ORIGINAL PATIENT RESEARCH · MAY 2026

AI Is a Double-Edged Tool in the Exam Room

Forty chronically ill patients describe — in their own words — how they really use AI for their health: the diagnoses it unlocked, the appeals it won, and the fake studies and cancer scares it handed them along the way.

40	38	2	30+
engaged patients, recruited & surveyed direct	have experienced medical gaslighting	trust AI more than their doctors	first-person stories of AI wins *and* failures

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THE HEADLINE

Patients aren't asking whether to trust AI. They've already decided: trust nothing, verify everything.

These forty patients are not casual users. They live with complex, contested, multi-system conditions — POTS, EDS, MCAS, endometriosis, immune deficiencies — and most have been disbelieved by the medical system at some point. They have turned to AI not for novelty but out of necessity, and they describe its value and its danger with the same breath.

> **The pattern is not adoption vs. skepticism. It is sophisticated, simultaneous use of both — patients leaning on AI for what their doctors don't have time to do, while fact-checking it against the medical literature they read themselves.**

This report lays out who these patients are, exactly how they use AI, and the double-edged reality in their own words. It is built from a survey I designed and fielded directly to my own audience — a panel of motivated, articulate patients who chose to share. Three findings stand out:

72%

use AI to research conditions — the most common use, ahead of any clinical task

38%

have changed or nearly changed a medical decision because of something AI told them

~1 in 5

spontaneously raised hallucinations or fake sources — unprompted

A note on scope: n=40 is a qualitative, self-selected sample of highly engaged chronic-illness patients. The value is in the depth and candor of the verbatim accounts, not statistical generalization to all patients.

WHO ANSWERED

A rare panel: complex patients who want to be studied

The respondents skew exactly toward the population that healthcare, femtech, AI and pharma teams find hardest to reach — and most valuable to understand.

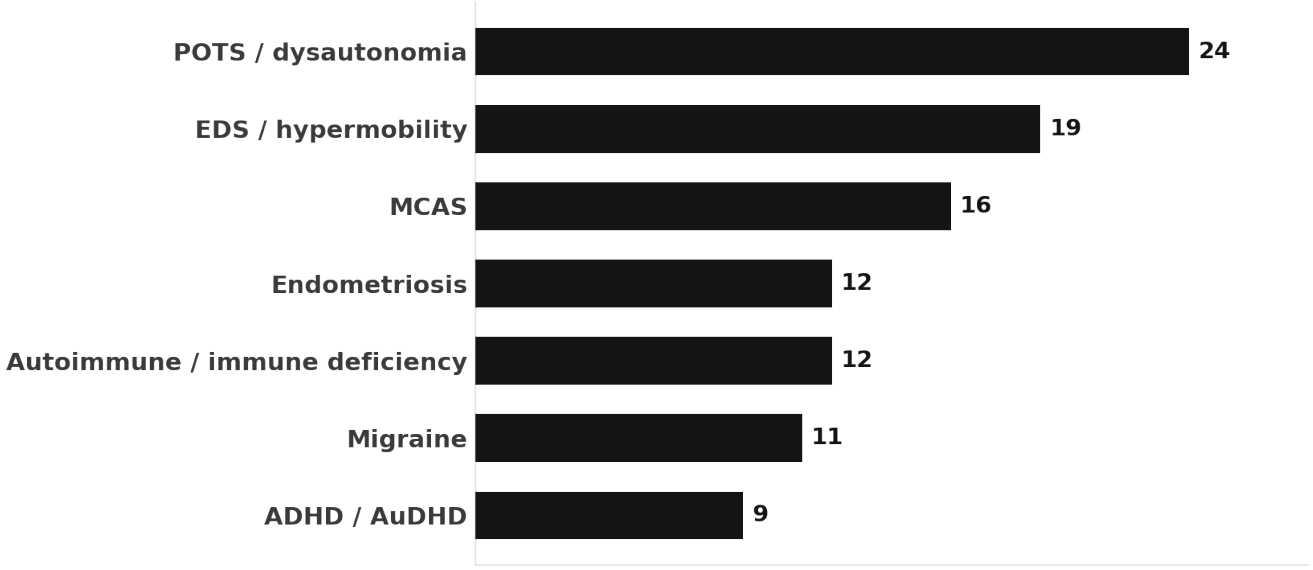
95%
women

73%
aged 25–44

75%
rate their own health literacy "advanced"

60%
identify as a patient advocate

Nearly every respondent carries multiple overlapping diagnoses. The condition clusters below are the textbook "diagnostic odyssey" populations — under-served, frequently dismissed, and deeply motivated to solve their own care.



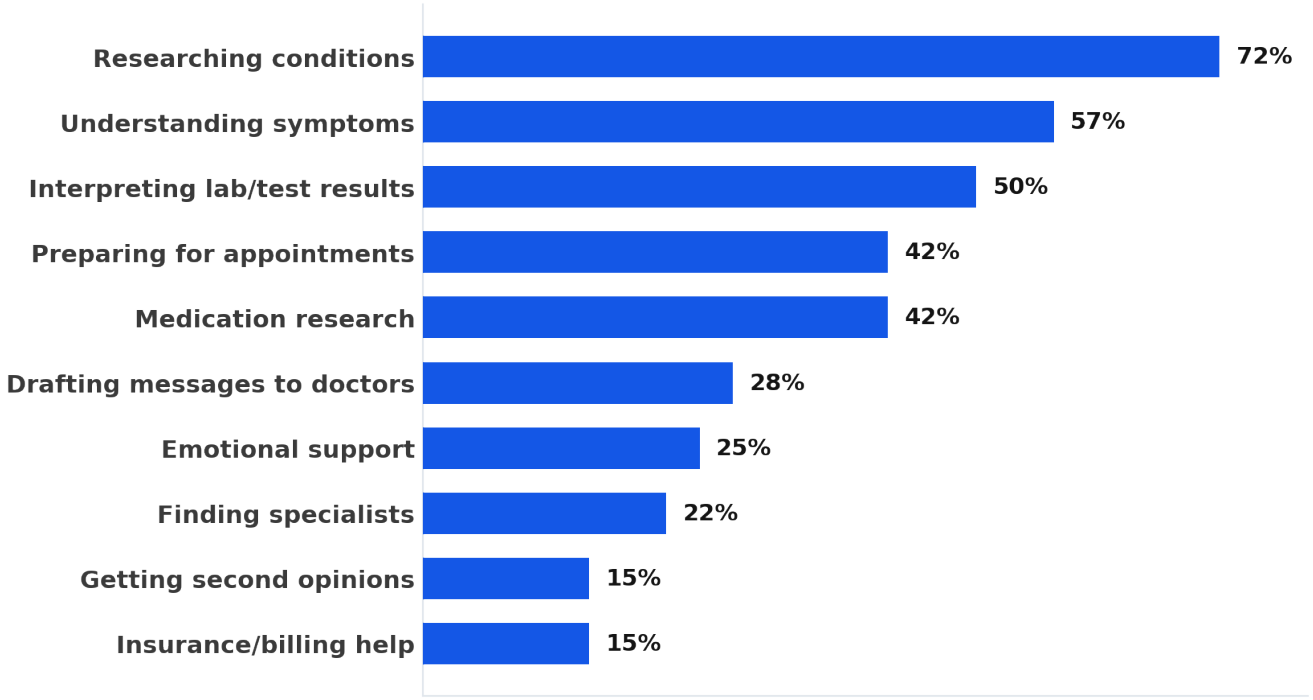
Mentions across primary and secondary conditions (a single respondent typically reports several).

> **38 of 40 told us they have experienced medical gaslighting. That single fact frames everything else in this report — AI is being used in the gap left by a system these patients no longer fully trust.**

HOW THEY ACTUALLY USE IT

Research and translation first. Clinical decisions second.

Patients reach for AI to *understand* — to decode lab results, research a condition, and walk into an appointment prepared. Emotional support and second opinions matter, but the dominant jobs are informational.



Share of 40 respondents selecting each primary use of AI for health (multiple selections allowed).

THE APPOINTMENT MULTIPLIER

"You wait sometimes months for these visits and then the dr comes in and barely gives you 5–10 minutes. So then when you regain your wits on the way home your busy looking at different checkers."

— Janel, Gastroparesis, 45–54

THE WHOLE-BODY VIEW

"It actually looks at my symptoms as a whole instead of by whatever system that doctor specializes in. It connected several symptoms my doctors had not."

— Fiona, Yao syndrome, 18–24

THE DOUBLE-EDGED TOOL

The same patients describe the wins and the harms

This is the core finding. These are not two camps of users. Again and again, one person recounts an AI win and an AI failure within the same survey — which is exactly why their trust is so calibrated.

▲ WHEN AI DELIVERED

"AI helped confirm that MCAS could explain my symptoms… I made an appointment with a specialist who re-diagnosed me, with confidence, and prescribed a low-dose GLP-1. **The GLP-1 is giving me my life and personality back.***"*

— Kristin, MCAS, 25–34 · PhD/MD/JD

"I spent years asking psychiatrists to give me concrete areas stimulant medication could help… Finally I wrote my request into ChatGPT and it gave me exactly what I'd been asking for years. **I think I actually cried because it was just such a relief.***"*

— Yuliya, POTS / Narcolepsy / ADHD, 25–34

"Dosing regimen that dr advised was unsafe based on half life of drug, which AI pointed out. Dr disagreed… I had an adrenal crisis bc dosing was insufficient. I stopped the dr's plan."

— Hannah, Crohn's / Adrenal Insufficiency, 35–44

▼ WHEN AI FAILED

"It offered studies with their titles and DOIs… so I searched for them and they don't exist. **It gave me 8 or 10 different studies and not one of them was real.** *It was eye opening as to how quickly and seriously AI can get things wrong."*

— Marie, Genetic disorder, 35–44

"AI made it seem like the only option was cancer… an 80% chance, if not higher. I had so much anxiety for months… **It was like WebMD but worse bc it came armed with full journal articles proving its case.***"*

— Yuliya, POTS / Narcolepsy / ADHD, 25–34

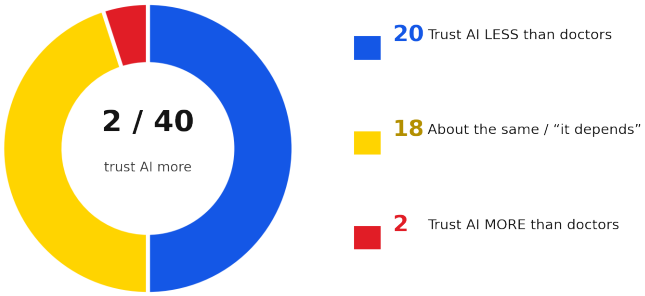
"Claude's results were wrong… ranging from incorrectly identifying medication classes to including medications no longer on the market. Had I not done my own extensive research, the inaccuracies would have been unidentifiable to me."

— Bernadette, hEDS, 25–34

THE TRUST CALCULUS

Heavy use. Low trust. No contradiction.

The defining mindset of this panel: AI is a starting point, never an authority. Only 2 of 40 trust it more than their doctors. Most use it constantly and believe almost none of it without checking.

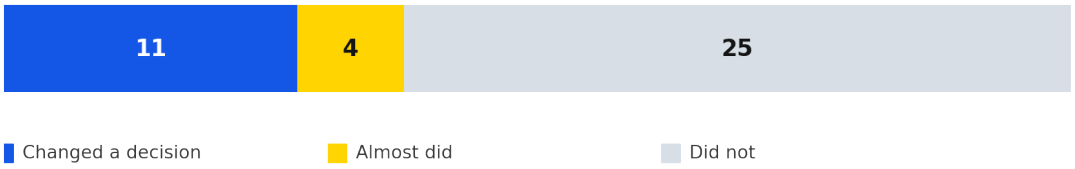


"Do you trust AI more, less, or about the same as your doctors?" (free-text responses, coded).

> *"I have to check what it tells me, which is frustrating. It's been wrong too many times for me… kinda like doctors I used to have being wrong too many times."*
>
> **— Marie, Genetic disorder, 35–44**

> *"I trust AI's pattern recognition skills more than most doctors, but privacy features MUCH less. I prefer to have a medical professional driving the process, even when I'm using AI tools."*
>
> **— Rachel-Anne, Ankylosing Spondylitis, 25–34**

And they act on it — carefully. 38% have changed or nearly changed a medical decision because of AI.



~1 in 5
raised hallucinations or fake sources — unprompted

~1 in 5
described fact-checking or verifying AI as routine

22%
have ever shown AI output directly to a doctor

WHAT IT MEANS FOR YOU

Implications for healthcare, femtech, AI & pharma teams

These patients are early adopters and harsh critics at once — the exact people whose feedback predicts where consumer health AI succeeds or backfires.

AI & product	**Sourcing is the trust battleground.** The single most-cited failure was fabricated studies and DOIs. For this audience, verifiable citations and honest uncertainty aren't features — they're the price of admission. The harm stories cluster around confident, well-formatted wrongness.
Femtech	**The unmet need is whole-person synthesis.** Patients praised AI most when it connected symptoms across specialties — the thing fragmented, time-boxed care can't do. Products that aggregate and translate a patient's own data (labs, history, symptoms) hit the strongest emotional notes.
Pharma & clinical	**AI is already shaping medication conversations.** Patients use it to research drugs, compare options, question dosing, and walk into appointments with a position. Education and adherence touchpoints now compete with — and are filtered through — an AI second opinion.
All teams	**Emotional safety is a clinical risk surface.** Several patients described AI escalating cancer fear or sycophantically validating a self-diagnosis. The line between "supportive" and "harmful" is thin for an anxious, traumatized population — and they notice when you cross it.

> **The opportunity isn't to make patients trust AI more. It's to build tools worthy of the verification reflex they already have.**

ABOUT THIS RESEARCH

The data is good because the audience is engaged

Method. A custom survey, "Patients & AI: Tell Me How You're Really Using It," fielded in May 2026 to my social audience. Forty chronically ill patients completed a long, demanding questionnaire — including multi-paragraph free-text accounts of specific moments AI helped and failed them. Quantitative items were tallied directly; trust and narrative responses were coded by hand. All quotes are verbatim.

Why it's rare. This is not a panel bought from a vendor. These are real, named patients who volunteered detailed, contradictory, deeply personal stories — and the majority opted in to follow-up interviews and paid research. That willingness is the asset.

- 40 complex chronic-illness patients, recruited directly from an engaged audience
- Rich verbatim data: 30+ first-person AI win-and-failure narratives
- Majority opted in to follow-up interviews and paid research sessions

Want to hear directly from this panel?

I design and run patient research with an audience that actually shows up — surveys, interviews, and message-testing with motivated chronic-illness patients across femtech, AI, and pharma. If these voices are the ones your product needs, **let's talk.**

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Figures reflect 40 valid responses after removing one test submission. Percentages rounded. This is qualitative, self-selected research intended for directional insight, not population-level estimates.