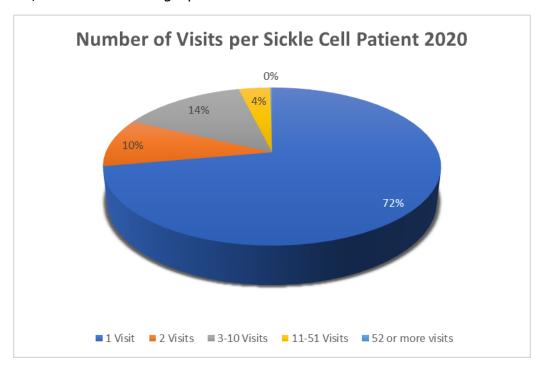
# Sickle Cell Disease in Texas Syndromic Surveillance Systems in 2020 Background

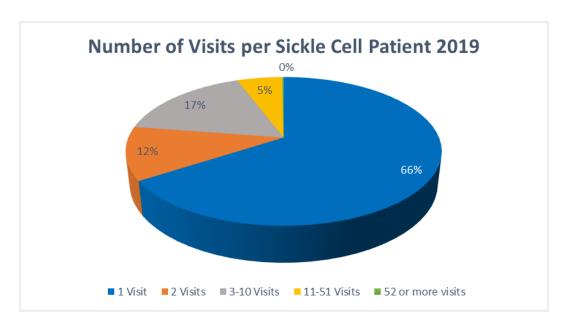
Three syndromic surveillance systems operate in Texas: The North Texas Syndromic Surveillance System (NTXSS) run by Tarrant County Public Health, the Syndromic Surveillance Consortium of Southeast Texas (SSCSeT) run by City of Houston Health Department, and the Texas Syndromic Surveillance System (TxS2) run by the Texas Department of State Health Services (DSHS). Both NTXSS and SSCSeT report data to TxS2. Between these three systems over 80% of hospital Emergency Departments are connected to a syndromic system. Free-standing Emergency Rooms and Urgent Care Clinics can also connect, and between the three types of facilities, over 50% in Texas are connected to a syndromic surveillance system.

#### Sickle Cell Disease in Texas Syndromic Surveillance Systems Overview

In 2020 there were a total of 33,914 visits to Texas facilities that were connected to syndromic surveillance systems for sickle cell disease related issues. In both 2020 and 2019 about 0.2% of all visits in syndromic surveillance in Texas were related to sickle cell disease.

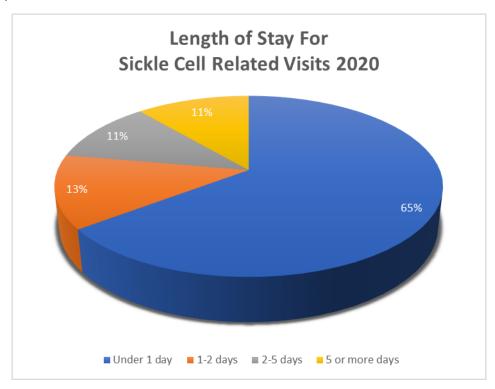
In 2020 there were 13,520 individual patients, including 27.8% who visited facilities multiple times. Patients who visited multiple times accounted for the majority of visits, even though a majority of patients only visited once. This includes 26 individuals who visited an ER or urgent care more than once a week on average, and 489 individuals who visited more than 10 times but less than 52, as shown in the graph below. These are similar numbers to 2019.





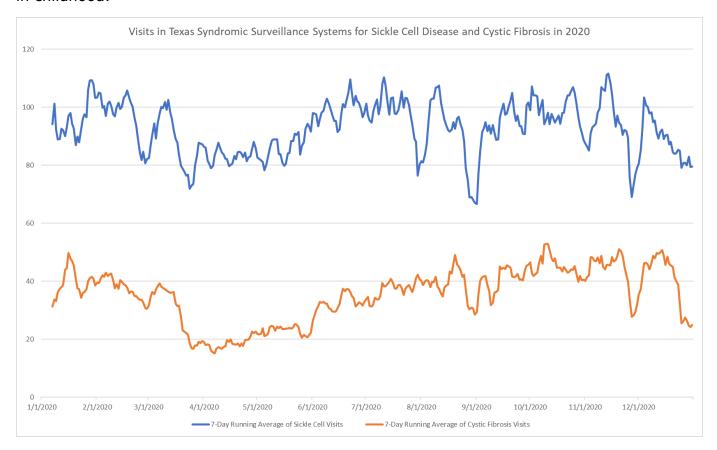
Only 65% of records included transfer information, but of these 23.3% of visits ended in the patient becoming an inpatient at a hospital after their initial observation in the emergency department.

Most visits lasted one day or less, but 35% of visits lasted multiple days, as shown in the graph below. The data quality from 2019 was not enough to confidently create the below data for that year, or to analyze whether it was similar to 2020.



### Sickle Cell Disease Compared to Similar Conditions

Sickle cell disease regularly results in more visits to Texas emergency rooms and urgent care clinics than cystic fibrosis a disease that similarly is genetic in origin and is regularly diagnosed in childhood.



## Demographic Breakdown for Sickle-Cell-Related Visits

| 2020                                      |       |       |       |       |         |         |
|---|-------|-------|-------|-------|---------|---------|
| Ages                                      | 00-04 | 05-17 | 18-44 | 45-64 | 65-1000 | Unknown |
| Race                                      |       |       |       |       |         |         |
| American Indian or Alaska Native          | 7     | 34    | 7     | 6     | 2       | 0       |
| Asian                                     | 101   | 110   | 70    | 22    | 15      | 6       |
| Black or African American                 | 2793  | 6901  | 12811 | 2010  | 324     | 615     |
| Native Hawaiian or Other Pacific Islander | 0     | 2     | 1     | 6     | 1       | 0       |
| Other Race                                | 108   | 73    | 1899  | 184   | 60      | 1       |
| Unknown                                   | 50    | 73    | 1042  | 248   | 36      | 1006    |
| White                                     | 538   | 770   | 1079  | 456   | 428     | 19      |
| Ethnicity                                 |       |       |       |       |         |         |
| Hispanic                                  | 628   | 863   | 1006  | 200   | 111     | 27      |
| Not Hispanic                              | 2906  | 6990  | 12258 | 2210  | 700     | 614     |
| Unknown                                   | 63    | 110   | 3645  | 522   | 55      | 1006    |
| Sex                                       |       |       |       |       |         |         |
| Male                                      | 1970  | 4231  | 7683  | 1508  | 345     | 858     |
| Female                                    | 1627  | 3732  | 9223  | 1424  | 521     | 789     |
| Unknown                                   | 0     | 0     | 3     | 0     | 0       | 0       |

| 2019                                      |       |       |       |       |         |         |
|---|-------|-------|-------|-------|---------|---------|
|   | 00-04 | 05-17 | 18-44 | 45-64 | 65-1000 | Unknown |
| Race                                      |       |       |       |       |         |         |
| American Indian or Alaska Native          | 15    | 34    | 25    | 1     | 0       | 0       |
| Asian                                     | 46    | 92    | 40    | 1     | 1       | 0       |
| Black                                     | 0     | 1     | 153   | 26    | 2       | 0       |
| Black or African American                 | 3579  | 8475  | 11227 | 1474  | 128     | 817     |
| Native Hawaiian or Other Pacific Islander | 1     | 6     | 5     | 1     | 0       | 0       |
| Other                                     | 159   | 135   | 2058  | 191   | 19      | 4       |
| Unknown                                   | 110   | 161   | 1686  | 270   | 29      | 1192    |
| White                                     | 520   | 747   | 422   | 32    | 16      | 26      |
| Ethnicity                                 |       |       |       |       |         |         |
| Hispanic                                  | 675   | 907   | 449   | 18    | 5       | 31      |
| Not Hispanic                              | 3546  | 8470  | 9929  | 1357  | 136     | 816     |
| Unknown                                   | 209   | 274   | 5238  | 621   | 54      | 1192    |
| Sex                                       |       |       |       |       |         |         |
| Male                                      | 2394  | 5227  | 7175  | 983   | 56      | 1008    |
| Female                                    | 2036  | 4423  | 8441  | 1013  | 139     | 1031    |
| Unknown                                   | 0     | 1     | 0     | 0     | 0       | 0       |

### ICD-10 Codes Used in Discharge of Sickle-Cell-Related Visits

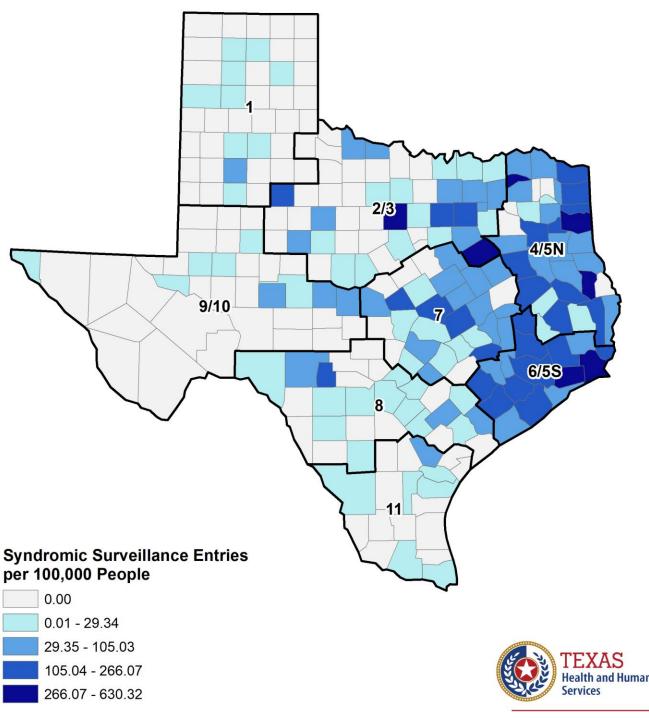
Syndromic surveillance in Texas regularly receives discharge diagnosis codes for 60% of patients. Some patients are never given a discharge diagnosis, but we continue to work to improve our data quality. Below is a summary of what syndromic surveillance did receive, with any ICD-10 codes with zero counts in both years cut out.

| ICD-10 Codes Present in Discharge                                   | # of Visits 2020 | # of Visits 2019 |
|---|------------------|------------------|
| D57.0 Hb-SS disease with crisis                                     | 89               | 151              |
| D57.00 Hb-SS disease with crisis unspecified                        | 397              | 402              |
| D57.01 Hb-SS disease with acute chest syndrome                      | 1521             | 1470             |
| D57.02 Hb-SS disease with splenic sequestration                     | 0                | 4                |
| D57.03 Hb-SS disease with cerebral vascular involvement             | 15               | 0                |
| D57.09 Hb-SS disease with crisis with other specified complication  | 2                | 6                |
| D57.1 Sickle-cell disease without crisis                            | 93               | 1                |
| D57.2 Sickle-cell/Hb-C disease                                      | 479              | 49               |
| D57.20 Sickle-cell/Hb-C disease without crisis                      | 128              | 243              |
| D57.21 Sickle-cell/Hb-C disease with crisis                         | 41               | 235              |
| D57.211 Sickle-cell/Hb-C disease with acute chest syndrome          | 55               | 86               |
| D57.212 Sickle-cell/Hb-C disease with splenic sequestration         | 0                | 5                |
| D57.213 Sickle-cell/Hb-C disease with cerebral vascular involvement | 3                | 6                |
| D57.218 Sickle-cell/Hb-C disease with other specified complication  | 26               | 2                |
| D57.219 Sickle-cell/Hb-C disease unspecified                        | 1                | 1                |
| D57.3 Sickle-cell trait   | 1                | 36               |
| D57.4 Sickle-cell thalassemia                                       | 401              | 2                |

| ICD-10 Codes Present in Discharge  | # of Visits 2020 | # of Visits 2019 |
|--|------------------|------------------|
| D57.40 Sickle-cell thalassemia without crisis                                    | 0                | 6                |
| D57.41 Sickle-cell thalassemia, unspecified, with crisis                         | 54               | 0                |
| D57.411 Sickle-cell thalassemia, unspecified, with acute chest syndrome          | 34               | 380              |
| D57.412 Sickle-cell thalassemia, unspecified, with splenic sequestration         | 1                | 0                |
| D57.413 Sickle-cell thalassemia, unspecified, with cerebral vascular involvement | 0                | 7                |
| D57.418 Sickle-cell thalassemia with other specified complication                | 0                | 7                |
| D57.419 Sickle-cell thalassemia, unspecified, with crisis                        | 0                | 178              |
| D57.433 Sickle-cell thalassemia beta zero with cerebral vascular involvement     | 248              | 66               |
| D57.438 Sickle-cell thalassemia with other specified complication                | 27               | 81               |
| D57.439 Sickle-cell thalassemia unspecified                                      | 16               | 5                |
| D57.44 Sickle-cell thalassemia beta plus without crisis                          | 1                | 0                |
| D57.45 Sickle-cell thalassemia beta plus with crisis                             | 26               | 0                |
| D57.451 Sickle-cell thalassemia beta plus with acute chest syndrome              | 63               | 0                |
| D57.452 Sickle-cell thalassemia beta plus with splenic sequestration             | 10               | 0                |
| D57.458 Sickle-cell thalassemia with other specified complication                | 11               | 0                |
| D57.459 Sickle-cell thalassemia unspecified                                      | 16               | 0                |
| D57.8 Other sickle-cell disorders  | 21               | 0                |
| D57.80 Other sickle-cell disorders without crisis                                | 2                | 274              |

| ICD-10 Codes Present in Discharge                                      | # of Visits 2020 | # of Visits 2019 |  |
|--|------------------|------------------|--|
| D57.81 Other sickle-cell disorders with crisis                         | 8                | 29               |  |
| D57.811 Other sickle-cell disorders with acute chest syndrome          | 11               | 20               |  |
| D57.812 Other sickle-cell disorders with splenic sequestration         | 107              | 0                |  |
| D57.813 Other sickle-cell disorders with cerebral vascular involvement | 1375             | 21               |  |
| D57.819 Other sickle-cell disorders unspecified                        | 7                | 65               |  |

# Visits Related to Sickle Cell Disease in Syndromic Surveillance Systems in 2020 per 100,000 People



Source: Texas Department of State Health Services, June 2021, AKleinert, VTewell



**Texas Department of State Health Services**