Estimating the U.S. Economic Burden of Autoimmune Diseases: A Pilot Systematic Literature Review

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BACKGROUND & OBJECTIVE

- Autoimmune diseases include multiple distinct conditions, affecting 5–8% of the U.S. population.
- This pilot systematic literature review characterized cross-study differences that pose a challenge to assessing the aggregate economic burden in the U.S. across all autoimmune diseases.

METHODS

Step 1 — Select 161 recognized autoimmune conditions from the Global Autoimmune Institute's disease catalog
- E.g., Acromegaly, Celiac disease, Pyoderma gangrenosum…

Step 2 — Conduct systematic review: cost literature from PubMed searches for US-based, English-language studies published from 2000 to 2024
- Abstract search: 2,878
- Abstract consensus: 379
- Required full text review: 326
- Cost extraction: 338

Step 3 — Conduct cost justification by applying algorithm to identify per person direct and indirect cost
- Direct cost: Disease-related treatment costs or total healthcare costs
- Indirect cost: Disease-related treatment costs or total healthcare costs

Step 4 — Estimate costs by applying algorithm to identify incidence or prevalence rate and project population cost
- Annual population cost = population ∗ incidence ∗ per patient per year cost
- Incidence = average annual prevalence / life expectancy

Step 5 — Predict costs by using expert surveys to estimate costs for diseases without cost-related studies.

Attribute	Option / level
Diagnosis & Initial Workup	(1) Primary care; (2) Specialist care; (3) Multidisciplinary
Treatment & Management Approach	(1) Self-managed; (2) Intermittent/Standard therapies; (3) Advanced therapies; (4) Experimental/rare therapies
Healthcare Utilization Frequency	(1) Occasional; (2) Episodic; (3) Regular; (4) Frequent; (5) Intensive
Care Delivery Setting	(1) Primary outpatient; (2) Specialized outpatient; (3) Hospital-based; (4) Extended inpatient or long-term care
Impact on Organ Systems	(1) Localized; (2) Single-system chronic; (3) Multi-system; (4) Severe systemic involvement
Demographic & Prognostic Factors	(1) Short-term, localized; (2) Chronic but stable; (3) Progressive; (4) Chronic, life-limiting
Burden of Post-Acute & Chronic Care	(1) Minimal; (2) Moderate; (3) High; (4) Extensive

RESULTS

Table 1. Examples of annual population cost estimates for autoimmune diseases based on published economic studies

Disease name	Direct costs ($)	Indirect costs ($)	Per patient per year costs ($)	Cost justification	Incidence	Annual population costs
Acromegaly	24.4K	31.2K	55.6K	Disease-related costs + total indirect costs	0.38/100,000	70.7M
Alopecia areata	6K	7.2K	13.4K	Disease-related costs + total indirect costs	20.2/100,000	906.8M
Autoimmune encephalitis	7.4M	-	7.4M (per population)	Total inpatient costs	1.0/100,000	7.4M
Chronic inflammatory demyelinating polyneuropathy	61.7K	-	61.7K	Disease-related costs	1.6/100,000	330.6M

Table 2. Examples of expert survey responses

Disease	(1) Diagnosis & Initial Workup	(2) Treatment & Management Approach	(3) Healthcare Utilization Frequency	(4) Care Delivery Setting	(5) Impact on Organ Systems	(6) Demographic & Prognostic Factors	(7) Burden of Post-Acute & Chronic Care
Acromegaly	2	3	4	2	3	3	3
Agammaglobulinemia, primary	2	3	3	2	3	2	3

Notes: Responses correspond to increasing levels of burden, each of which has a qualitative descriptor (see Step 5 methods).

Step 5: Regression to estimate annual per-population costs for autoimmune diseases without published cost-related studies:

$$Cost = \alpha + \beta_1 L_1 + \beta_1 L_1 + \cdots + \beta_7 L_7$$

- L variables represent burden level for each of 7 attributes.
- Step 5a – Estimate regression coefficients using data from diseases for which the literature provides cost estimates.
- Step 5b – Using expert-identified burden levels and resulting regression equation to estimate costs for diseases for the literature does not provide cost estimates.

CONCLUSION

- Notable methodological differences complicating literature synthesis included differences in (1) how studies defined the diseased population, (2) data sources (e.g., claims vs. survey data; or cost vs. charge data), and (3) types of costs included (e.g., procedure costs only vs. procedure costs plus drugs).
- Methodological heterogeneity across studies poses a substantial challenge to the synthesis of information for estimating the aggregate cost of autoimmune disease in the U.S. We encourage characterization of uncertainty attending synthesis efforts and harmonization of methods to overcome these challenges.

SUPPORT

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CONTACT

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