



# Defining an appropriate healthy reference cohort within a network of children's hospital health systems

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## Background

**Goal:** Develop **reusable** and **generalizable** approach to defining a reference cohort in PEDSnet which is representative of the general pediatric population in the US

- General pediatric population in the US is **mostly healthy**; e.g., 86.3% of children in the US aged 5-11 are in excellent or very good health<sup>1</sup>
- PEDSnet<sup>2</sup> is a multi-institutional Learning Health System
  - Aggregates EHR data from 7 large US children's hospital health systems
  - Uses expanded version of OMOP CDM

**Context:** Comparison with general pediatric population for a population-based retrospective cohort study investigating skeletal outcomes in children with rare kidney diseases<sup>3</sup>

## Methods

- Restricted to institutions with **primary care network** (3 institutions)

|                          | Inclusion criteria                                                                                                                                                      | Exclusion criteria                                                                                                                                                                                                                                       |
|--------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| REFERENCE + STUDY COHORT | <b>1. Follow-up ≥ 1 year</b><br><i>Patients with 2 outpatient encounters separated by ≥ 1 year to select for patients regularly seeking medical care within network</i> | <b>2. Most encounters related to outcome under study</b><br><i>Patients with more orthopedic specialty visits than other visit types combined to remove patients who interact with network predominantly for treatment of skeletal outcomes</i>          |
| REFERENCE ONLY           | <b>3. Ongoing primary care</b><br><i>Patients with ≥ 2 general practice clinics visits or provider and ≥ 1 general practice visits every 18 months</i>                  | <b>4. Progressive condition<sup>4</sup></b><br><b>5. Member of cohort(s) under study</b><br><i>Patients with a condition associated with deteriorating health or reduced life expectancy and patients who are members of rare kidney disease cohorts</i> |

### Attrition table

| Criterion | N patients | % patients at 3 institutions with primary care network |
|-----------|------------|--------------------------------------------------------|
| 1         | 1,633,940  | 46.5                                                   |
| 2         | 1,488,443  | 42.4                                                   |
| 3         | 635,001    | 18.1                                                   |
| 4         | 553,912    | 15.8                                                   |
| 5         | 553,694    | 15.8                                                   |

## Results

### 1. Demographics

|                                                   | Healthy reference (%) | US population (%) |
|---------------------------------------------------|-----------------------|-------------------|
| Female                                            | 49                    | 50.8              |
| Male                                              | 51                    | 49.2              |
| White, Not Hispanic or Latino                     | 40.7                  | 50.2              |
| Black or African American, Not Hispanic or Latino | 29.2                  | 13.3              |
| Asian, Not Hispanic or Latino                     | 3.7                   | 4.7               |
| Hispanic or Latino                                | 9.6                   | 25.4              |

\*Race and ethnicity estimates for children aged 0-17 in the US<sup>5</sup>

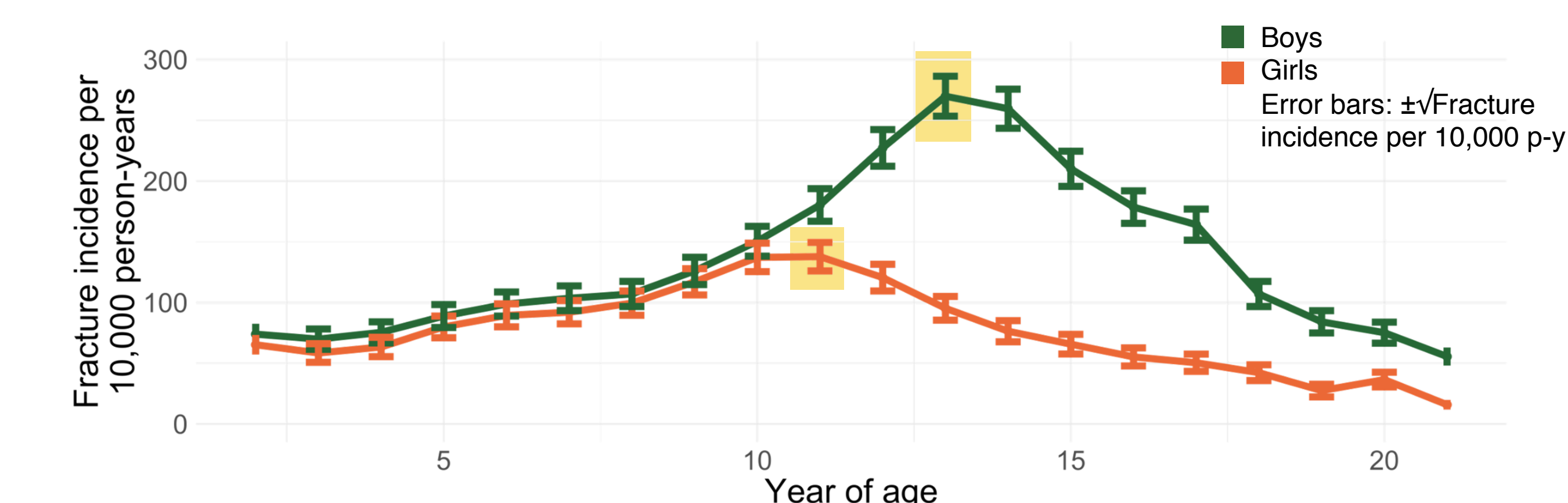
Sex estimates from total US population<sup>6</sup>

Source: 2018 U.S. Census Bureau American Community Survey

### 2. Skeletal outcomes

- Fracture (per 10,000 person-years):

|                | Healthy reference | Cooper et al. 2004 <sup>7</sup> |
|----------------|-------------------|---------------------------------|
| Peak for boys  | 270, age 13       | ≈280, age 14                    |
| Peak for girls | 138, age 11       | ≈160, age 11                    |



- Rare skeletal outcomes (per 10,000 person-years):

- Slipped Capital Femoral Epiphysis: 1.39
- Avascular Necrosis: 0.28

### 3. Most frequent conditions

| Rank | Condition                         | N patients |
|------|-----------------------------------|------------|
| 1    | Well child visit                  | 426,856    |
| 2    | Needs influenza immunization      | 412,487    |
| 3    | Child examination                 | 334,676    |
| 4    | Prevention status                 | 265,671    |
| 5    | Preventive procedure              | 263,602    |
| 6    | Acute pharyngitis                 | 239,543    |
| 7    | Acute upper respiratory infection | 221,779    |
| 8    | Cough                             | 216,435    |
| 9    | Acute suppurative otitis media... | 203,575    |
| 10   | Normal body mass index            | 203,557    |

### 4. Comparisons with CDC-reported rates

|                  | Age group (years) | Healthy reference (%) | 2 outpatient visits ≥ 1 year apart (%) <sup>*</sup> | CDC-reported (%) <sup>†</sup> |
|------------------|-------------------|-----------------------|-----------------------------------------------------|-------------------------------|
| Asthma           | < 18              | 15.4%                 | 10.8%                                               | 7.5%                          |
| Obesity          | 2-5               | 17.3%                 | 14.6%                                               | 13.9%                         |
|                  | 6-11              | 19.3%                 | 17.4%                                               | 18.4%                         |
|                  | 12-19             | 23%                   | 21.6%                                               | 20.6%                         |
| Hospitalizations | < 12              | 9.92%                 | 12.5%                                               | 6.5%                          |
|                  | 12-17             | 3.65%                 | 7.35%                                               | 1.8%                          |

<sup>\*</sup>Step 1 of the healthy reference cohort attrition table

<sup>†</sup>Asthma & Hospitalizations – 2018 National Health Interview Survey<sup>8</sup>

Obesity – Health, United States, 2018 [data 2015-16]<sup>9</sup>

## Discussion

### Strengths

- Fit-for-purpose
- Simple, rule-based approach
- Reusable across comparisons with multiple cohorts
- Generalizable across studies

### Limitations

- Approach to validity exploratory
- Over-representation of urban and suburban areas and geographic gaps
- Patients with some conditions may be more likely to seek primary care, inflating rates
- Does not extend to adult populations

### Future directions

- Apply to studies investigating different outcomes in different cohorts
- Compare with other approaches (including traditional matching)
- Develop assessment of validity
- Network study to assess across children's hospital health systems

• The research reported here was conducted using PEDSnet ([pedsnet.org](https://pedsnet.org)) and includes data from the following PEDSnet institutions: Children's Hospital of Philadelphia; Nationwide Children's Hospital; and Nemours Children's Health.

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• References provided separately.