



High burden of disease and associated costs for eosinophilic gastrointestinal diseases: Results from an online patient-centered research network



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Introduction

- Data regarding health care-related costs and the burden of disease for non-EoE eosinophilic gastrointestinal diseases (EGIDs) are lacking, particularly from the patient perspective.
- We aimed to determine the patient-reported health care burden of disease and costs related to care for non-EoE EGIDs.

Methods

- Study design:** Case-control pilot study based in EGID Partners (egidpartners.org), an online patient-centered research network designed and implemented by patient advocacy groups (PAGs) and EGID researchers and launched in 2020 (Figure 1).
- Subjects:** Recruited via emails and social media, directed messages to EGID patients through medical record patient portals, webinars, and by physicians.
- Adults (≥18 years) with EGIDs, non-EGID adult controls, and these same groups but for caregivers of children <18 years of age could join.
- Data:** Subjects completed surveys on demographics, disease and medical history, and a burden of disease questionnaire. This instrument recorded patient-reported healthcare utilization over the prior year related to health care visits and procedures, as well as out-of-pocket costs/payments.

- Analysis:** We calculated the median total costs and number of visits overall, and also compared these between adults and pediatric (care giver report) cases.

Results

- We analyzed 58 non-EoE EGID patients with health care utilization data (mean (SD) age 29 (19) years; 69% female; 95% white; 88% with an atopic condition; mean (SD) 7.4 (9.9) years of symptoms prior to diagnosis).
- Of the non-EoE EGID cases, 13 had eosinophilic gastritis (EoG), 17 had eosinophilic enteritis (EoN), 6 had eosinophilic colitis (EoC), and 22 had multiple areas of overlap; additionally, 27 had esophageal involvement.

Figure 1: EGID Partners website

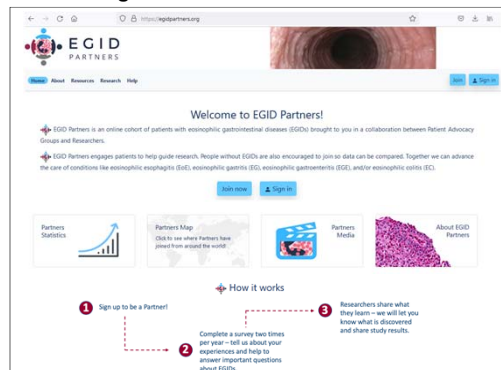


Table 1: Non-EoE EGID costs overall, and by adult patient compared to caregiver of the pediatric patient

| | Overall non-EoE EGID population (n = 58) | Adult report (n = 42) | Caregiver report (n = 16) | p |
|--|--|-----------------------|---------------------------|------|
| Health care encounters (median [IQR]) | | | | |
| Total number of encounters | 12 (5-33) | 12 (5-29) | 13.5 (6-33.5) | 0.81 |
| Outpatient visits | 5 (3-15) | 5 (3-19) | 5 (3-15) | 0.65 |
| Urgent care/ER/hospital | 3 (2-5) | 3 (1-3) | 3.5 (2-9) | 0.32 |
| Endoscopies | 2 (1-3) | 2 (2-3) | 2 (1-3) | 0.43 |
| Testing | 5 (3-12) | 5 (3-12) | 4 (1-7) | 0.27 |
| Costs in USD (median [IQR]) | | | | |
| Total costs | \$1000 (\$100-\$3570) | \$1050 (\$100-\$3600) | \$350 (\$0-\$2600) | 0.57 |
| Outpatient visits | \$250 (\$0-\$1845) | \$500 (\$0-\$1846) | \$250 (\$0-\$1000) | 0.87 |
| Urgent care/ER/hospital | \$215 (\$0-\$1200) | \$230 (\$0-\$1800) | \$200 (\$0-\$300) | 0.69 |
| Testing | \$400 (\$0-\$1400) | \$525 (\$0-\$1400) | \$225 (\$0-\$2750) | 1.0 |
| Medications (EGID-related) | \$325 (\$100-\$1010) | \$400 (\$100-\$1010) | \$135 (\$100-\$440) | 0.37 |

- The annual median out-of-pocket costs were \$1000 (IQR: \$100-\$3570; range: 0-\$100,400). Median costs for outpatient visits, testing, and medications were \$250, \$400, and \$325, respectively (Table 1).
- Costs were similar for adult patients and caregivers (Table 1).

Conclusions

- Patients with non-EoE EGIDs experience a high health care burden, with frequent health care encounters (median of 1 encounter/month) and substantial out-pocket costs (median of \$1000/year).
- Both adult and pediatric providers must maintain awareness of the substantial burden in costs to EGID patients, including challenges for patients to manage their disease given these costs.
- Future investigations should include out-of-pocket costs, such as the ones found here, when burden of disease is assessed.

References

- The median number of health care visits over the prior year was 12 (IQR: 5-33; range 1-90), with a median of 5 outpatient doctor visits, 3 urgent care/ED visits or hospitalizations, and 2 endoscopy visits (Table 1).
- Results were similar for adult patient report (n=42) or caregiver report for pediatric patients (n=16).

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