

Identification of Adult Dermatomyositis Patients Using Real-World Data Sources

Ben Martin, Will Kelly, Christopher Mecoli

Johns Hopkins Dept. Rheumatology - Myositis Center

Johns Hopkins Biomedical Informatics and Data Science

<https://doi.org/10.1002/acr.25625>

Original Article |  Full Access

Identification of Adult Dermatomyositis Patients Using Real-World Data Sources

Benjamin Martin, Will Kelly, Hannah Morgan-Cooper, Thomas Falconer, Elizabeth Park, Priya Desai, David Fiorentino, Lorinda Chung, Sean Yen, Zachary Wang, Didem Saygin, Michael George, Gowtham A. Rao, Joel Swerdel, Azza Shoaibi, Christopher A. Mecoli  ... See fewer authors 

First published: 12 August 2025 | <https://doi.org/10.1002/acr.25625>



Objective: Develop and evaluate computable phenotypes for DM to enable coordinated analysis across multiple data sources.

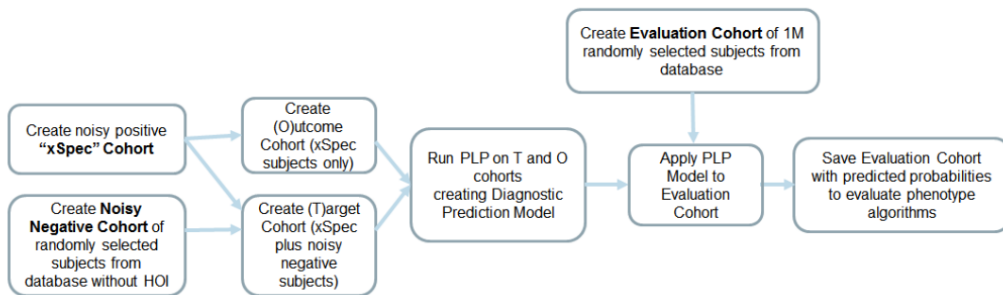
Rationale: Myositis is a rare disease that stands to benefit greatly from distributed data harmonization (incidence: 0.2 to 2 per 100,000 person-years; prevalence: 2 to 25 per 100,000 people)

OHDSI Tools: Atlas, CohortDiagnostics, PheValuator

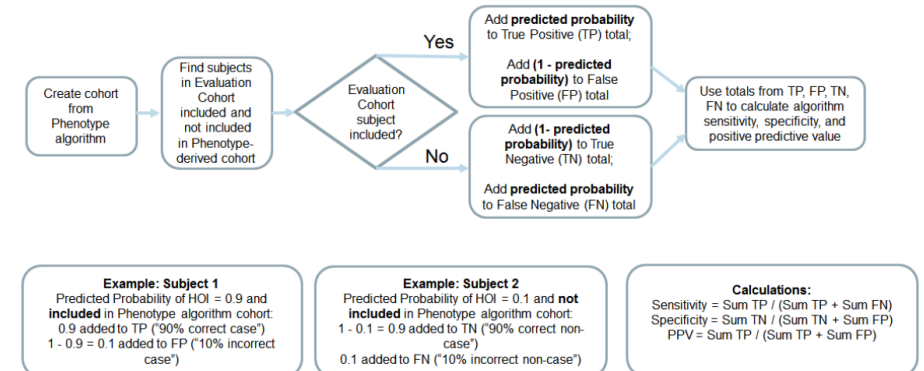
PheValuator

1. Developing a “diagnostic predictive model” using PLP
2. Using the model to test one or more phenotype algorithms

Step 1: Develop Evaluation Cohort from Diagnostic Predictive Model



Step 2: Evaluate Phenotype Algorithms



<https://ohdsi.github.io/PheValuator/>

<https://doi.org/10.1016/j.jbi.2022.104177>

Phenotypes Tested on 11 Databases

Johns Hopkins OMOP CDM	EHR
Stanford Research Repository (STARR)	EHR
Columbia OMOP CDM (CUMC)	EHR
JMDC	Claims
Truven MDCCD - Merative MarketScan® Multi-State Medicaid Database	Claims
Truven MDCCR- Merative MarketScan® Medicare Supplemental and Coordination of Benefits Database	Claims
Optum DOD , Optum's Clinformatics® Extended Data Mart – Date of Death (DOD)	Claims
Optum EHR	EHR
IQVIA Pharmedics-PharMetrics Plus	Claims
Truven CCAE-Merative MarketScan® Commercial Claims and Encounters Database	Claims
Health Verity Comprehensive Claims - Closed Claims Enrollment	Claims/EHR

Results

Cohort ID	Case Identification Criteria Algorithm	Database	Cohort Count	Sensitivity (95% CI)	PPV (95% CI)	
1781804	1	- Age >18 at index date	Johns Hopkins	740	0.525 (0.462 - 0.588)	0.951 (0.901 - 0.980)
		- 2nd diagnostic code of DM within 30-365 days of index date	STARR	603	0.624 (0.574 - 0.673)	0.886 (0.842 - 0.921)
			Columbia	444	NR	NR
		- Incident: 365 day min observation period prior to index	Optum EHR	7442	0.561 (0.479 - 0.640)	0.599 (0.515 - 0.679)
			Optum DOD	8006	NR	NR
			Health Verity	18575	0.614 (0.529 - 0.693)	0.574 (0.492 - 0.653)
			IQVIA Pharmetrics	9849	0.571 (0.467 - 0.671)	0.709 (0.596 - 0.806)
			JMDC	4494	0.662 (0.616 - 0.706)	0.818 (0.774 - 0.856)
			Truven CCAE	9421	0.542 (0.448 - 0.634)	0.780 (0.675 - 0.864)
	Truven MDCCD	1534	0.488 (0.398 - 0.579)	0.635 (0.531 - 0.731)		
	Truven MDCR	1897	0.375 (0.321 - 0.432)	0.768 (0.693 - 0.833)		
1787425	2	- Age >18 at index date	Johns Hopkins	485	0.389 (0.329 - 0.452)	0.962 (0.904 - 0.989)
		- 2nd diagnostic code of DM within 30-365 days of index date	STARR	434	0.484 (0.434 - 0.536)	0.917 (0.870 - 0.951)
			Columbia	248	NR	NR
		- At least one immunosuppressive medication prescribed	Optum EHR	4999	0.503 (0.422 - 0.584)	0.725 (0.631 - 0.806)
			Optum DOD	5729	NR	NR
		- Incident: 365 day min observation period prior to index	Health Verity	13567	0.534 (0.450 - 0.617)	0.703 (0.609 - 0.786)
			IQVIA Pharmetrics	5853	0.378 (0.282 - 0.481)	0.881 (0.744 - 0.960)
			JMDC	2070	0.340 (0.296 - 0.386)	0.944 (0.897 - 0.974)
			Truven CCAE	7098	0.458 (0.366 - 0.552)	0.857 (0.746 - 0.933)
	Truven MDCCD	975	0.336 (0.254 - 0.426)	0.724 (0.591 - 0.833)		
	Truven MDCR	1398	0.307 (0.256 - 0.362)	0.812 (0.729 - 0.878)		
1789289	3	- Age >18 at index date	Johns Hopkins	697	0.638 (0.576 - 0.697)	0.911 (0.860 - 0.948)
		- At least one immunosuppressive medication prescribed	STARR	621	0.687 (0.638 - 0.733)	0.858 (0.814 - 0.895)
			Columbia	427	NR	NR
		- Incident: 365 day min observation period prior to index	Optum EHR	8920	0.777 (0.704 - 0.840)	0.646 (0.573 - 0.714)
			Optum DOD	9435	NR	NR
			Health Verity	21109	0.651 (0.567 - 0.728)	0.534 (0.458 - 0.609)
			IQVIA Pharmetrics	8290	0.643 (0.540 - 0.737)	0.750 (0.644 - 0.838)
			JMDC	2443	0.423 (0.377 - 0.470)	0.922 (0.876 - 0.955)
			Truven CCAE	11457	0.695 (0.603 - 0.776)	0.752 (0.660 - 0.830)
	Truven MDCCD	1666	0.544 (0.453 - 0.633)	0.567 (0.473 - 0.657)		
	Truven MDCR	2363	0.612 (0.555 - 0.666)	0.756 (0.698 - 0.808)		

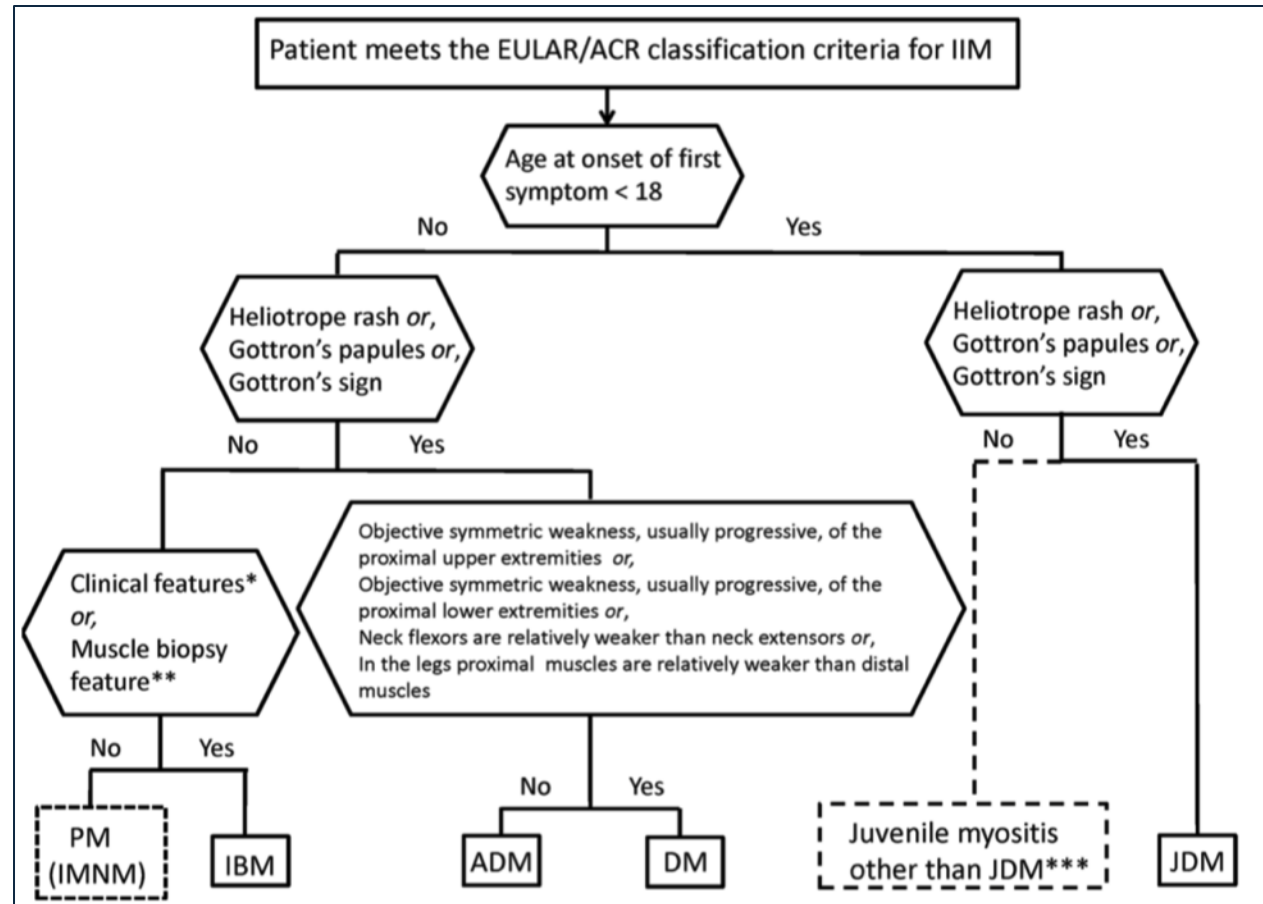
Cohort ID	Case Identification Criteria Algorithm	Database	Cohort Count	Sensitivity (95% CI)	PPV (95% CI)	
1788503	4	- Age >18 at index date	Johns Hopkins	637	0.440 (0.412 - 0.467)	0.982 (0.968 - 0.992)
		- 2nd diagnostic code of DM within 30-365 days of index date	STARR	476	0.502 (0.459 - 0.544)	0.927 (0.891 - 0.954)
			Columbia	301	NR	NR
		- At least one immunosuppressive medication prescribed	Optum EHR	5402	0.536 (0.466 - 0.606)	0.750 (0.672 - 0.817)
			Optum DOD	7320	NR	NR
		- Prevalent: 0 days min observation period prior to index	Health Verity	16274	0.586 (0.524 - 0.645)	0.701 (0.636 - 0.760)
			IQVIA Pharmetrics	7874	0.489 (0.429 - 0.550)	0.824 (0.757 - 0.879)
			JMDC	2308	0.363 (0.323 - 0.403)	0.950 (0.912 - 0.975)
			Truven CCAE	9275	0.544 (0.482 - 0.606)	0.850 (0.787 - 0.901)
	Truven MDCCD	1175	0.411 (0.348 - 0.475)	0.783 (0.702 - 0.851)		
	Truven MDCR	1779	0.398 (0.360 - 0.437)	0.837 (0.790 - 0.876)		
1788567	5	- Age >18 at index date	Johns Hopkins	1043	0.712 (0.686 - 0.737)	0.971 (0.958 - 0.981)
		- 2nd diagnostic code of DM within 30-365 days of index date	STARR	656	0.628 (0.586 - 0.668)	0.899 (0.865 - 0.928)
			Columbia	519	NR	NR
		- Prevalent: 0 days min observation period prior to index	Optum EHR	8143	0.594 (0.524 - 0.662)	0.609 (0.538 - 0.677)
			Optum DOD	10649	NR	NR
			Health Verity	23036	0.664 (0.604 - 0.720)	0.571 (0.514 - 0.626)
			IQVIA Pharmetrics	13519	0.716 (0.659 - 0.768)	0.703 (0.646 - 0.756)
			JMDC	5261	0.669 (0.629 - 0.708)	0.829 (0.791 - 0.862)
			Truven CCAE	12910	0.636 (0.574 - 0.694)	0.769 (0.706 - 0.823)
	Truven MDCCD	1976	0.573 (0.509 - 0.636)	0.681 (0.613 - 0.744)		
	Truven MDCR	2473	0.515 (0.475 - 0.554)	0.783 (0.740 - 0.821)		
1789031	6	- Age >18 at index date	Johns Hopkins	308	0.193 (0.171 - 0.215)	0.968 (0.938 - 0.986)
		- Myositis-specific autoantibody test ordered	STARR	138	0.119 (0.093 - 0.149)	0.835 (0.735 - 0.909)
		- Prevalent: 0 days min observation period prior to index	Columbia	138	NR	NR
			Truven CCAE	383	0.023 (0.008 - 0.049)	0.600 (0.262 - 0.878)
	Truven MDCR	43	0.005 (0.001 - 0.014)	0.750 (0.194 - 0.994)		
1789032	7	- Age >18 at index date - Myositis-specific autoantibody test positive - Prevalent: 0 days min observation period prior to index	All Databases	0	---	---
178875	8	- Age >18 at index date - 2nd diagnostic code of DM within 30-365 days of index date - Seen by Rheumatologist, Neurologist, or Dermatologist - Prevalent: 0 days min observation period prior to index	All Databases	0	---	---

PheValuator vs. Gold Standard Review

Actual gold standard
manual chart review

**EULAR/ACR classification criteria
for adult and juvenile idiopathic
inflammatory myopathies and their
major subgroups**

<https://doi.org/10.1136/rmdopen-2017-000507>



PheValuator vs. Gold Standard Review

Table 2. Comparison between manual chart review and probabilistic gold standard (PheValuator) using data at Johns Hopkins.

Case Identification Algorithm	Sensitivity			PPV		
	Reference = Manual Chart Review for ACR/EULAR 2017 Classification Criteria	Reference = Probabilistic Gold Standard (PheValuator)	Delta	Reference = Manual Chart Review for ACR/EULAR 2017 Classification Criteria	Reference = Probabilistic Gold Standard (PheValuator)	Delta
1	0.55	0.53	0.02	0.93	0.86	0.07
2	0.35	0.39	-0.04	0.91	0.91	0.01
3	0.41	0.64	-0.22	0.88	0.74	0.14
4	0.40	0.44	-0.04	0.90	0.95	-0.06
5	0.68	0.71	-0.03	0.92	0.93	-0.004
6	0.24	0.19	0.04	0.83	0.91	-0.08

Kappa agreement: 0.70 “substantial agreement”

Key Collaborators



<https://github.com/OHDSI/PheValuator>

- Developed and maintains the **PheValuator** package
- Limitless patience in helping our team understand and apply this tool

Thank you, Joel Swerdel!

Key Collaborators

- Gowtham Rao, Azza Shoaibi (OHDSI Phenotyping WG)
- Hannah Morgan-Cooper (for running our package!)
- Thomas Falconer (for running our package!)

