TRINITY

NAVIGATING SCARCITY: LEVERAGING AI TO ADDRESS THE CHALLENGES OF IDENTIFYING RARE DISEASE KEY OPINION LEADERS (KOLS)

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INTRODUCTION

- Identifying and engaging key opinion leaders (KOLs) is critical to informing research, medical education, and market shaping activities for HEOR, Medical Affairs and Market Access professionals. However, in rare and ultra-rare diseases, the paucity of clinical experts, limited literature, and lack of centralized data pose unique challenges to effective KOL identification (ID) / mapping. Traditional methods rely on publication track record (citation analysis), congress presence, and internal networks—often excluding non-traditional experts or "rising stars."
- Artificial intelligence (AI)-driven platforms have emerged as a potential solution, offering rapid access to a broad range of data inputs across digital, clinical, and professional domains. The extent to which current tools meet the specialized needs of rare disease Medical Affairs professionals remains unclear.
- This study aimed to benchmark current KOL ID / mapping practices in rare disease, evaluate perceptions of AI-enabled tools, and identify gaps and opportunities to improve future ID / mapping strategies.

OBJECTIVES

- . Understand current KOL ID workflows and challenges specific to identification of experts in rare and ultra-rare indications
- Benchmark existing AI-tool capabilities against stakeholder needs and desired functionalities
- Identify remaining gaps, functionality preferences, and opportunities to advance AI-based KOL ID to facilitate industry partnerships and future research collaborations

METHODS

Primary Research

• Five in-depth 45-minute interviews were conducted with Medical Affairs experts across pharmaceutical and biotech companies with experience in rare disease KOL ID / mapping. Each interview followed a structured discussion guide, covering professional experience, ID criteria, tool usage, perceptions of AI, and future needs. Experts provided both qualitative insights and quantitative ratings on the effectiveness of traditional and AI-enabled tools using a 1–7 Likert scale. Quantitative results were analyzed using descriptive statistics; sample was not powered to assess statistical significance or comparative analyses.

Secondary Research

- To benchmark existing AI-driven KOL ID / mapping tools against traditional methods, targeted research of available commercial platforms was conducted. Each tool was assessed against a framework derived from interviews, evaluating capabilities across seven core input domains:
- Publication track record
- Clinical trial involvement
- Conference participation
- Social media / Digital footprint
- Gray literature
- Real World Evidence claims data
- Industry partnerships
- Findings were synthesized to identify **methodological archetypes** distinct platform approaches defined by the primary data sources and techniques used for KOL ID / mapping. Each archetype was evaluated for capability coverage, platform gaps, real-time update frequency, setup timelines, and overall alignment with unique needs of rare disease Medical Affairs teams.

RESULTS **Primary Research: Quantitative Insights**

Primary Research: Qualitative Themes

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Quick, intuitive **filtering of SMEs by key metrics** – disease, topic, and advocacy potential

Secondary Research: Al-driven Tool Benchmarking

Social

Signal Platforms

Claim-Based Profilers

Trial-Centric Identifiers

Indication-Tailored Engines

Multi-Source Integrators

Ask A Question:

Figure 1 | Perceived Effectiveness of KOL Identification Data Sources





Figure 1. Average effectiveness ratings of traditional and emerging data inputs for rare disease KOL ID / mapping (1–7 scale).

rent Gaps: Experts voiced some limitations with traditional trics (e.g., publications) that do not comprehensively reflect Jence, sentiment, or relevance in underserved indications.

- ward-Looking Benefits: Experts appreciated the speed, breadth, automation of AI-driven tools, particularly for top-down identification and a "first pass" at filtering.
- **Considerations and Implications:** Manual validation remains essential to tailor outputs, validate affiliations, and correct for inaccuracies in data.
- Rare disease experts provided specific preferences around capabilities of AI-enabled KOL ID / mapping solutions, including: **Continuously and regularly** monitor expert sentiment across
- languages and formats **Proactively identify rising stars** and multi-language influencers
- **Track shifts** in expert positioning over time (e.g., sentiment trendlines, engagement frequency)
- **Figure 2** | Archetypes of Al-Driven KOL Identification Tools



Figure 2. Heatmap illustrates the capability coverage across five identified archetypes of AI-driven KOL mapping tools. While many platforms excel in specific domains, none offer comprehensive functionality across all seven key data inputs prioritized by rare disease medical affairs experts. Each archetype plays a distinct role in the KOL mapping ecosystem, but major gaps remain—particularly in integrating real-time sentiment analysis, gray literature, and early identification of emerging influencers. No single tool fully meets the diverse, evolving needs of rare disease stakeholders, highlighting the opportunity for more holistic, multi-source AI platforms.

- for early-stage filtering.
- out of 7.
- around data quality and interpretability.
- rising stars, advanced care providers, or crossdisciplinary influencers
- " they're aligned with your medical strategy. – Medical Director, Large Pharma
- from a publication title.
- every quarter.
- starting to tweet in the field.

Based on secondary research, five core archetypes emerged in the AI-enabled KOL mapping landscape. While each brings unique strengths, no single platform offers complete coverage across all critical data pillars prioritized by medical affairs leaders in rare diseases:

- academic depth.
- broader scientific influence.
- disciplinary influencers.
- real-time sentiment.



Across all respondents, AI-driven tools were perceived to reduce KOL identification time by >75%, especially

• Traditional sources (e.g., publications, conferences, etc.) remain the primary foundation of KOL mapping, with mean effectiveness scores ranging from 3.2-4.6

Emerging sources such as social media and gray literature were rated lower (1.8–2.6), with concerns

Experts highlighted the limitations of relying solely on publication track record, noting gaps in identifying

Some of the tools get you fast data, but they miss nuance.

For example, they'll tell you someone is active, but not if

Give me a tool that understands sentiment—are they an advocate, neutral, or opposed? I shouldn't have to guess

– Medical Director, Clinical-stage Pharma, **Rare Disease Expert**

We need something that updates in real time and learns from our inputs. Like a dynamic shortlist that improves

- Medical Director, Mid-size Pharma, Rare Disease Expert

If The dream is a tool that picks up on rising stars. People who just gave an informative presentation, or who are

> - Senior Medical Director, Clinical-stage Biotech, **Rare Disease Expert**

Social Signal Platforms specialize in identifying digital opinion leaders and online engagement patterns but often lack clinical or

Claims-Based Profilers deliver insights into real-world prescribing behavior and treatment adoption but typically overlook

Trial-Centric Identifiers are effective for locating investigators with clinical trial experience but may miss rising or cross-

Indication-Tailored Engines are custom-built for specific rare diseases and can incorporate multiple data inputs, but they require lengthy setup timelines (4–8+ weeks) and come with high cost and limited scalability.

Multi-Source Integrators aggregate data from key traditional domains – such as publications, clinical trials, claims, and conference participation – but often lack

coverage of social media, gray literature, and

KOL Mapping for Rare Disease Experts

Figure 3 | Current State and Future Direction of Rare Disease KOL Identification





Figure 3. (A) Current State: Often requires strategic layering or SME supplementation due to fragmented solutions that lack integration of critical inputs like clinical reach, digital influence, and advocacy potential. (B) Future Direction: AI-enabled platform with real-time updates, capable of integrating all inputs to dynamically understand influence.

DISCUSSION & CONCLUSION

Al is accelerating KOL ID / mapping — but gaps persist, especially in rare diseases.

advocacy potential

Conventional methods remain standard practice but are time-intensive.

Al tools offer speed — but require manual validation.

desired engagement goals.

A vision for the future is emerging.

Across interviews, experts shared preferences for future-state platforms; experts envision tools that:

- Continuously monitor sentiment and topic focus across publications, presentations, and social channels
- Detect rising stars, including early-career experts and multi-language influencers
- Enable custom filters by disease, therapeutic area, geography, and level of advocacy

Al is a powerful accelerator — but not a replacement.

in rare disease KOL ID / mapping.

FUTURE DEVELOPMENTS

needed to:

- Integrate siloed data streams into a single, dynamic environment
- Leverage real-time sentiment analysis to track evolving KOL perspectives
- Tailor discovery and engagement tools for Medical Affairs users through intuitive filtering and context-aware personalization

The next generation of AI-driven solutions not only identify experts but also anticipate influence, adapt to strategic needs, and redefine KOLs to support research partnerships, publications, and P2P engagement.

ABBREVIATIONS

SME – Subject Matter Expert | KOL – Key Opinion Leader | AI – Artificial Intelligence | HEOR – Health Economics and Outcomes Research | P2P – Peer-to-Peer

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Our findings highlight a fragmented landscape; no single platform effectively integrates the full range of data sources cited as critical for rare disease settings — including gray literature, sentiment tracking, and advanced filtering by

Experts reported relying heavily on publications and congress data (average effectiveness rating: 3–4 out of 7). These traditional sources were valued for their credibility but lacked context, sentiment, and real-time adaptability

• Experts estimated AI-driven tools saved >75% in time compared to manual mapping. However, SME input remains essential to refine KOL lists, validate data for accuracy, and tailor outputs by geography, therapeutic expertise, and

• Until tools can holistically integrate quantitative reach with qualitative relevance, SME involvement will remain vital

As the focus on rare the disease landscape and research partnerships within continue to grow, agile AI platforms are