Defining Value in a Severe, Multisystem Disease:
Lessons from Economic Models of Systemic Lupus Erythematosus

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KEY MESSAGE

Despite the complexity of SLE and its broad and heterogeneous economic burden, extended value domains were generally not considered in economic evaluations to date.

BACKGROUND

Health economic evaluations have traditionally focused on direct healthcare costs and patient outcomes (QALYs). However, decision-makers increasingly recognize broader value dimensions, as articulated in the ISPOR value flower framework, which encompasses twelve domains including productivity, caregiver burden, and equity. [1,2,3,4]

Systemic lupus erythematosus (SLE) is a severe, multisystem, chronic autoimmune disease with multi-organ involvement and significant morbidity. SLE imposes a substantial burden on patients, caregivers, and society, including indirect costs such as productivity loss and long-term disability. [6,7]

Recent reviews of HTA guidelines suggest that while broader value elements are not consistently included, domains such as productivity, equity, and caregiver spillovers are increasingly recognized in decision-making frameworks. [5,8]

OBJECTIVES

1. Assess the extent to which published model-based economic evaluations have incorporated value elements beyond direct costs and QALYs
2. Map reported value elements to 11 relevant domains of the ISPOR value flower*

Note: The 'fear of contagion' domain was excluded as it is not applicable to systemic lupus erythematosus.

METHODS

Literature Search Update

Building on a previously published systematic review of decision-analytic economic evaluations in SLE (Gavan et al., 2020), the literature search was updated to 6th January 2026 using predefined inclusion criteria for full economic evaluations in SLE populations.

Value Element Mapping

Reported value elements were systematically extracted from included studies and mapped against the 11 relevant domains of the ISPOR value flower (Lakdawalla et al., 2018; 2022), spanning traditional, broader, and novel value categories.

Inclusion Criteria

- Full economic evaluations (CEA, CUA, CBA) in SLE populations.
- Decision-analytic model-based studies.
- English-language, peer-reviewed publications.

RESULTS

Original review (Gavan et al., 2020): 2,330 records → 6 included

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Updated search (to Jan 2026): 769 additional records → 17 further studies

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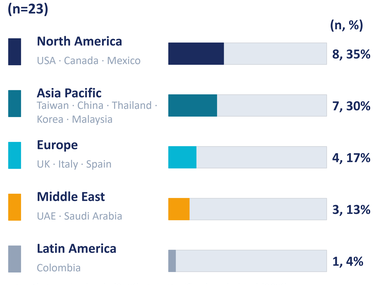
Total: 23 economic evaluations included

Table 1: Conceptual Relevance of ISPOR Value Domains in SLE

Value Domain (ISPOR)	Relevance to SLE	Rationale
Direct Costs	✓ Yes	Chronic management, hospitalizations, multi-organ complications
QALYs	✓ Yes	Significant morbidity and HRQoL impact
Productivity	✓ Yes	Affects working-age population; disability and fatigue common
Caregiver Burden	✓ Yes	Long-term care needs in severe disease
Adherence	✓ Yes	Complex treatments (IV/SC), chronic therapy challenges
Scientific Spillovers	✓ Yes	Autoimmune therapies often applicable across indications
Uncertainty Reduction	✓ Yes	Unpredictable disease progression and treatment response
Insurance Value	✓ Yes	High-cost, severe condition → financial risk protection important
Severity of Disease	✓ Yes	Progressive, multi-organ, potentially life-threatening
Value of Hope	◐ Moderate	Relevant in severe/advanced cases
Real Option Value	◐ Limited	Less immediate mortality vs other diseases
Equity	✓ Yes	Disproportionately affects women and certain populations
Fear of Contagion	✕ No applicable	Not applicable (non-communicable disease)

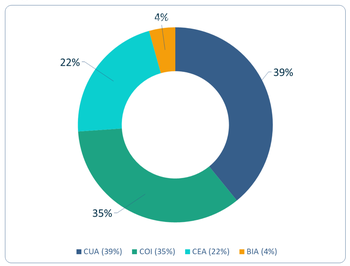
Value Elements Reported Across 23 SLE Economic Evaluations

Figure 1: Distribution of Studies by Region (n=23)



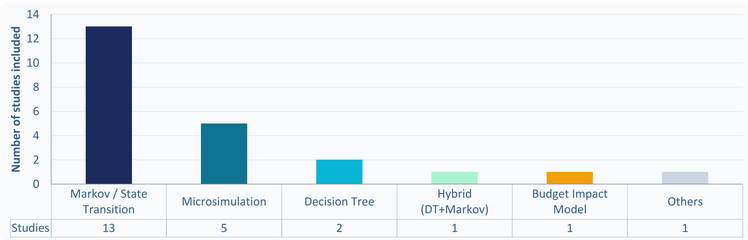
North America leads (35%); Asia Pacific close behind (30%)

Figure 2: Economic Evaluation Methods (n=23)



Abbreviations: BIA: Budget Impact Analysis ; CEA: Cost-Effectiveness Analysis; COI: Cost of Illness; CUA: Cost-Utility Analysis;

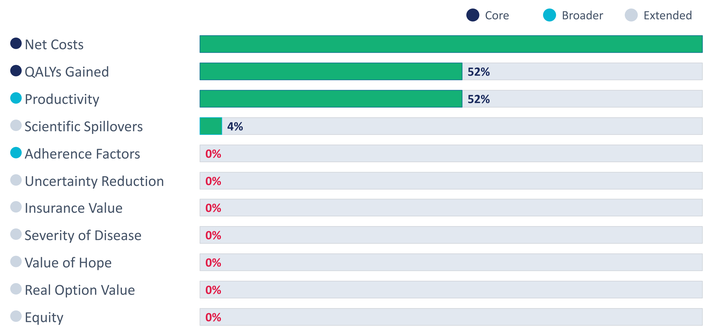
Figure 3: Model Type Distribution (n=23)



Markov models dominate, suited to chronic disease with recurring state transitions in SLE.

RESULTS (continued)

Figure 4: Proportion of Included Studies Reporting Each Value Element



Extended value elements are almost entirely absent; a major evidence gap for payers & HTA bodies.

Discussion

Persistent gap between framework and practice: Despite the ISPOR value flower's inclusion of 12 value domains, and high conceptual relevance for multiple domains, SLE economic evaluations remained focused almost exclusively on direct costs and QALYs.

Productivity was included in approximately half of the studies, primarily as work-related productivity loss (e.g., absenteeism or reduced work capacity), while broader societal impacts such as caregiver burden were largely absent.

Novel domains uniformly absent: Equity, insurance value, caregiver spillovers, and other novel domains were not incorporated in any study, consistent with limited uptake of novel value elements in HTA.

Implications: In a disease with significant non-healthcare burden, limited value capture may underestimate the true value of effective treatments, potentially affecting reimbursement decisions.

CONCLUSIONS

Economic evaluations in SLE remain narrowly focused on direct costs and QALYs, with minimal incorporation of broader value domains despite the disease's substantial societal burden. While not all value domains are formally recognized across HTA guidelines, there is increasing consideration of elements such as equity, disease severity, productivity, and caregiver spillovers. However, their integration into economic evaluations of SLE remains limited. Future research should priorities methods to incorporate these broader domains to better reflect the full value of interventions and support more comprehensive HTA decision-making. [8]

REFERENCES

1. Lakdawalla DN, et al. Defining Elements of Value in Health Care, A Health Economics Approach: An ISPOR Special Task Force Report. Value Health. 2018.
2. Lakdawalla DN, et al. The ISPOR Value Flower, Revisited. Value Health. 2022.
3. Phelps CE, Lakdawalla DN, et al. Adoption of Novel Value Elements in HTA: A Review of Guidelines.
4. Garrison LP, et al. Expanding the Scope of Value in Health Care: The Value Flower. Value Health.
5. Neumann PJ, et al. Challenges in Incorporating Broader Value Elements into Economic Evaluation.
6. Doria A, et al. Systemic Lupus Erythematosus: Clinical Burden and Unmet Needs. Lancet Rheumatology.
7. Zhu TY, et al. Direct and Indirect Costs of Systemic Lupus Erythematosus: A Systematic Review. Arthritis Care Res.
8. Breslau et al. (2023). A review of HTA guidelines on societal and novel value elements.

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