National Committee on Vital and Health Statistics April 1, 2021

### Measuring Racial/Ethnic Disparities in COVID-19 in Children and Teens: The Problem of Missing Race/Ethnicity Data

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The COVKID Project

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## The COVKID Project www.covkidproject.org

- Project team
  - Dr. Elizabeth Pathak, WiiSE
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  - Ms. Rebecca Garcia, WiiSE
  - Dr. Jason Salemi, University of South Florida
- Volunteer effort, funded by small donations

### Overview of COVID-19 Data for Kids

### Understanding COVID-19 in Kids

- To understand incidence of disease, we need testing and case data.
- ◆ To understand disease severity, we need hospitalization and intensive care admissions data.
- ◆ To understand disease fatality, we need death certificate data.
- To understand racial and ethnic disparities, we need ALL of these types of data!

### COVID-19 Testing Data by Age

### State COVID-19 Dashboards

 Only 1 state reports C19 testing denominators for racial/ethnic groups by age: Illinois

### No Other Sources of Testing Denominator Data

### COVID-19 Case Data by Age

### State COVID-19 Dashboards

- Only 2 states report C19 case counts for racial ethnic groups by age: CA and IL
- Michigan provides these data in an excel sheet.

## State Case Reporting to CDC

- All states report individual cases with age and race/ ethnicity to CDC.
- For kids, 45% of cases are missing race/ethnicity.

### COVID-19 Hospitalization Data by Age

### State COVID-19 Dashboards

 No states report number of hospitalizations for racial/ethnic groups by age.

### State Case Reporting to CDC

- ◆There is a hospitalization yes/no indicator variable for each case.
- High degree of missingness across all states.

## DHHS COVID-19 Hospitalization File

No race/ ethnicity data reported for any patients.

### COVID-19 Intensive Care Data by Age

### State COVID-19 Dashboards

- Only 2 states report C19 intensive care admissions by age: Minnesota and Wisconsin
- No states report these data by race/ethnicity.

### Virtual Pediatric Systems COVID-19 Dashboard

- Voluntary hospital registry of PICU admissions.
- Race/ethnicity reported for 96% of patients about whom clinical details were provided.
- covid19.myvps.org

### COVID-19 Death Data by Age

## State COVID-19 Dashboards

- Only 2 states report C19 deaths for racial/ethnic groups by age: California and Illinois.
- Michigan provides these data in an excel sheet, but suppressed for kids.

### State Case Reporting to CDC

- ◆There is a death yes/no indicator variable for each case.
- Death counts are HIGHER than reported on state dashboards.

#### NCHS COVID-19 Death Tabulations

- Death counts by race/ethnicity and age are available for kids at the national level.
- State level data are (effectively) suppressed.

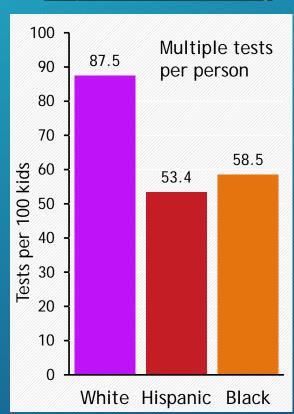
# Results: Illinois Testing Data

## COVID-19 in Kids 0-19 Years in Illinois: Testing, Positivity, Incidence

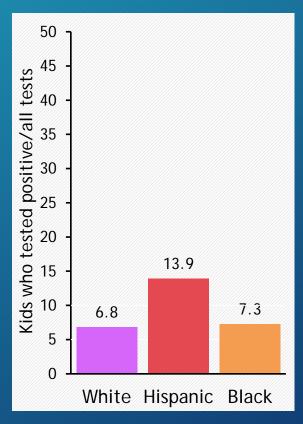
Testing/case data from Illinois COVID-19 dashboard 3/28/2021. Population data for 2019 from CDC WONDER. Race/ethnicity imputed for all missing test and case data.

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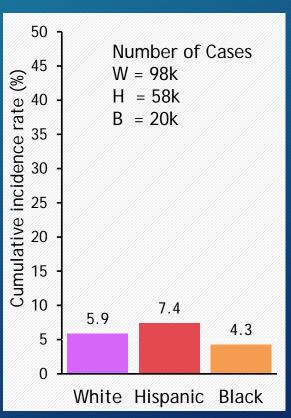
#### Population Testing



#### Test Positivity



#### Population Incidence

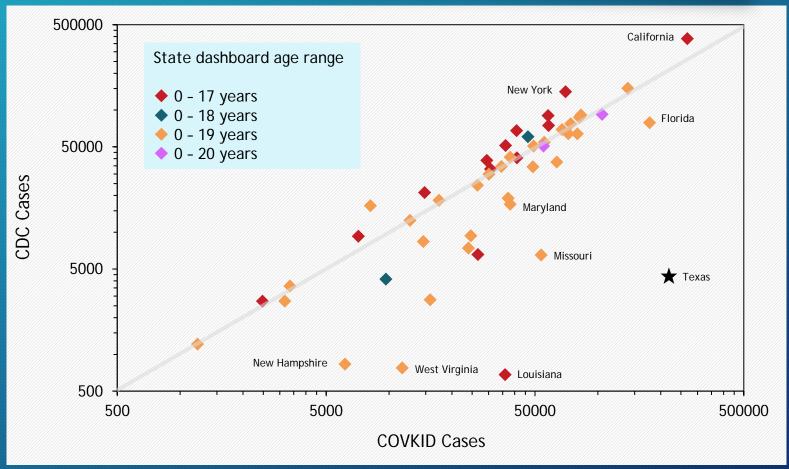


# Results: National Case Data

## CDC vs. COVKID Cumulative COVID-19 Case Counts

- COVKID cumulative case counts extracted on December 31, 2020
- CDC case counts from January 31, 2020 restricted file release, with earliest case date no later than December 31, 2020. Ages 0-19 years for all states.
- COVKID Total = 2,556,187
- CDC Total = 2,286,554

## Discrepancies in Case Counts Between CDC Restricted File and COVKID Tally for 2020



## Best Estimate of COVID-19 Cases in Kids for CY 2020

- COVKID Total = 2,556,187
- CDC Total = 2,286,554
- Best Estimate = 2,893,855 55% of in

55% of increase from CA, NY

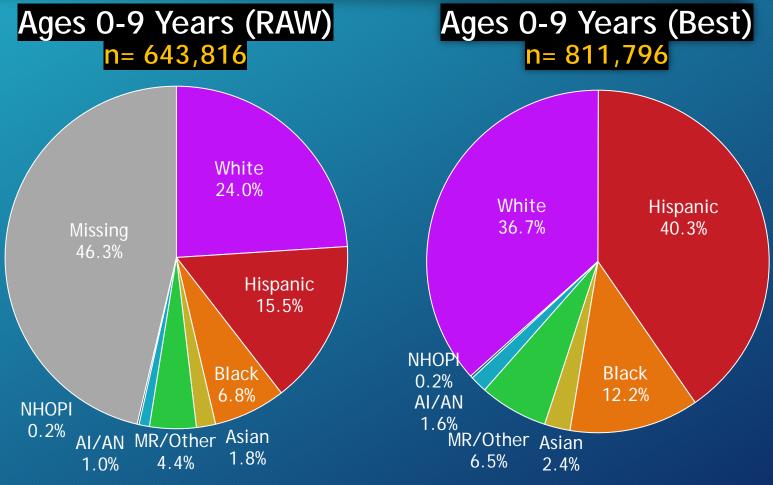
- We used CDC totals for 13 states, and COVKID totals for 38 states.
- We had to use 0-17 year totals for AL, LA, MS, and 0-18 year old totals for RI and WY.

# Method for Imputing Race/Ethnicity I

- GOAL: Impute race/ethnicity for aggregate sums to permit calculation of cumulative incidence rates
- Imputation at the individual case level is NOT recommended (high degree of missingness across all descriptive variables in the dataset)
- "Simple" method: assume the racial/ethnic distribution of the "missing" cases is the same as the "non-missing" cases.

## COVID-19 in Kids 0-9 Years in 2020: Raw vs. Best Estimate Counts

RAW = CDC file. Best Estimate = COVKID/CDC best count with R/E imputation.

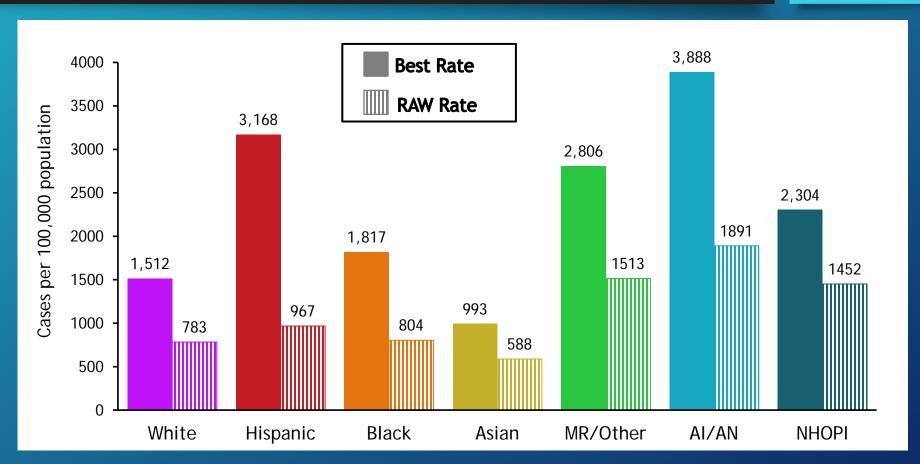


Dr. Elizabeth Pathak, Women's Institute for Independent Social Enquiry, April 1, 2021

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## COVID-19 in Kids 0-9 Years in 2020: Cumulative Incidence Rates (CIR)

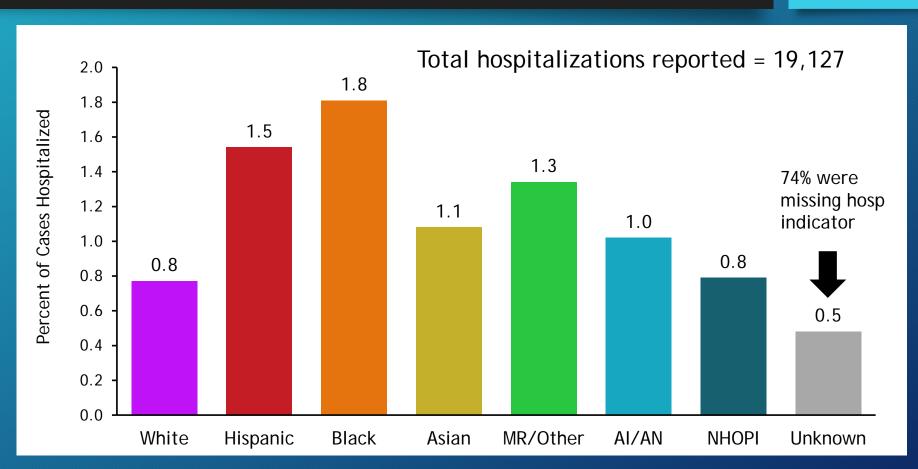
RAW = CDC file. Best Estimate = COVKID/CDC best count with R/E imputation.



# Results: National Hospitalization Data

## COVID-19 Hospitalization Indicator from the CDC Case File, Kids 0-19 Years

January 31. 2021 release. Missing/UNK hosp = 59%. Missing/UNK R/E = 45%.



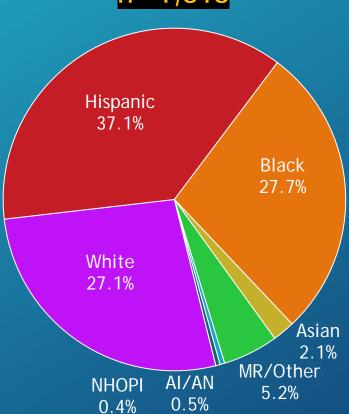
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# Results: National Intensive Care Data

## COVID-19 Intensive Care Admissions for Children 0-17 Years Old

Data extracted from https://covid19.myvps.org on March 28, 2021

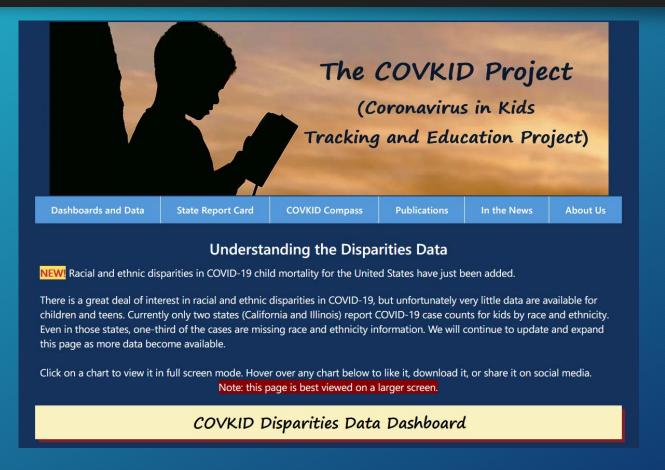




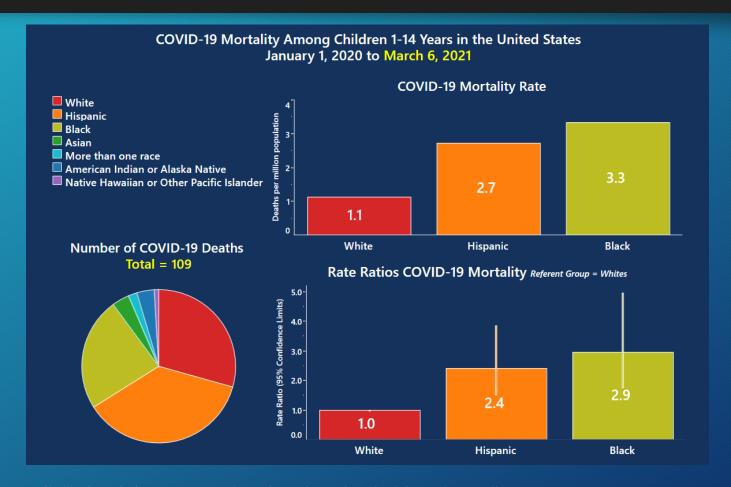
- Voluntary hospital registry with 185 hospitals participating.
- Hospital non-participation rate is unknown!
- 2,772 PICU admissions of US patients aged 0-17 years.
- Detailed clinical data submitted for 1,901 US patients.
- Race/ethnicity available for 96% with clinical data

# Results: National Death Data

# Visit The COVKID Project Disparities Dashboard



### https://www.covkidproject.org/disparities



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### Priorities for all data types

- Race/ethnicity data without age stratification is of very limited utility.
- Missingness of race/ethnicity data needs to be systematically investigated and then actively intervened upon.
  - STILL HAPPENING in 2021!!
- End excessive suppression of data, particularly death counts.

### Priorities for states

- Expand state dashboard reporting for kids
- Use standardized cutpoints and definitions to improve comparability among states.
- Include vaccination, testing, case, hospitalization, and death data.
- Report all data items by race and ethnicity.
- See COVKID Project Report Card for detailed suggestions: https://www.covkidproject.org/state-report-card

### Priorities for hospitals/DHHS

- We need mandatory hospital reporting of all COVID-19 hospitalizations of kids, with demographics, length of stay, and discharge disposition.
- We need expanded clinical registries for all intensive care hospitalizations of kids.
- We need emergency department visit registries.

### Imagine the Possibilities

- The state of Florida releases a COVID-19 case-line data file every single day.
- Data on nearly 2 million cases released to the public - no restrictions!
- Dr. Jason Salemi, epidemiology professor at University of South Florida publishes a daily dashboard with over 75 detailed metrics and visualizations.
- https://covid19florida.mystrikingly.com/

#### 1. Overview of Outcomes Among Cases

Mortality status

Deaths, hospitalizations, and ED visits

#### The only thing missing is race and ethnicity!

Case Dt

3/2/2020

✓ 40-44



Hospitalization

Case classification

# Mortality status Residents selected: All Counties currently selected: All Age groups currently selected: None Total cases % of Total Nu.. NA 1,748,413 98.2% Recent 40 0.0% Yes 32,418 1.8%

### Hospitalization documented?

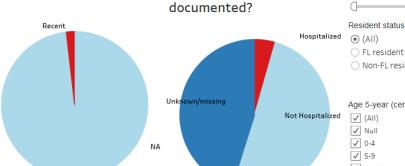
	Tota.	% of To
Not Hospitalized	898,330	50.4%
Unknown/missing	803,729	45.1%
Hospitalized	78,812	4.4%

#### ED visit documented?

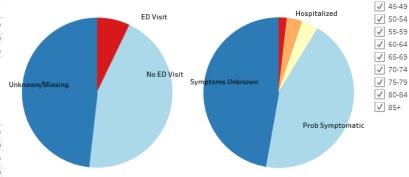
	Total cases =	% of Total Number
Unknown/Missing	858,481	48.2%
No ED Visit	795,406	44.7%
ED Visit	126,984	7.1%

#### Case classification

	Total cas	% of Tot
Died	32,418	1.8%
ED Visit	63,256	3.6%
Hospitalized	59,644	3.3%
Prob Symptomatic	785,146	44.1%
Symptoms Unkno	840,407	47.2%



#### ED visit documented?



#### FL resident ✓ Brevard Non-FL resident ✓ Broward ✓ Calhoun √ Charlotte Age 5-year (census) ✓ Citrus ✓ (AII) ✓ Clay ✓ Null ✓ Collier ✓ 0-4 ✓ Columbia √ 5-9 ✓ Dade ✓ 10-14 ✓ 15-19 ✓ Desoto ✓ 20-24 ✓ Dixie ✓ 25-29 ✓ Duval √ 30-34 √ 35-39



✓ Jefferson

County

✓ (AII)

✓ Alachua

✓ Bradford

✓ Baker

✓ Bay

2/7/2021

### Thank you for your attention!

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# SUPPLEMENT: DATA, METHODS, AND BIAS

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## The COVKID Project www.covkidproject.org

- Coronavirus in Kids Tracking and Education Project
- Public-facing dashboard reporting incidence, hospitalization and mortality data for kids 0-19 years
- Primary data sources:
  - State health departments for case data
  - Virtual Pediatric Systems (myvps.org) for PICU admissions data
  - National Center for Health Statistics (NCHS) for death certificate data

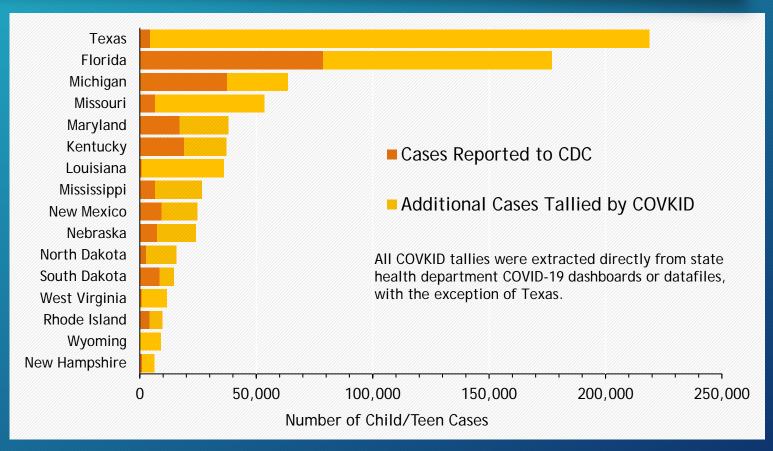
# "Mandatory" COVID-19 Case Reporting to the CDC

- State health departments are required/requested to submit COVID-19 case data to the CDC using a uniform and detailed data reporting form.
- Age, gender, and detailed race/ethnicity categories are requested.
- This is the main data source for all CDC analytic studies and reports of national trends.

### CDC Restricted Access Case File

- CDC makes available a case-level datafile to researchers after application and approval.
- This datafile contains all cases reported to CDC from state health departments.
- Some dates are redacted, and age is aggregated into 10-year ranges.
- The file is updated monthly latest update (Feb 28) contains approximately 20 million case records.

## States for which CDC Case Total is <60% COVKID Tally *(problem states)*



### The Problem with Texas

- Total COVID-19 cases (all ages) reported by Texas on its dashboard 12/31/2020
  - = 1,563,758
- Percent of cases with any demographics reported
  - = 2%
- COVKID Solution: We obtain the age distribution of cases from Harris and Dallas County TX local health department COVID-19 dashboards, and multiply the percent 0-19 by the state total
- Assumes that age distribution of cases for entire state is same as Houston/Dallas area.

# Method for Imputing Race/Ethnicity II

- IMPORTANT: Imputation must happen at the state level - apply state-specific race/ethnicity distributions to the "missing" cases.
- WHY?
- Not all states report all of the available race/ethnicity categories.
- Race/ethnicity of kids varies widely across states, per census.
- Missingness of race/ethnicity varies widely by state.

### Imputation Details

- We used the state-level racial/ethnic (R/E) distribution of all child/teen cases with non-missing R/E, from the CDC case file, to impute R/E for all cases.
- Separate imputation for 0-9 years and 10-19 years.
- Exceptions:
- California we used the state dashboard R/E distribution for cases 0-17 years as recorded by COVKID.
- Delaware and Wyoming we used the state dashboard R/E distribution for all ages
- Louisiana and North Dakota we used the census population R/E distribution for ages 0-19 years, because state dashboard case R/E distributions did not include Hispanics.

# Misclassification for Smaller Ethnic Groups I

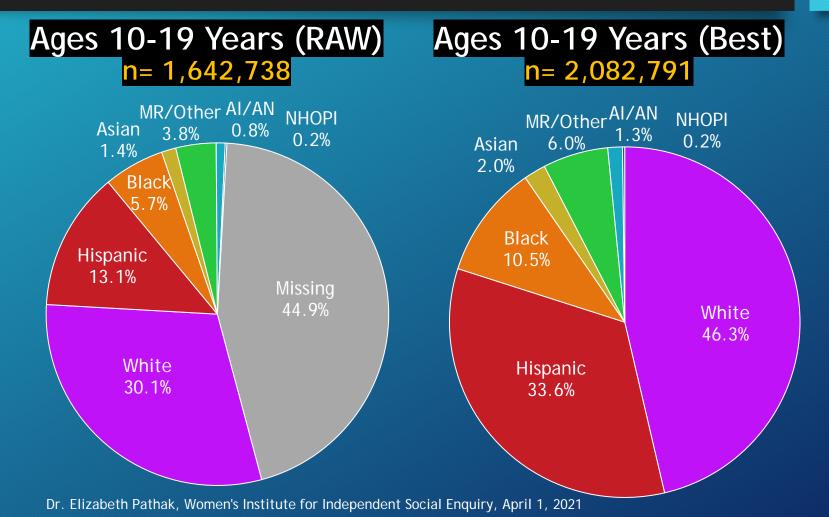
- Some states grouped numerically smaller ethnic groups (i.e. Asians, Native Hawaiians, other Pacific Islanders, American Indians, Alaska Natives) into the "Multi-Race/Other" category.
- Hawaii reported 66% of kid cases were Asian, 7% Hispanic, 2% White, 25% MR/O, and 0% NHOPI.
- Multi-racial children are likely undercounted by the census, which would result in higher rates.

# Misclassification for Smaller Ethnic Groups II

- Misclassification of the AI/AN cases results in a bias of the disparity RR toward the null.
- Missclassification of the Asian cases results in a bias of the disparity RR away from the null.
- Grouping all these groups together for rate calculation solves the misclassification problem, but averages out the differences among these groups.

## COVID-19 in Kids 10-19 Years in 2020: Raw vs. Best Estimate Counts

RAW = CDC file. Best Estimate = COVKID/CDC best count with R/E imputation.



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## COVID-19 in Kids 10-19 Years in 2020: Cumulative Incidence Rates (CIR)

RAW = CDC file. Best Estimate = COVKID/CDC best count with R/E imputation.

