Syneos Health | Shortening the distance from lab to life®.

Identification of Patients Diagnosed with Rare and Emerging Diseases Utilizing the TriNetX Network: A Case Study of African and American Trypanosomiasis

Jacquelyne Brauneis[1], Keely Madaj[1], Jyothi Menon[2], Veena Seshadri[1], Brian Buysse[3]

[1]Syneos Health®, US; [2]Syneos Health®, Denmark; [3]Syneos Health®, Spain; correspondence: Jacquelyne.Brauneis@syneoshealth.com

BACKGROUND

- With large sample sizes, real-world EMR databases can provide pivotal insights into patients diagnosed with rare, orphan, or emerging diseases.
- African (sleeping sickness) & American (Chagas disease) trypanosomiasis, both vector-borne parasitic diseases, are life-threatening, neglected tropical diseases (NTDs).
- No publication to date has explored patients diagnosed with African or American trypanosomiasis utilizing real-world electronic medical records (EMR).

African trypanosomiasis

- Endemic to 36 sub-Saharan African countries.
- Transmitted by the tsetse fly.
- Approximately 60 million people at risk of infection in sub-Saharan African countries (or those travelling to endemic areas), with 2.5 million screened per year.

American trypanosomiasis

- Endemic to the Americas with recent increased prevalence in the United State and Europe.
- Transmitted by triatomine bugs (also known as kissing bugs).
- An estimated 8 million people in Mexico, Central, and South America are infected, most of whom are unaware.

Table 1. ICD-10 Codes

	ICD-10 Code	ICD-Description
African Trypanosomiasis	B56.0	Gambiense trypanosomiasis
	B56.9	African trypanosomiasis, unspecified
	B56.1	Rhodesiense trypanosomiasis
American Trypanosomiasis	B57.32	Megacolon in Chagas' disease
	B57.0	Acute Chagas' disease with heart involvement
	B57.2	Chagas' disease (chronic) with heart involvement
	B57.31	Megaesophagus in Chaga's disease
	B57	Chagas' disease
	B57.5	Chagas' disease (chronic) with other organ involvement
	B57.39	Other digestive system involvement in Chagas' disease
	B57.30	Chagas' disease with digestive system involvement, unspecified
	B57.4	Chagas' disease (chronic) with nervous system involvement
	B57.42	Meningoencephalitis in Chagas' disease
	B57.49	Other nervous system involvement with Chagas' disease
	B57.40	Chagas' disease with nervous system involvement, unspecified
	B57.3	Chagas' disease (chronic) with digestive system involvement
	B57.1	Acute Chagas' disease without heart involvement

Data sourced from TriNetX, LLC

OBJECTIVES

- Explore patient profiles of African and American trypanosomiasis, using the TriNetX Global health research network.

METHODS

- Data from 88 million patients from the United States (US), Europe, the Middle East, Africa, Latin America, and Asia Pacific were queried between Jan 1, 2018 – Nov 30, 2019 (pre-COVID) and Jan 1, 2020 – Nov 30, 2021 (post-COVID).
- Eligible patients with an ICD-10 diagnosis code of African trypanosomiasis or American trypanosomiasis were identified and analyzed separately, pre- and post-COVID (**Table 1**).

RESULTS

- 340 patients pre- and 190 patients post-COVID with African trypanosomiasis and 960 patients pre- and 790 patients post-COVID with American trypanosomiasis were identified.
- Most patients resided in the US for both pre- and post-COVID patients with either African or American Trypanosomiasis.
- Patients with African trypanosomiasis were younger and more likely to be female compared to patients with American trypanosomiasis (**Table 2**).

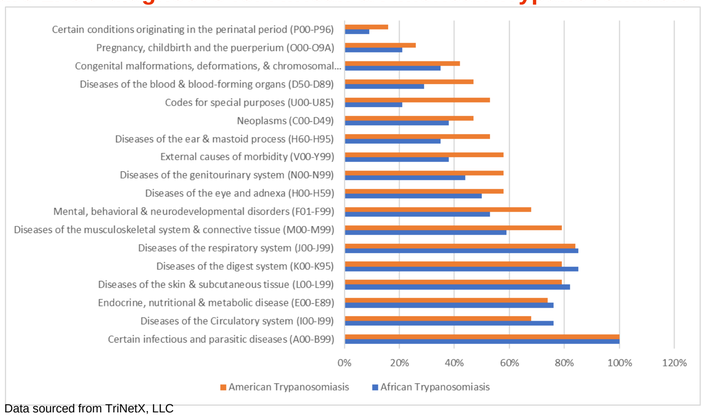
Table 2. Patient Demographics

	African trypanosomiasis		American trypanosomiasis	
	Pre	Post	Pre	Post
Age in years (mean)	38.0	34.3	49.3	48.6
Gender (female)	59%	57%	57%	53%
Top co-diagnoses	Diseases of the respiratory system		Diseases of the digestive system	

Data sourced from TriNetX, LLC

- Top co-diagnoses included diseases of the respiratory (85%, 84%) , digestive (85%, 79%), and nervous systems (82%, 79%) for patients with African trypanosomiasis and diseases of the digestive (69%, 54%) and circulatory systems (68%, 61%) for patients with American trypanosomiasis in both the pre- and post-COVID cohorts, respectively (**Table 2**).
- **Figure 1** shows a bar graph of co-diagnoses for African & American trypanosomiasis, pre- and post-COVID.

Figure 1. Co-diagnoses for African & American Trypanosomiasis



Data sourced from TriNetX, LLC

CONCLUSIONS

- Using real-world EMR data we were able to obtain patient profiles for a rare disease (African trypanosomiasis) and a common, emerging disease (American trypanosomiasis).
- This information supports utilizing EMR data for describing patient populations in rare, orphan, or emerging diseases, which may aid drug development for these indications.

REFERENCES

1. Control and surveillance of human African trypanosomiasis. Report of a WHO Expert Committee. World Health Organization.
2. Echavarria NG, Echavarria LE, Stewart M, et al. Chagas Disease: Chronic Chagas Cardiomyopathy. Cur Prob Cardiology. 2021 Mar 46(3): doi.org/10.1016/j.cpcardiol.2019.100507.
3. Neau P, Hänel H, Lameyre V, Strub-Wourgaft N, Kuykens L. Innovative Partnerships for the Elimination of Human African Trypanosomiasis and the Development of Fexinidazole. Trop Med Infect Dis. 2020 Jan 27;5(1):17. doi: 10.3390/tropicalmed5010017. PMID: 32012658; PMCID: PMC7157581.
4. Parasites – American Trypanosomiasis and African Trypanosomiasis. Centers for Disease Control and Prevention.
5. Trypanosomiasis, human African (sleeping sickness). World Health Organization.

DISCLOSURES

This research was funded by Syneos Health. All authors are salaried employees of Syneos Health.

§ Patient counts in the 'Results' section have been updated since the abstract submission as the TriNetX network updates numbers periodically for accuracy