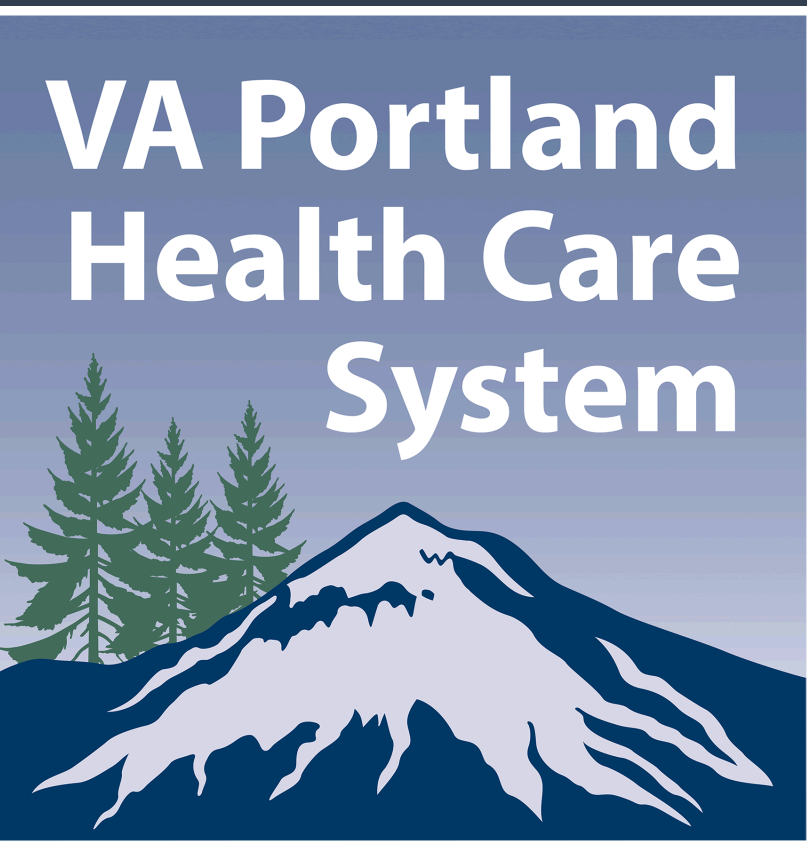




Desmoid Tumor Cohort Creation and Characteristics in the Veterans Affairs (VA) National Database

Sarah E. Lindsay MD¹; Cecelia Madison MS²; Dipam Doshi PharmD³; Susan Scott, MSN³; Tim Bell MHA³; Sunny Cho PharmD³; Duncan Ramsey MD, MS¹; Yee-Cheen Doung MD¹; Kenneth R. Gundle MD^{1,2}

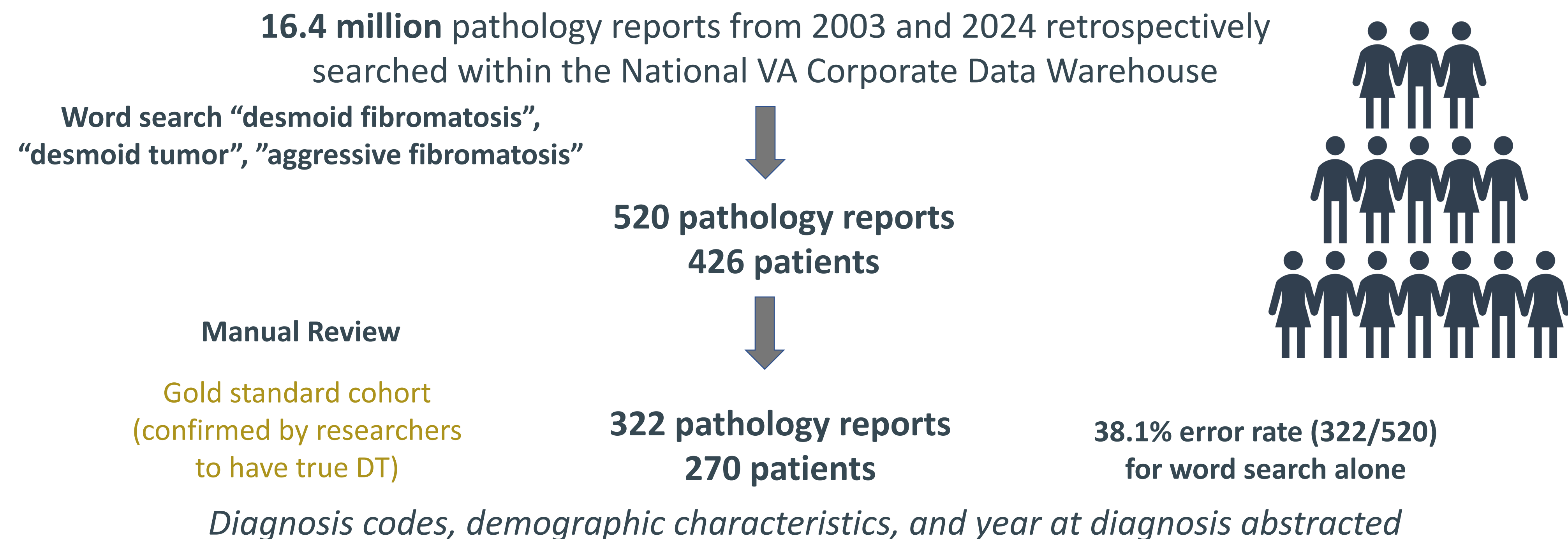
(1) OHSU Department of Orthopaedics & Rehabilitation | (2) Portland VA Medical Center Operative Care Division | (3) SpringWorks Therapeutics Inc.



Background

- Databases are useful for clinical research to better understand epidemiology and health outcomes, especially for rare diseases like desmoid tumors (DT).
- Many databases are organized by International Classification of Diseases (ICD) codes. Diagnostic coding practices vary widely, potentially limiting the utility of database research. Prior to October 2023, no DT-specific ICD code existed.
- The United States Veterans Affairs (VA) national database provides a unique opportunity for DT research due to the availability of all clinical results and pathology reports.
- 1. What proportion of patients with DT in the VA database lack DT ICD codes?
 2. What are the demographic characteristics of DT patients in the VA database cohort?
 3. What is the incidence of DT in the VA database?

Methods



Results

Diagnostic Coding Patterns

Number of Patients	ICD Code	ICD Description
78	D48.1*	Neoplasm of uncertain behavior of connective and other soft tissue and DT-specific codes by location
33	R22.2	Localized swelling, mass and lump, trunk
21	R10.9	Unspecified abdominal pain
18	R19.00	Intra-abdominal and pelvic swelling, mass and lump, unspecified site
16	M72.4	Pseudosarcomatous fibromatosis
16	R19.09	Other intra-abdominal and pelvic swelling, mass and lump
12	R68.89	Other general symptoms and signs
11	R19.07	Generalized intra-abdominal and pelvic swelling, mass and lump
10	C49.4	Malignant neoplasm of connective and soft tissue of abdomen
10	D21.6	Benign neoplasm of connective and other soft tissue of trunk, unspecified

- Appropriate ICD codes (D48.1*) absent for **71.1%** of patients (192/270)
- Most commonly (i.e., ≥ 10 patients) used codes shown

Epidemiology and Incidence

	VA DT Cohort	Historical DT Cohorts	Overall VA National Database
Age at diagnosis, mean	56.5	20-44 ^{1,2}	58
Female sex (%)	19.3	69-74 ²	11

- Age at diagnosis ranged from 21.5 to 86.7 years (mean: 56.5 years ± 14.4 years)
- Incidence rate of DT within the VA database is approximately 3 patients per million person-years

Conclusions

- DT diagnostic coding practices vary greatly and may lead to an underrepresentation of DT within large databases and underestimates of DT incidence
- The incidence rate of DT within the VA database is consistent with previously reported incidence rates of 3-5 per million person-years, despite a predominantly male population
- Other methods are needed to identify patients with DT for cohort-based research. The new DT-specific ICD 10 code may facilitate future cohort-based research

References

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