

### Using EMERSE to Improve Research Involving Rare Cancers

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### Issues with studying rare cancers

• Rare cancers are defined as fewer than 40,000 new cases per year in the U.S.



- Prospective trials take an EXTREMELY long time low incidence → difficult to reach significance
- NEED well-designed retrospective studies that capture all patients of interest





### Finding rare cancers in the electronic medical record

• Identifying rare cancers in the EMR using ICD codes

Not common – easily mislabeled

Changing names over time

Malignant Fibrous Histiocytoma

WHO changed name to

Undifferentiated Pleomorphic Sarcoma

Pathologists may call the same entity different things

Location specific biology

Well differentiated lipomsarcoma

is the same thing as

**Atypical Lipomatous Tumor** 





### Finding rare cancers in the electronic medical record

### 2022 ICD-10 LOOKUP

Find ICD-10 diagnosis codes by code name, code description or clinical term. Partial searches are allowed. Result set includes synonyms

Atypical Lipomatous Tumor

#### ICD-10 search results for atypical lipomatous tumor

ICD Code	Description	Category
D23.9	Other benign neoplasm of skin, unspecified atypical histiocytoma of skin; lipomatous hamartoma; lipomatous hamartoma; Benign tumor of skin with sebaceous differentiation; tumor of skin with sebaceous differentiation; Benign tumor of dermis; tumor of skin with sebaceous differentiation; Benign skin tumor with apocrine differentiation; Eccrine dermal duct tumor; Eccrine mixed tumor; Benign skin tumor with eccrine differentiation; Benign tumor of skin with pilar differentiation; tumor of follicular infundibulum;	Other benign neoplasms of skin (D23)





### Finding rare cancers in the electronic medical record

Issue with codes for sarcoma = cancers of the soft tissues

Primary ICD-10 billing code is by site

Example: Atypical lipomatous tumor (well differentiated liposarcoma) in the arm

ICD10 C491 = Soft tissue of the upper limb/shoulder

Additional histology code

88513 = liposarcoma, well differentiated 88503 = liposarcoma, not otherwise specified





### My experience with EMERSE

Example of a research project on a rare cancer





### Cutaneous Leiomyosarcoma (cLMS)

#### Incidence of 0.2 per 100,000 per year



Bhatt, M. D., & Nambudiri, V. E. (2019). Cutaneous sarcomas. Hematology/Oncology Clinics, 33(1), 87-101.





### **Study Objectives**

To better understand the role of imaging in detection of distant recurrence for cLMS

To assess if there is a difference in recurrence between cLMS with and without subcutaneous extension

NEED STANDARIZED GUIDELINES for clinical care





### Search Results





ER CENTER

- **311 patients** with potential **cLMS** were identified by **EMERSE**.
- **128 patients** were found to truly have **cLMS** after manual chart review.
- The Cancer Registry comparatively found only **101 patients.**

Nearly <u>21% of patients</u> would have been missed if EMERSE had not been used

#### But why the 183 false positives from EMERSE?

Standardized language in genetics consultation notes states risk for "cutaneous leiomyosarcoma".



### Results

#### Poster presentation at Society of Surgical Oncology Annual Meeting 2021, Harter, C, et al.

Gold standard treatment is WLE with negative margins

- No consensus guidelines for margins exist
- Impact of margin size on recurrence is unknown

#### **Patient and Tumor Characteristics**

Sex	Male 71%; Female 29%		
Age (years)	Median 60 (range, 12-94)		
Subtype	Dermal 60%; with subcutaneous ext 30%; Subcutaneous only 8%		
Tumor Location	Head and neck: 8.4% Truncal 23% Upper extremity: 30% Lower extremity: 39%		
Median Follow-up(mth)	25 (range, 1-160)		







### Results

Poster presentation at Society of Surgical Oncology Annual Meeting 2021, Harter, C, et al.

Table 2 – Local and Distant Recurrence by cLMS Subtype and Margin Size					
Patients (n=100)	Cutaneous only (n= 61)	With Subcutis Extension (n=31)	Subcutaneous (n=8)		
< 1cm	Local: 0	Local: 1/31 (3.2%)	Local: 0		
(n=8)	Distant: 1/61 (1.6%)	Distant: 0	Distant: 0		
1cm	Local: 0	Local: 0	Local: 0		
(n=47)	Distant: 0	Distant: 0	Distant: 1/8 (12.5%)		
1cm < x < 2cm	Local: 0	Local: 0	Local: 0		
(n=7)	Distant: 0	Distant: 1/31 (3.2%)	Distant: 0		
2cm	Local: 0	Local: 1/31 (3.2%)	Local: 0		
(n=26)	Distant: 1/61 (1.6%)	Distant: 1/31 (3.2%)	Distant: 3/8 (37.5%)		
> 2cm	Local: 0	Local: 0	Local: 1/8 (12.5%)		
(n=12)	Distant: 0	Distant: 1/31 (3.2%)	Distant: 2/8 (25%)		





### Results

#### Oral presentation at Society of Surgical Oncology Annual Meeting 2021, Hoff, L, et al.



	Dermal	Dermal with SubQ Extension	SubQ
Imaging Detected Distant Recurrence Rate	1% (1/78)	8% (3/39)	36% (4/11)
Recurrence Site(s)	Lung	Lung x 2, Bone	Lung x 4





### Another example...

#### Patients with metastatic melanoma are treated with immunotherapy



# Patients who develop the side effect vitiligo have long term survival







### Using EMERSE to identify patients

<b>Ə</b> EMERSI	E						Christina Angeles ^
Patients	All Local Patients (2,765,247)	)					
Filters							
Terms							
Results	HIGHLIGHT DOCUMENTS	FIND PATIENTS					
Temporary Pa	atient List Saved Patient List	s All Local Patients Network					
						NEW PATIENT LIST	COMPARE PATIENT LISTS
Name		Description	Owner	Created	Modified	Last Used	↓ Patient Count
Immunothera	ару	immunotherapy dataset	Christina Angeles	03/14/2021	05/03/2021	09/13/2021	383
Mesenteric c	desmoid		Christina Angeles	10/19/2020	12/14/2020	01/31/2021	128
desmoid fibr	romatosis desmoid		Christina Angeles	12/14/2020	12/14/2020	12/14/2020	85





## Using EMERSE to identify patients

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orted by: Inser	t Order 🗸 🗸						Numb
MRN	Name	MiChart	Careweb	Radiology	Pathology	Other	Comment
							0 / 255
	Patient						
							0 / 255
	Patient						
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	Patient						
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	Patient						
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