AI-Enabled Social Media Listening to Understand Patient Experience in Lupus

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Disclosures

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Why SML Matters for Patient-Focused Drug Development & HEOR?

Treatment experience & management

Adherence; Dosage & administration patterns; Treatment usage patterns; Treatment decision drivers; Off-label use; Treatment switch/discontinuation

Disease burden & comorbidities

Symptoms & severity; Impact of disease on QoL; Disease progression; Epidemiology of disease; Severity and impact of comorbidities

Disease awareness & diagnosis

Disease awareness; Barriers to diagnosis; Diagnosis experience

Effectiveness

Perceived benefit; Unmet needs; Quality of Life impact; preferences & tradeoffs; relevant outcomes

Safety

Adverse events; Abuse & misuse

Traditional qualitative methods vs social media listening (SML)

	Focus Groups/Interviews	Questionnaires	SML
Geographical constraints	High	Setup dependent	Low
Time and cost	Very time consuming	Time-consuming	Scalable; Low cost
Level of burden to subject	High stress and pressure	Low if done anonymously	Low, patients report voluntarily
New topic identification	Low chance	Very low	Very high
Representativeness	Strongly dependent on patient selection	Strongly dependent on patient selection	Self-reporting biases, but quantitative assessments can be applied
Access to caregivers and other voices	Needs to be predefined in the study	Increases study complexity	Low cost
Time range	Cross-sectional	Depending on the setup	Longitudinal
Difficulty in extracting information from the data	High — manual coding, subjective	Low – pre-structured responses	High – noisy text requires NLP
Biases	Selection bias, reporting bias, recall bias, framing bias	Selection bias, question selection	Selection bias, negativity bias, naive audience bias
Complexity for patients	Medium	Medium	Low

Background of SLE

- Systemic Lupus Erythematosus (SLE) is a **complex, chronic autoimmune disease** affecting multiple organ systems, **with no cure** .[1,2]
- **~ 9:1 female-to-male ratio of incidence**.[3]
- Often **“invisible”:** symptoms may not be obvious to others, complicating recognition and support.[4]
- Life impact:
    - **40-50%** SLE patients reported leaving workforce.[5,6]

Understanding SLE patient experiences is key to improving patient-centered care.

- **FDA Patient-Focused Drug Development Guidance (2022)** recognizes social media as a potential source of patient experience data and outlines ethical considerations for its use.[8]

- AI breakthroughs since 2023, especially **large language models (LLMs)**, enabled the large-scale processing and analysis of unstructured social media text.[9]

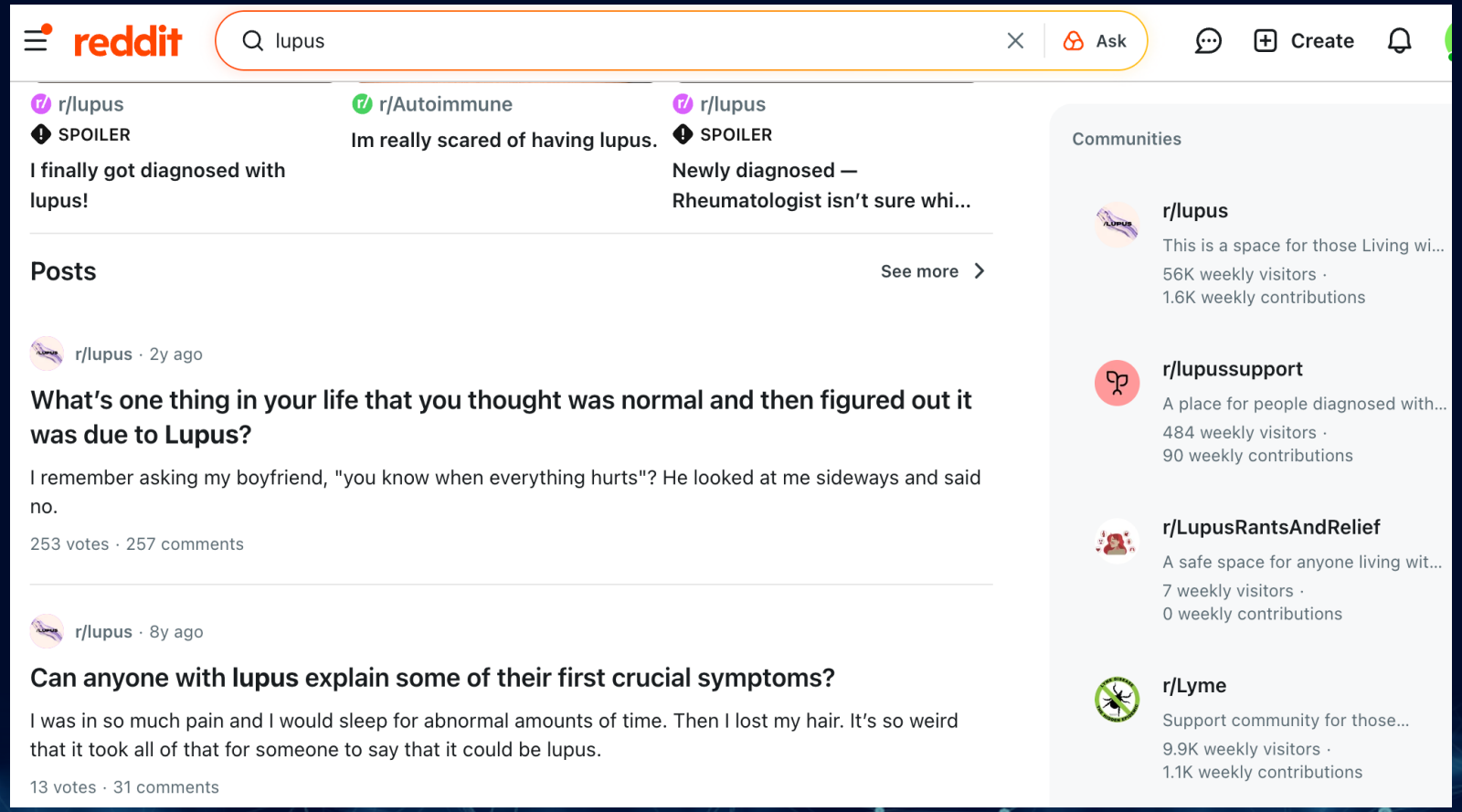
Objective

To apply LLMs to analyze Reddit posts about SLE, identify patient-expressed unmet needs, symptom experiences, and healthcare challenges, and demonstrate how AI-enabled social media listening complements traditional patient-experience research.

Data and Methods

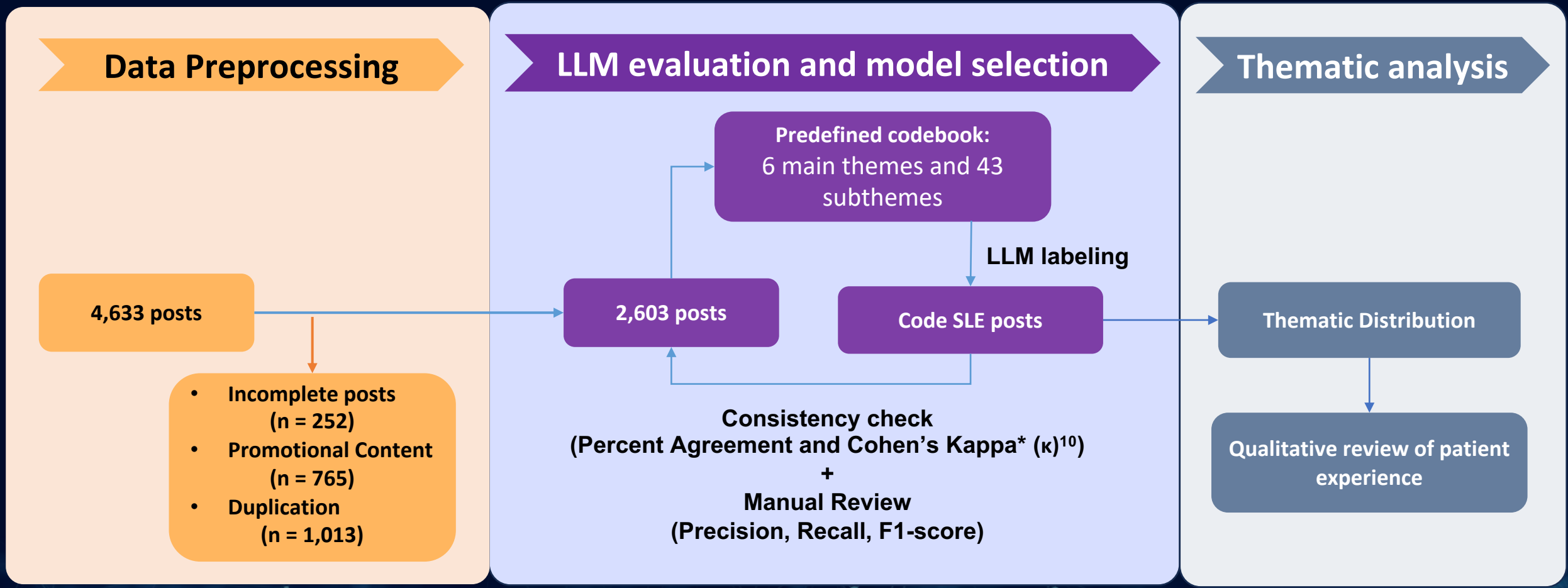
- **Reddit:** **a** public online discussion platform where users share experiences and ask questions

- **4,633** posts were collected from ten lupus-related Reddit subforums* between **October 14, 2025 and November 25, 2025**



Subforums: Topic-specific online communities within Reddit

Workflow for data collection, preprocessing, and LLM-based thematic analysis



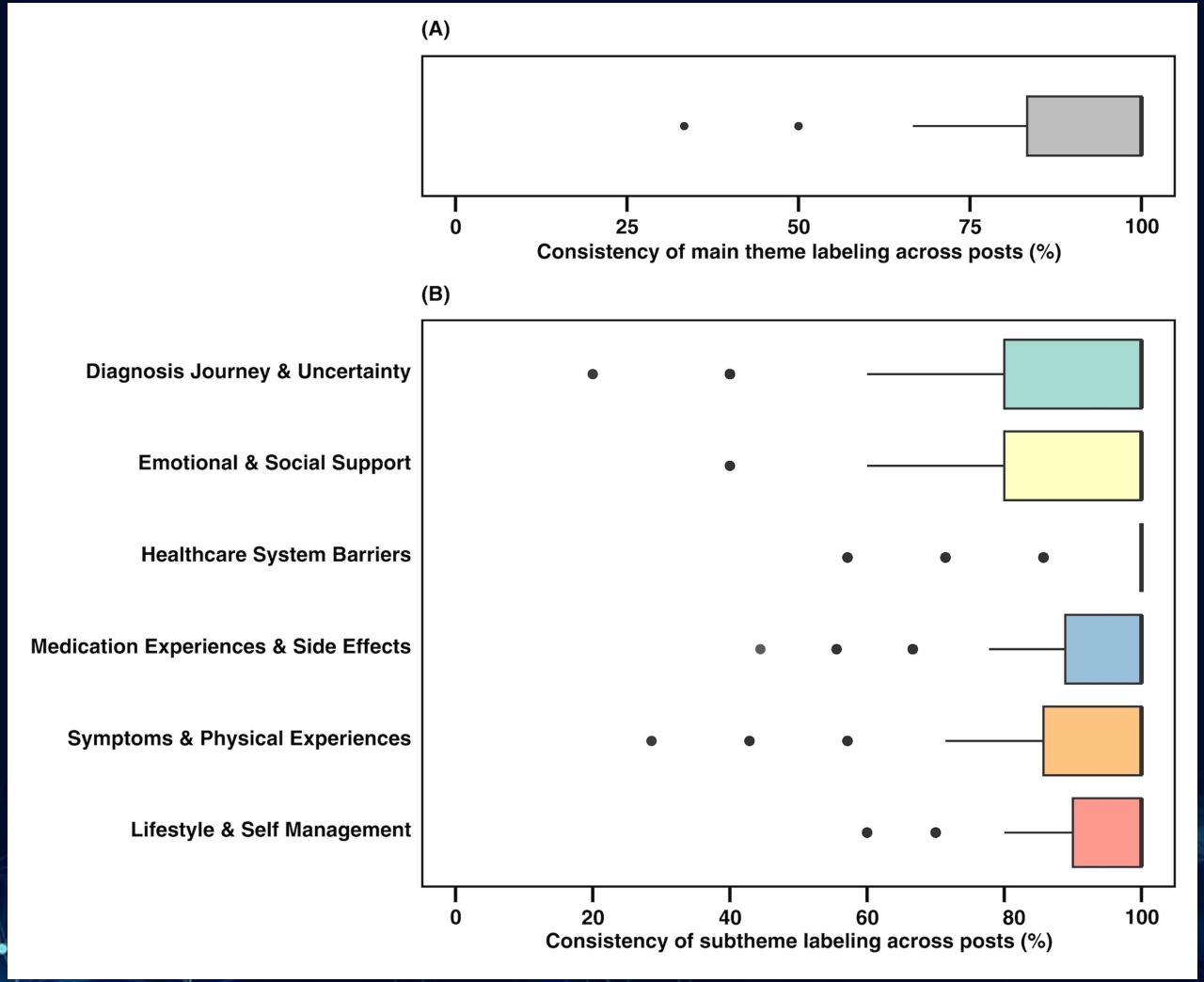
Cohen's Kappa: a statistic used to measure agreement between two raters while accounting for agreement that could happen by chance

Results

- **2,603 unique posts**, with 98.4% published after 2020.
- **Main themes**: 91.04% agreement;
  mean κ = 0.71 (range 0.42 – 0.88)
- **Subthemes**: 94.43% agreement;
  mean κ = 0.71 (range 0.16 – 0.91)
- LLMs performance

	Gemini 3.0 Pro	**OpenAI GPT 5.2**
Precision	0.694	**0.743**
Recall	0.975	**0.977**
F1	0.811	**0.844**

Figure. Thematic consistency of LLMs



Main themes	Subthemes	OpenAI GPT 5.2
Diagnosis Journey & Uncertainty	Delayed, Difficult, or Incorrect Diagnosis	432 (16.6%)
	Emotional Impact of Uncertainty and Disease Progression	860 (33.0%)
	Testing & Results Confusion (ANA, dsDNA, complements)	624 (24.0%)
	Provider Trust/ Distrust	426 (16.4%)
	Other	82 (3.2%)
Emotional & Social Support	Advice Seeking	2190 (84.1%)
	Emotional Coping (e.g., venting, hope, resilience)	1448 (55.6%)
	Identity and/or Future Uncertainty	572 (22.0%)
	Relationship Strain / Interpersonal Challenges	278 (10.7%)
	Bereavement / Loss	47 (1.8%)
Healthcare System Barriers	Access To Care (availability, wait times, transport)	290 (11.1%)
	Patient Education Gaps & External Misinformation	332 (12.8%)
	Dismissal Or Minimization By Providers	424 (16.3%)
	Insurance Challenges (coverage, prior auth)	104 (4.0%)
	Financial Burden Beyond Insurance	122 (4.7%)
	Care Coordination Challenges (referrals, records)	205 (7.9%)
	Clinical Care Errors / Safety Events	46 (1.8%)
Symptoms & Physical Experiences	Acute or Worsening Flares	785 (30.2%)
	Fatigue	642 (24.7%)
	Pain	969 (37.2%)
	Skin Manifestations (rashes, photosensitivity)	632 (24.3%)
	Cognitive Symptoms (brain fog, memory)	183 (7.0%)
	Other Symptom Presentation (e.g., renal, cardio)	980 (37.6%)
	Other	82 (3.2%)

Main themes	Subthemes	OpenAI GPT 5.2
Medication Experiences & Side Effects	Medication Effectiveness / Response	656 (25.2%)
	Medication Side Effects / Adverse Events	527 (20.2%)
	Infusion Experience (e.g., infusion centers, scheduling)	82 (3.2%)
	Treatment Recommendations	435 (16.7%)
	Supplements Or Alternative Therapies	152 (5.8%)
	Treatment Adherence Challenges (forgetting, intolerance)	161 (6.2%)
	Biologics vs Traditional Medications	120 (4.6%)
	Clinical Trials Or Research Participation	23 (0.9%)
	Other	30 (1.2%)
Lifestyle & Self-Management	Symptom Management Strategies	569 (21.9%)
	Diet and Nutrition Changes	190 (7.3%)
	Exercise Adaptations	111 (4.3%)
	Stress Management Strategies	124 (4.8%)
	Workplace Disclosure / Accommodations & Disability Benefits	210 (8.1%)
	Sun Exposure Management	133 (5.1%)
	Self-Tracking / Tools (journals, apps)	71 (2.7%)
	Activities Of Daily Living Adjustments	479 (18.4%)
	Body Image / Identity Adjustments	162 (6.2%)
	Reproductive / Fertility Treatment Considerations	98 (3.8%)

Selected Patient Narratives

Uncertain Diagnosis

*"He (Doctor) said it could be nerve damage, but there was **no way to know for certain**, and since **it could be lupus related**, I needed to see my 'lupus doctor.' He wasn't even willing to try."*

Emotional Distress

*"I've had to have someone **babysit my son almost 24/7**, and I feel like **a failure of a mother** because I can't even hold myself up most days."*

Pain

"I was **swollen everywhere** and so sensitive to touch that **everything hurt** — even getting blood drawn."

Multisystem Burden

*"High-dose prednisone, **mood swings, dizziness, loss of focus, withdrawal symptoms** — it doesn't pick one system; it attacks them all."*

Testing Confusion

*"Most results I understand, but low, total immunoglobulin E… **what does it mean for what I have going on**? I don't see the doctor for another 2 months."*

Diagnostic Delay

*"I've been in and out of a terrible flare for 8 months… and **battling for 6 years just to be diagnosed**."*

Discussion

- Our finding indicated that patients described **a multidimensional burden** spanning from **diagnosis uncertainty**, **emotional and social needs**, **healthcare system barriers**, **treatment experiences**, **symptom burden**, and **self-management challenges**.

  - **Credible complementary methods**
    - Multiple main themes were consistent with existing literature on unmet medical needs and patient-reported experience in SLE. [11-20]
  - **Testing and results confusion (e.g., ANA, dsDNA, complements)** emerged as a frequent unmet need not well captured in existing literature.

- Limitations
  - Self-selection bias in Reddit users
  - Anonymity of the Reddit platform limits sociodemographic information
  - SLE diagnosis is self-reported without clinical verification
  - LLM outputs may vary across runs

Conclusion

- Diagnostic uncertainty and test confusion represent actionable gaps for lupus patients.
- Social media listening captures psychosocial burden at scale.
- LLMs can reliably support thematic extraction with human oversight.
- SML is a complementary—not replacement—method for PFDD.
- HEOR and PFDD teams can use SML for

    Early signal generation prior to qualitative research

    Hypothesis generation for PRO development

    Continuous patient insight between formal studies

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Questions?

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