



Steroids and Me (Sam): Development and Validation of a Patient-Centered Digital Platform for Glucocorticoid Education and Shared Decision-Making

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Abstract

Background/Purpose

Glucocorticoids represent both a therapeutic necessity and a source of significant morbidity for millions of patients with inflammatory and autoimmune diseases.

Despite abundant documentation in the medical literature of the damage caused by steroid use, there had been no dedicated instruction for patients about how to mitigate these side effects until 2024. This educational vacuum had left patients isolated in their steroid journey, overwhelmed by contradictory information, and inadequately prepared for shared decision-making with their healthcare providers.

Objectives

Steroids and Me (Sam) is a novel approach to patient empowerment in glucocorticoid therapy. This abstract presents the development, implementation, validation, and ongoing outcomes of Sam over its first 24 months. This effort demonstrates how a patient-centered digital platform can 1) address a longstanding unmet need in steroid education and 2) deliver a practical mechanism for shared decision-making that optimizes steroid use.

Methods

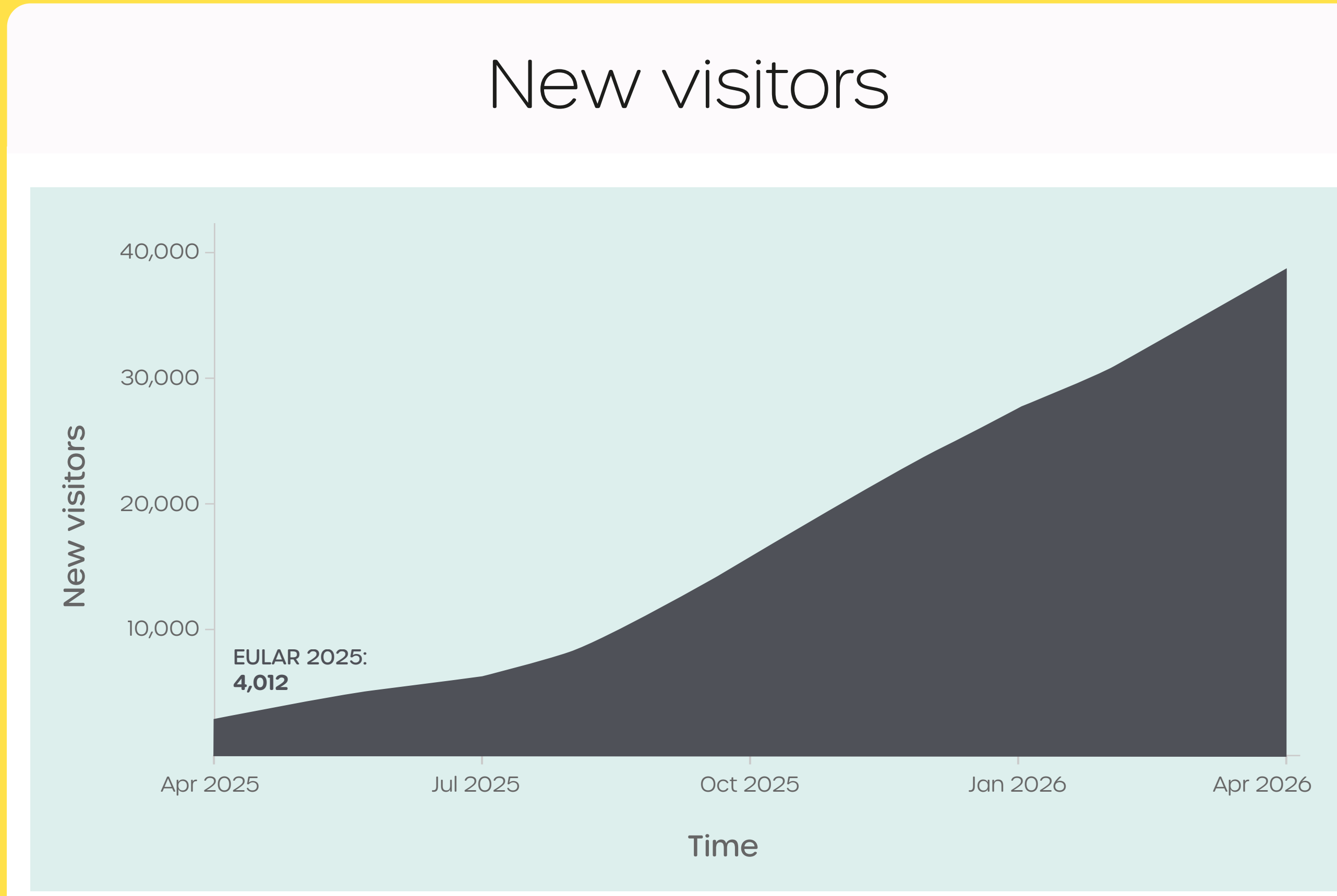
Phase 1: The Resource Review identified no single source of comprehensive patient education on managing these effects.

Phase 2: The Needs Assessment consisted of two international roundtable meetings with patient advocacy group leaders and industry representatives, three patient focus groups, and meetings with industry representatives from five companies, meetings with six patient advocacy groups: lupus, vasculitis, pemphigus, myasthenia gravis, sarcoidosis, and IgG4-related disease participated.

Phase 3: Platform Construction was the buildout of a web-based platform accessible by phone, tablet, or computer, with stringent privacy policies fulfilling requirements of both HIPAA/GDPR and state-specific data privacy laws. The platform has a journey tracker for registered users to capture steroid side effects in real-time and share results with their doctors at follow up visits. This tool is configured to integrate with EMR systems in future releases.

Phase 4: Content Development, all content is original, developed and recorded by internationally recognized clinicians. Educational materials include written content on dozens of known steroid side effects, tips about prevention and management of steroid-toxicities, and videos created by physician experts. The educational content and adverse event monitoring align with validated clinical outcome assessments that measure steroid-toxicity: the Glucocorticoid Toxicity Index (GTI), GTI-Metabolic Domains (GTI-MD), and GT-SNAPSHOT baseline score.

Phase 5: Implementation Strategy. Implementation proceeded through two complementary channels. First, Patient Advocacy Partnerships were established with the Vasculitis Foundation, Foundation for Sarcoidosis Research, Lupus Research Alliance, IgG4ward! Foundation, Global Asthma Airways Patient Portal, and Crohn's and Colitis Foundation. Second, organic search optimization was implemented to capture patients actively seeking information about specific steroid-related concerns.



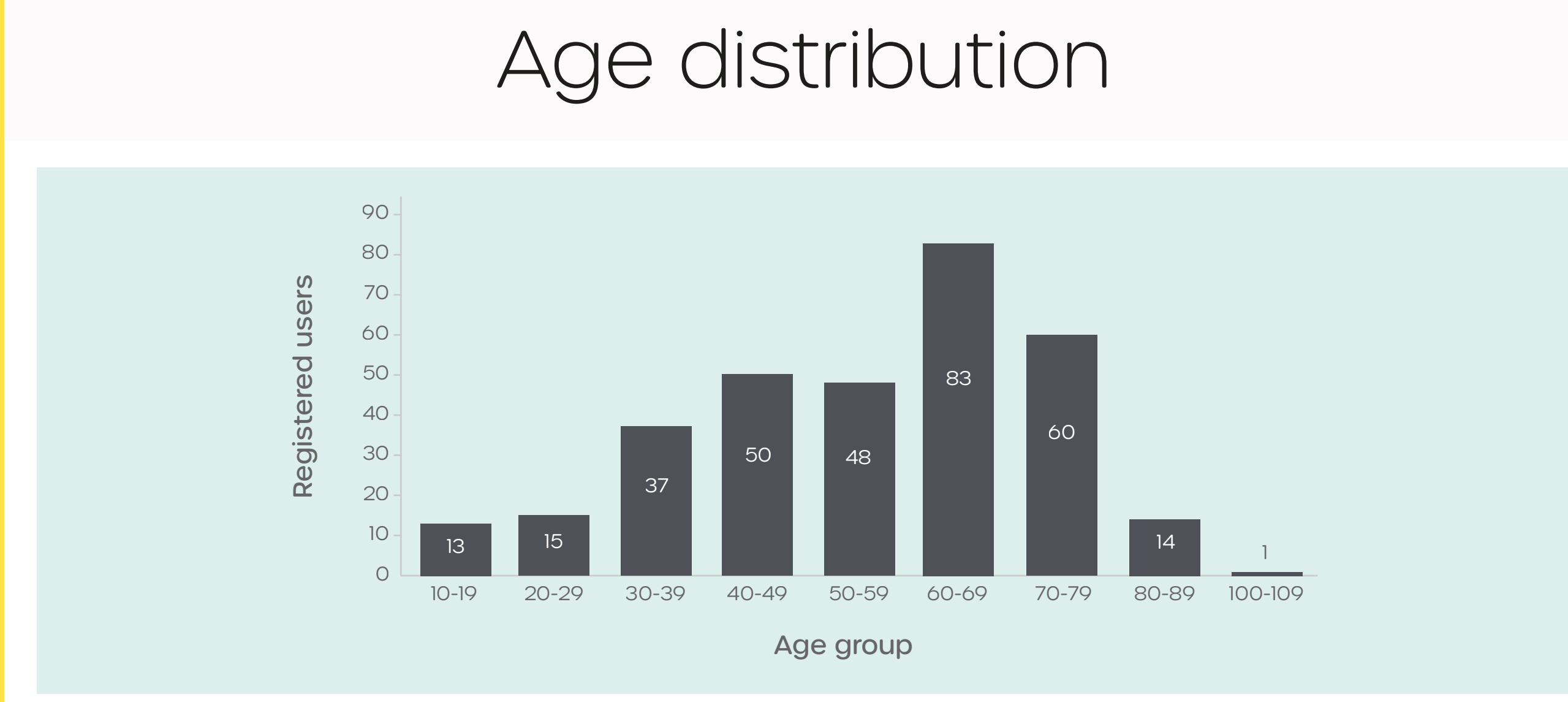
Key findings

- **Sam is a key patient resource for learning about steroid-toxicity. #1 on Google for 350 keywords**
- **30,000+ new visitors in 12 months (10x growth since EULAR 2025)**
- **Each learner spends 13 minutes on Sam on average, learning about steroid-toxicity**
- **Patients searching for answers about life on steroids drive 70% of new traffic to Sam**
- **Adherence anxiety, and coping with life on steroids drive the learning journey to Sam**
- **Registered users have a greater appetite for learning, spending 48x longer on Sam than visitors**
- **Registered users are seeking help on how to talk to their doctors**

Engagement

Metric	Registered Users	Visitors
Total pageviews	6,700	62,000
Unique learners	300	37,000
Avg pages / learner	22	1.70
Total time (mins)	130,000	320,000
Avg time (mins)	440	9
Total 7,700 hrs - 322 days Learning		

Page type	Pages	Pageviews	Avg time
CMS article pages (web, long reads)	44	36,484	5.37 min
SAM app article views	55	3,733	1.66 min
SAM app surfaces (Home, Journal, etc)	17	25,477	1.01 min
PAG landing pages	8	2,405	1.23 min
Article categories	4	12	2.78 min



Top articles read

Visitors			
Rank	Article Title	Total Views	Total Mins Read
1	Oops... I missed my steroid dose again	12,930	5,942
2	Understanding brain fog and confusion	6,147	2,657
3	Should I get vaccinated while taking steroids?	4,017	1,268
4	Struggling to sleep on steroids?	3,566	1,130
5	Coping with depression and anxiety while on steroids	2,323	827
6	Reclaiming your sleep	1,401	628
7	How to talk to your doctor about steroids	1,141	797
8	Avoiding the pain of additional side effects when reducing your steroids	917	534
9	Understanding your child's behavioral changes	901	380
10	Handling changes in your weight and appearance	654	396
Total		33,997	14,559

Registered users			
Rank	Article Title	Total Views	Total Mins Read
1	How to talk to your doctor about steroids	156	251
2	Taking an active role in your steroid journey with shared decision-making	89	155
3	Why we taper	70	181
4	Taking care of your mental health	61	122
5	Reclaiming your sleep	61	53
6	Tackling muscle weakness	54	98
7	Handling changes in your weight and appearance	49	71
8	Avoiding the pain of additional side effects when reducing your steroids	48	90
9	What nobody tells you about long-term steroid treatment	46	29
10	9 things every steroid-treated patient should know	44	107
Total		678	1,157

Results

User Engagement and Growth (25,000 users as of January 2026)

Sam has demonstrated remarkable growth since its 2024 launch, with a 300% growth in the first 90 days following successful Google search optimization and patient advocacy group partnerships. Users spent an average of 5.4 minutes learning on Sam pages, which is 10 times the global average for health websites, indicating deep engagement with educational content.

Search Performance and Accessibility

Sam achieved exceptional search engine optimization results, ranking #1 on Google for 350 keywords and phrases, and in the top 10 for a further 900 terms. This visibility proved crucial for reaching patients at their moment of need. The platform's content effectively captured search queries ranging from specific side effects ("steroids and brain fog") to broader concerns about steroid management, successfully directing patients to relevant education and maintaining their engagement once they arrived.

Conclusion

Steroids and Me (Sam) successfully addresses a critical gap in patient education for glucocorticoid therapy. Through systematic development grounded in patient needs, the platform demonstrated exceptional engagement: as of January 1, 2026, 25,000 visitors (average reach is 1000 new users per week), driven by search engine optimization and answer engine optimization, and patient advocacy partnerships, 5.4-minute average sessions (10x global average).

The platform transforms patients from isolated, confused individuals into informed partners in their own care. Sam's trajectory from concept to engaging nearly 1000 per week writing demonstrates the hunger for trusted steroid education resources. Future directions include clinical integration, outcome studies, and expanded disease community partnerships.

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Disclosure of interest:

Martha Stone Subject matter expert on steroid-toxicity: AMGEN, ARGENX, Michelle Petri: None declared, Kurtis Kaminishi: None declared, George Papiodis: None declared, Jane McDowell: None declared, Camille Cotton: None declared, Huma Ansari: None declared, Meredith Marinaro: None declared, Jeffrey Gelfand: None declared, John H. Stone Industry grants Q32Bio Chair, Scientific Advisory Board Steritas Chair, Data & Safety Monitoring Board Merck Industry consulting: Amgen, Zenas, Sanofi, AcepodiaBio, Novartis, HingeBio, ZipBio, Argenx.