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Steroids and Me: A Practical Tool For Shared Decision-making About Glucocorticoid Tapers

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Equipping Steroid-treated Patients to Work with Their Doctors

Abstract

Background/Purpose

Before 2024, patients had no comprehensive, curated educational resource about steroid use to facilitate collaboration in their own care. Consequently, shared decision-making around steroid treatment had been challenging.

"Steroids and Me" (Sam) was co-created by academic clinicians, patients, patient advocacy groups and industry leaders to develop a patient-focused program to help patients and doctors work together to optimize steroid use.

Objectives

We report on two years of Sam Development and two quarters of Sam Engagement. We present aggregated data from 2024 Sam users from the Vasculitis Foundation, and follow up with 2025 data from steroid-treated Sam users with inflammatory diseases such as Sarcoidosis, IgG4-RD, Lupus, Asthma, Myasthenia Gravis, and Crohn's Disease.

Methods

Sam Development:

Phase 1 (Resource Review) was a survey of the medical literature and internet for current, scientifically rigorous, patient-focused content on steroid use in clinical care.

Phase 2 (Needs Assessment) consisted of 2 international roundtable meetings of patient advocacy group leaders and industry representatives (total participants, n=36); separate meetings with 6 patient advocacy groups; 3 patient focus groups; and meetings with industry representatives from 5 companies.

Phase 3 (Sam Build) consisted of designing a cloud platform optimized for the mobile phone and tablet. In this phase, a 34-member Sam engagement team of steroid-treated patients was recruited for one-on-one meetings for user testing and journey validation toward learning and symptom tracking.

Sam is a patient companion structured to provide learning modules and side effect tracking, which align with several glucocorticoid toxicity clinical outcome assessments: the Glucocorticoid Toxicity Index (GTI), the Glucocorticoid Toxicity Index-Metabolic Domains (GTI-MD), and the Glucocorticoid Toxicity - Baseline Score (GT-SNAPSHOT). Finally, we confirmed side effect inventory the patient-reported companion to the GTI, which is in process.

Sam User Engagement:

Phase 1 (Sam Early Engagement) consisted of introductions to and audits by multiple patient advocacy groups (PAGs). Once approved by each PAG scientific advisory board, Sam is integrated into communication channels (e.g. direct invitation to members, as educational resources on PAG sites, backlinks to Sam from PAG URLs, webinars on steroid-toxicity).

Acknowledgements:

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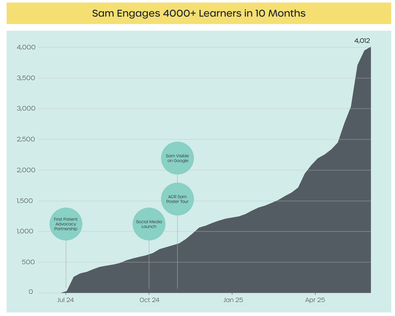
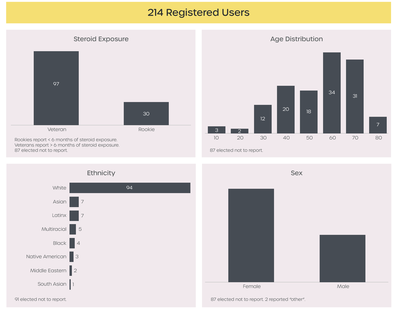
Trends



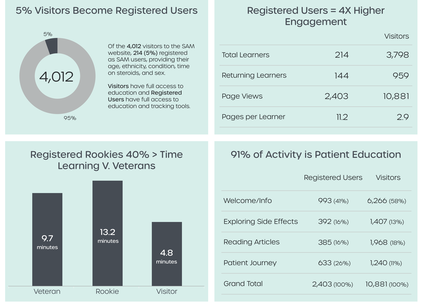
Key findings

- **Sam educates steroid-treated patients and activates them to speak with their doctors about tapering**
- **The information users access and the side effects they log vary by disease**
- **Audience grew to 4,000 steroid-treated users in 10 months: 4-fold growth since ACR 2024**
- **Patient Engagement Time: 350 times longer than the global average**
- **Registration rate is 5%: two times higher than the global average**
- **90% of activity on Sam relates to patient education**

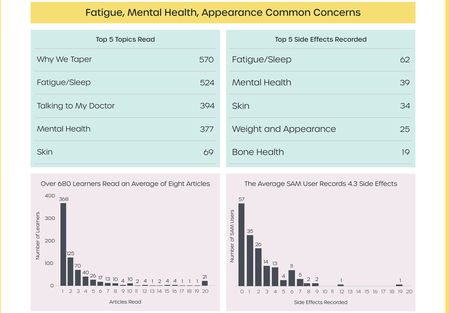
Demographics



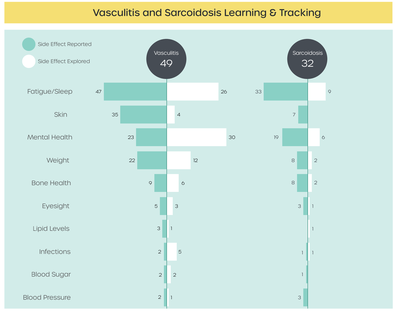
Engagement



Learning



Diagnosis



Development support from abbvie, Amgen, argenx, Sterilos, Zenas

Results

Sam Development:

In **Phase 1** (Resource Review), audits identified not a single source of curated, comprehensive, patient-focused material on steroid-toxicity.

In **Phase 2** (Needs Assessment), patient advocacy groups representing lupus, vasculitis, pemphigus, myasthenia gravis, sarcoidosis and IgG4-related disease participated. Discussions with individual patients and groups of patients identified major unmet needs that were amplified by patient advocacy group leaders and industry. The wish was for original, scientifically rigorous, patient-friendly information all in one place. The focus groups asked for tracking tools and journal capabilities as well. Sam provides tools, including mood and side effect tracking, that prepare patients for shared decision-making conversations with their providers. Sam collects and stores longitudinal patient-reported data and displays a 30-day look back to summarize side effects in anticipation of follow-up clinic visits.

Phase 3 (Sam build), was delivered as minimum viable product at EULAR 2024. Within a few months, early user data showed impressive engagement, intuitive design, steroid rookies (steroid initiated for < 6 months) as well as veterans (steroid initiated for > 6 months), useful content and effective tracking tools. Sam includes teaching videos and written modules about steroid adverse events from experts in: ophthalmology, infectious disease, psychiatry, nutrition, rheumatology, gastroenterology, and asthma. Sam has 50 disease indications preloaded, teach and tracking of over 25 common, important, and dynamic steroid toxicities and side effect tracking capacity for any steroid treated patients.

Honoring HIPAA, GDPR and state-specific data privacy laws that unfold continually, Sam is a free, intuitive educational platform. The same educational content is available to visitors as well to users, who register to use the tracking mechanisms.

Sam User Engagement:

Phase 1 (Sam user cohorts) from one email invitation to the membership of the Vasculitis Foundation, early user data reflected:

- Strong engagement in learning about steroid-toxicity
- High conversion rate: 18% of all visitors became registered users
- Major interest in "Why we taper" and "How to talk to my doctor"
- Average number of articles read: 5
- Average number of side effects tracked: 4
- Average session time: 5 minutes with a maximum of 100 minutes

Conclusion

Steroids and Me (Sam) is a unique, curated, patient-focused resource that has been missing over the 75 years during which steroids have been the standard of care. Sam's core is a rigorous, patient-facing program that engages and educates lay users in plain language, results in deeper understanding of the power and pitfalls of steroid treatment - including ways to mitigate steroid side effects on quality of life. By empowering patients for meaningful conversations with their medical providers that foster shared decision-making around steroid use is an essential step toward safe steroid tapers.

Sam delivers a vital tool in shared-decision making models in patient care. Early data indicate robust adoption that addresses a major unmet need in patient education around steroid use, strategies for tapering, and working with clinicians to optimize treatment.

Steroids and Me is a practical approach to shared decision-making by educating and engaging steroid-treated patients in their own care.

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