

Demographics and Language Needs of Guardians Caring for Patients with Hemoglobinopathies in Nebraska

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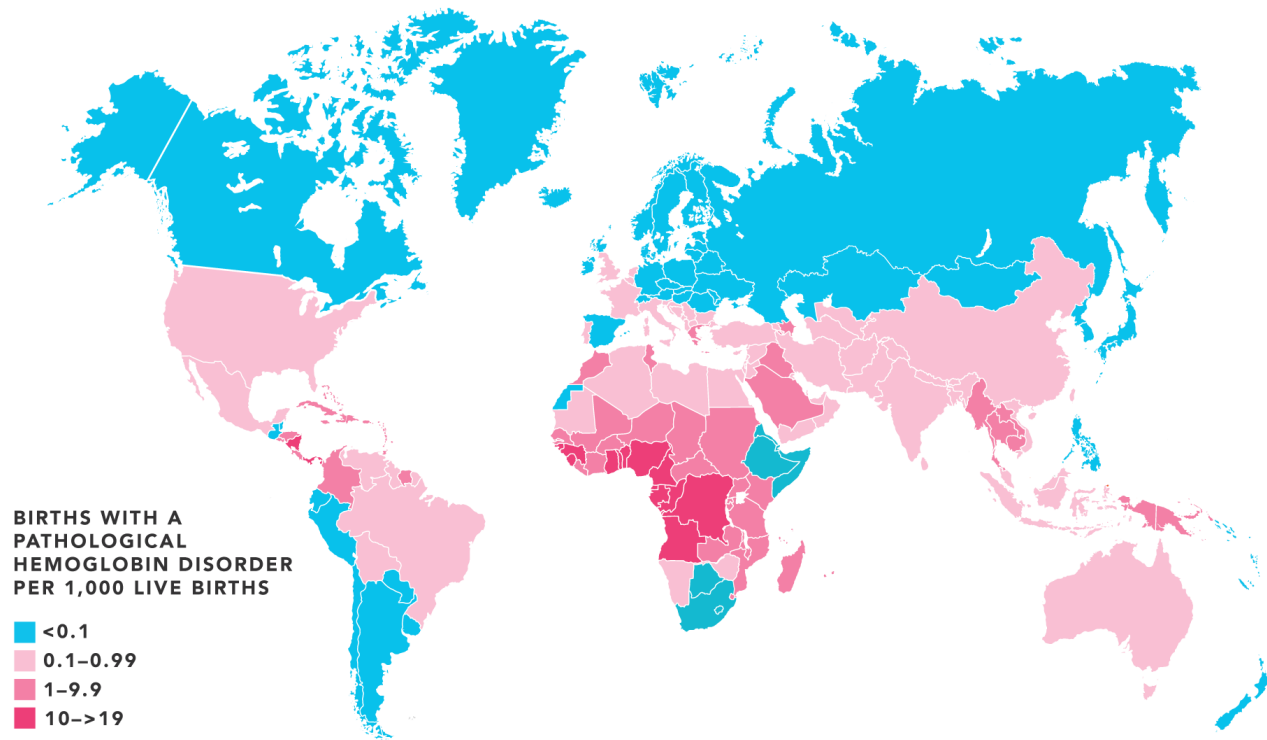


What are hemoglobinopathies?

Hemoglobinopathies are disorders where there is abnormal production or structure of the hemoglobin molecule.¹

- Quantity → thalassemia
- Quality → sickle cell disease; Hemoglobins C, D, E, O, etc.
- Passed down through families, typically in autosomal recessive manner
- Variable clinical course

It is estimated that 7% of the world's population is a carrier for a hemoglobinopathy.



² <https://caringcross.org/scd-bt-cure-project/>

Background

- National surveillance for hemoglobinopathies does not exist in the United States
- Previous attempts to characterize populations with hemoglobinopathies has not included data from Nebraska
- Nebraska population is changing over time
 - NE welcomed the highest number of refugees per capita of any state in 2016
 - In 2018, 1 in 14 Nebraskans were born outside the US

Background

- No national surveillance for hemoglobinopathies
- Hemoglobinopathy registries to date have no NE data
- Nebraska is changing
 - Welcomed the highest per capita rate of refugees in 2016 ^{3,4}
 - In 2018, 1 in 14 NE residents born outside the US ⁵



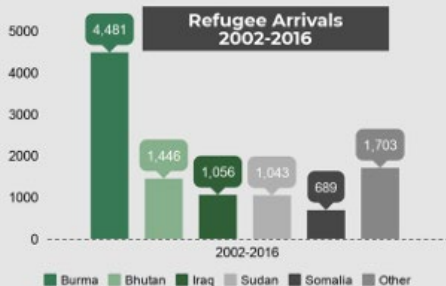
Hemoglobinopathies in NE

Hemoglobinopathies Reported by Nebraska Newborn Screening			
Year	Number of births	Number of hemoglobinopathies identified	Rate per 10,000 births
2012	26283	408	155
2013	26419	394	149
2014	27115	444	164
2015	27120	481	177
2016	27109	451	166
2017	26246	489	186
2018	25900	427	165
2019	25150	465	185
2020	24663	444	180
2021	24882	458	184
2022	24559	496	202

Courtesy of the Nebraska Newborn Screening Program and the
Nebraska Department of Health and Human Services

Top Five Refugee Arrivals in Nebraska

From 2002-2016, Nebraska welcomed **10,418** refugees from **48** countries.



Languages Spoken

Burma (Myanmar): Karen, Burmese

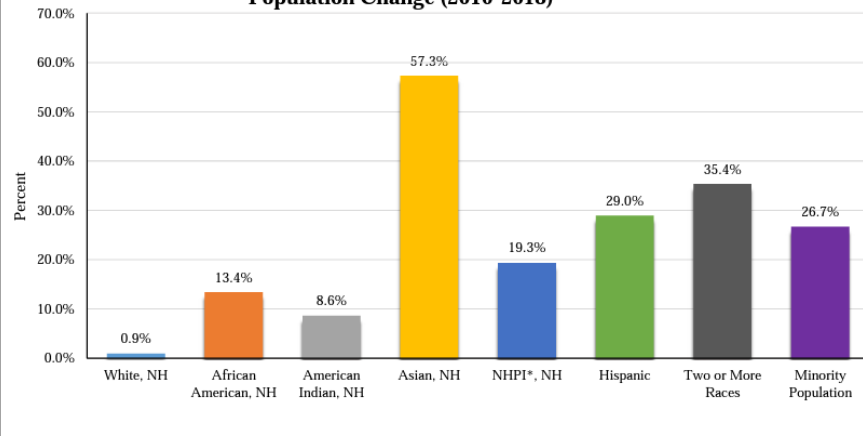
Bhutan: Nepali, Dzongkha

Iraq: Arabic, Kurdish

Somalia: Arabic, Somali

Sudan: Arabic, Nuer, Dinka

Population Change (2010-2018)



Source: US Census Bureau, Population Division. (2019).

Note: *Native Hawaiian/Pacific Islander, NH: Non-Hispanic

6.7 Courtesy of the Nebraska Department of Health and Human Services

Research Questions

What are the demographics of infants with hemoglobinopathies in NE?

What are the preferred languages of the guardians of these infants?

How often are interpreter services used in a clinical setting for patients with hemoglobinopathies?

Methods

Medical record reviews at Children's Hospital and Medical Center (CHMC) and the University of Nebraska Medical Center (UNMC)

Inclusion criteria

- Infants aged 1 or younger
- ICD-10-code corresponding with hemoglobinopathy
- Seen between 2012 and 2020

Data extracted from patient chart

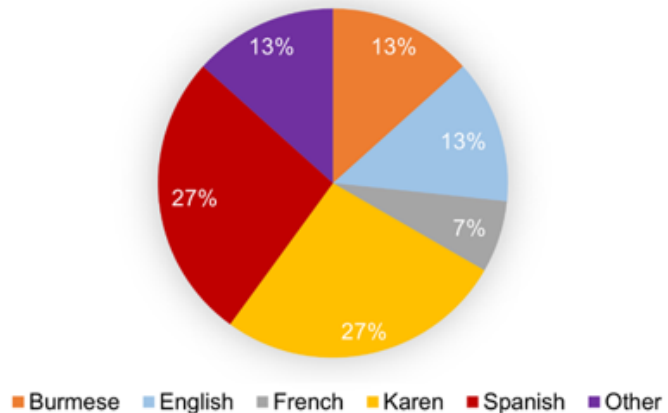
- Birth year
- Sex
- Race
- Ethnicity
- Caregiver preferred language
- Use of interpreter services

Results

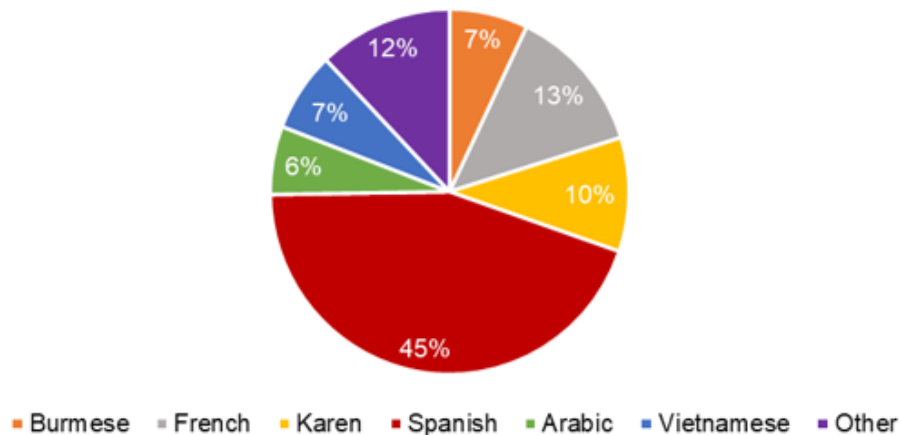
2012 – 2020 Data for Patients with Hemoglobinopathies		
Record data	UNMC (%)	CHMC (%)
Total records	251 (18.8)	1081 (81.2)
Ethnicity		
Hispanic	14 (5.6)	109 (10.1)
Non-Hispanic	221 (81.0)	954 (88.3)
Did Not Indicate	16 (6.4)	18 (1.6)
Race		
Black or African American	170 (67.7)	610 (56.4)
White	35 (13.9)	152 (14.1)
Hispanic	--	86 (8.0)
Asian	9 (3.6)	77 (7.1)
Other	19 (7.6)	15 (1.3)
Two or More Races	--	120 (11.1)
Did Not Indicate	18 (7.2)	21 (1.9)
Interpreter Services Requested	15 (6.0)	99 (9.2)

Results

**UNMC Interpreter Services Requested
2012-2020**



CHMC Interpreter Services Requested 2012-2020



Languages Identified



Takeaways

- 16 unique languages identified across both hospitals
- Most patients were Black/African American and English-speaking. White, English-speaking people comprised the second largest group.
- Spanish, French, Karen, and Burmese comprised the largest non-English speaking groups
- Continuing analysis of NE population changes and hemoglobinopathy incidence are important for providing culturally competent care.

Limitations

Does not include all infants with hemoglobinopathies

State vital records unavailable to investigators

Demographics and language were self-reported

Differences in data captured

Future Directions

Development of patient-facing materials

Sustainable population surveillance at state or national level

Patient experience

Provider experience

Hemoglobinopathy incidence

Capstone Committee

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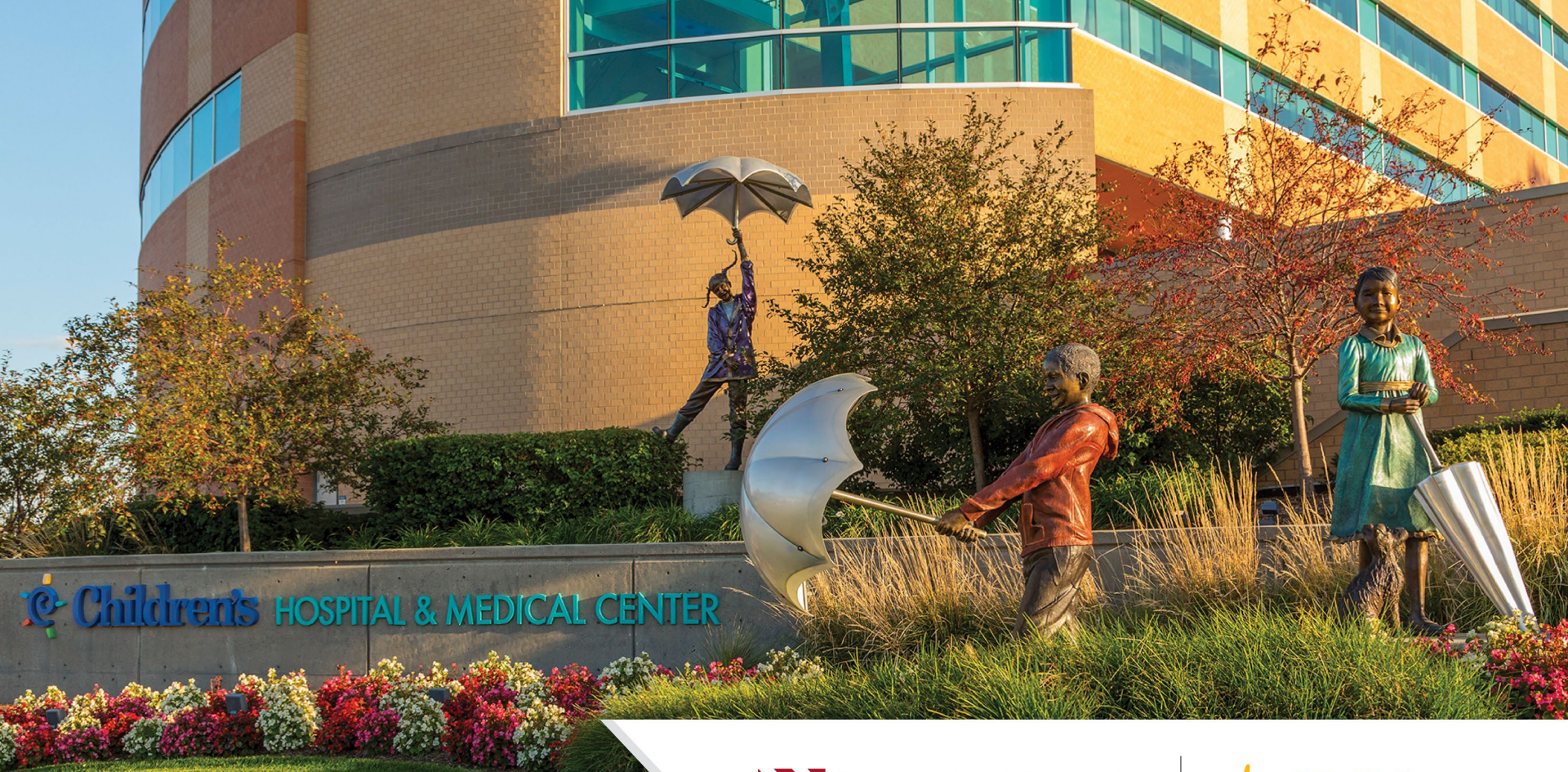
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