

REFINING METHODS FOR IDENTIFYING CHILDREN WITH MEDICAL COMPLEXITY USING DIAGNOSIS, HEALTH CARE NEEDS, UTILIZATION, AND SPENDING

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INTRODUCTION

Children with medical complexity (CMC) are the most medically fragile subgroup of children with special health care needs, representing 1-4% of children in the United States^{1,2} and 5-6% of pediatric Medicaid beneficiaries.^{3,4} CMC have serious, chronic, and often multiple medical, behavioral, or developmental health conditions, significant functional limitations, considerable health service needs, and high utilization.⁵ They often require multi-specialty care, inpatient care, behavioral health care, and physical or occupational therapy; additionally, many CMC rely on medical technology,

durable medical equipment (DME), or supplies. Health spending for CMC is disproportionately high,⁶ often for years at a time.⁷

The health care system is not always set up to support CMC and their families:⁸ health care and health coverage for CMC are often fragmented, requiring coordination across multiple settings and systems. To measure and improve care for CMC, it is necessary to accurately identify them in administrative data.

OBJECTIVES

Although the use of diagnosis codes to identify CMC in administrative data is well-established,^{9,10} diagnoses do not necessarily reflect health care needs or functional impairments. Relying only on diagnoses may inaccurately identify some children as medically complex, and may fail to identify CMC who lack clear diagnoses or face health care access barriers.^{11,12}

To understand the population of CMC and their health care landscape in Massachusetts, the Massachusetts Health Policy Commission (HPC) sought to refine existing methodology to identify CMC in commercial and Medicaid medical claims.

STUDY DESIGN

The HPC used diagnosis, spending, and utilization criteria to identify CMC in commercial and Medicaid claims data using the Massachusetts all-payer claims database.

First, the Pediatric Medical Complexity Algorithm¹³ (PMCA) was used, which uses diagnoses to sort individuals under age 22 into three categories: no chronic conditions, non-complex chronic conditions, and complex chronic conditions (Exhibit 1). Prior research has classified children with complex chronic conditions as CMC.¹⁴

Next, the PMCA categories were refined with care needs and spending criteria. Individuals in the non-complex chronic and complex chronic groups

who met any of the following criteria were identified as CMC: spending in the 90th percentile in both 2017 and 2018, inpatient utilization, use of two or more types of DME (identified using modified 2021 BETOS code groupings), or two or more months of home health use.

This study includes individuals ages 1-21 insured by the five largest commercial payers in Massachusetts in 2018, representing 15% of Massachusetts commercially insured lives, as well as individuals ages 1-21 insured by Massachusetts Medicaid (MassHealth) managed care plans in 2018. This analysis excluded individuals younger than one year old to omit conditions due to prematurity or delivery complications that may not reflect true, ongoing medical complexity.

Exhibit 1. Identification of children with medical complexity using the Pediatric Medical Complexity Algorithm

PMCA CATEGORY	INCLUDED INDIVIDUALS	EXAMPLES
Non-Chronic	Health care utilization but no diagnoses	Pediatric well visit
	Diagnoses that resolve in under one year	Ear infection, pneumonia
Non-Complex Chronic	Chronic diagnoses lasting more than one year	Type I diabetes, ADHD
Complex Chronic	Multiple chronic diagnoses	Type I diabetes and ADHD, developmental delay and a chronic pulmonary condition
	Progressive conditions	Cystic fibrosis, muscular dystrophy
	Continuous dependence on technology	Renal dialysis, tracheostomy with ventilator assistance
	Malignancies	Leukemia, Lymphoma

Source: Simon TD, Cawthon ML, Stanford S, Popalisky J, Lyons D, Woodcox P, Hood M, Chen, AY, Mangione-Smith R. Pediatric Medical Complexity Algorithm: A New Method to Stratify Children by Medical Complexity. *Pediatrics*. 2014; 133(6): e1647-e1654.

RESULTS

There were 201,657 individuals ages 1-21 in 2018 commercial claims: 148,916 (74%) without chronic conditions, 36,238 (18%) with non-complex chronic conditions, and 16,503 (8%) with complex chronic conditions. Refinement reclassified 3,152 (9%) of the non-complex chronic group as CMC, and 10,538 (64%) of the complex chronic group as non-CMC (Exhibit 2). This analysis identified 4.5% of the commercial population ages 1-21 (9,117) as CMC (Exhibit 4).

Exhibit 2. Identification of commercially-insured children with medical complexity

	INDIVIDUALS IDENTIFIED AS CMC	
	Complex Chronic	Non-Complex Chronic
Two years of 90th percentile spending	4,327	1,710
Inpatient utilization	361	485
Two years of 90th percentile spending and inpatient utilization	961	180
Two or more types of DME	314	776
Two or more months home health	<11	<11
Total Identified as CMC	9,114	

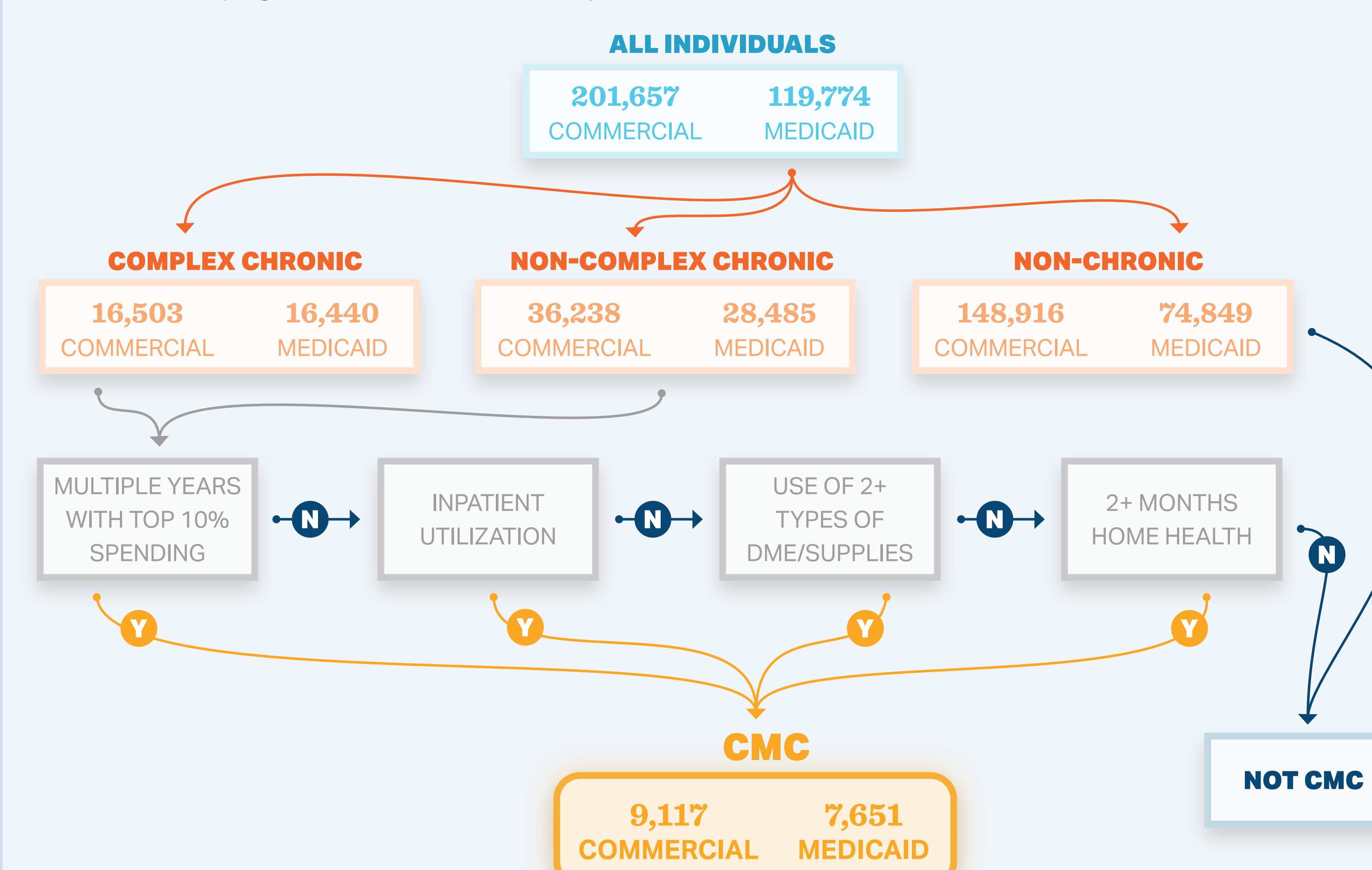
There were 119,774 individuals ages 1-21 in 2018 Medicaid managed care claims: 74,849 (62%) without chronic conditions, 28,485 (24%) with non-complex chronic conditions, and 16,440 (14%) with complex chronic conditions. Refinement reclassified 2,640 (9%) of the non-complex chronic group as CMC, and 11,429 (70%) of the complex chronic group as non-CMC. This analysis identified 7,651 (6.4%) Medicaid beneficiaries ages 1-21 as CMC.

Exhibit 3. Identification of children with medical complexity among Medicaid managed care beneficiaries

	INDIVIDUALS IDENTIFIED AS CMC	
	Complex Chronic	Non-Complex Chronic
Two years of 90th percentile spending	3,581	1,589
Inpatient utilization	397	431
Two years of 90th percentile spending and inpatient utilization	726	181
Two or more types of DME	296	434
Two or more months home health	*	<11
Total Identified as CMC	7,651	

* Cell size of ≥11 suppressed

Exhibit 4. Identifying children with medical complexities in claims data



Source: HPC analysis of All-Payer Claims Database 8.0

CONCLUSIONS

Analysis of diagnosis codes is necessary, but alone is insufficient to identify children with medical complexity. Existing methodology that relies only on diagnoses appears to over-identify children with complex chronic diagnoses as CMC, and to under-identify CMC among children with non-complex chronic diagnoses. Refinement of diagnosis-based identification methods with spending and utilization criteria allows for greater precision.

POLICY IMPLICATIONS

Children with medical complexity (CMC) are a heterogeneous and high-need population, with significant use of health services in a system that is often fragmented and poorly coordinated for their needs. Likewise, CMC often lack adequate care continuity due to coverage churn, and often face challenges in transitioning from pediatric to adult care as they become young adults. Identifying CMC in administrative data is an essential first step to measuring their service use, understanding any gaps in care, and tracking progress on efforts to improve how their care is delivered.

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- Children's Hospital Association. Coordinating All Resources Effectively for Children with Medical Complexity (CARE Award): Early Lessons Learned from the Project. Sept 2016. Available at: https://www.childrenshospitals.org/-/media/Files/CHA/Main/Programs_and_Services/Quality_Safety_and_Performance/CARE/CARE_award_early_lessons_learned_sept2016.pdf
- NASHP. National Care Coordination Standards for Children and Youth with Special Health Care Needs. Oct 16, 2020. Available at: <https://www.nashp.org/national-care-coordination-standards-for-children-and-youth-with-special-health-care-needs/#toggle-id-1>
- Berry JG, Hall M, Neff J, Goodman D, Cohen E, Agrawal R, Kuo D, Feudtner. Children With Medical Complexity And Medicaid: Spending And Cost Savings. *Health Affairs*. 2014; 33(12): 2199-2206.
- Reuland CP, Collins J, Chiang L, Stewart V, Cochran AC, Coon CW, Shinde D, Harguani D. Oregon's approach to leveraging system-level data to guide a social determinants of health-informed approach to children's healthcare. *BMJ Innovations*. 2020; 7(1): 1-8.
- Berry JG, Agrawal RK, Cohen E, Kuo DZ. The Landscape of Medical Care for Children with Medical Complexity. *Children's Hospital Association*. June 2013. Available at: http://www.columbia.edu/itc/its/medicaid/residency/peds/new_compeds_site/pdfs_new/PL3%20new20readings/Special_Report_The_Landscape_of_Medical_Care_for_Children_with_Medical_Complexity.pdf
- Neff JM, Sharp VL, Muldoon J, Graham J, Myers K. Profile of Medical Charges for Children by Health Status Group and Severity Level in a Washington State Health Plan. *Health Services Research*. 2004;39(1):73-90.
- Agrawal R, Hall M, Cohen E, Goodman DM, Kuo D, Neff JM, O'Neill M, Thomson J, Berry JG. Trends in Health Care Spending for Children in Medicaid With High Resource Use. *Pediatrics*. 2016;138(4).
- Allshouse C, Comeau M, Rodgers R, Wells N. Families of Children with Medical Complexity: A View from the Front Lines. *Pediatrics*. 2018;141(s3):s195-s201.
- Feudtner C, Feinstein JA, Zhong W, Hall M, Dai D. Pediatric complex chronic conditions classification system version 2: updated for ICD-10 and complex medical technology dependence and transplantation. *BMC Pediatrics*. 2014;8(4).
- Maypole J, Gavin T, de Banate MA, Sadof M. Lessons Learned, Best Practices: Care Coordination for Children with Medical Complexity. *Pediatric Annals*. 2020;1(11):e457-e466.
- Cohen E, Kuo DZ, Agrawal R, Berry JG, Bhagat SKM, Simon TD, Srivastava R. Children With Medical Complexity: An Emerging Population for Clinical and Research Initiatives. *Pediatrics*. 2011; 127(3): 529-538.
- Reuland, supra note iv
- Simon TD, Cawthon ML, Stanford S, Popalisky J, Lyons D, Woodcox P, Hood M, Chen, AY, Mangione-Smith R. Pediatric Medical Complexity Algorithm: A New Method to Stratify Children by Medical Complexity. *Pediatrics*. 2014; 133(6): e1647-e1654.
- Reuland, supra note iv

