

- 40 COVID vaccination appointments made to date for Chagas disease patients.

Coordinator/Navigators: the heart of Strong Hearts.

Katie Collins

Jim Gomes

Thanks to our funders: Mundo Sano, Miami Foundation Secular Humanistic Fund, NIH