COMMON SYNAPSE

2026 IN REVIEW

The Unprompted Patient Journey

GenAI has made explanation abundant. Recognition is still scarce.

Here's what that means for healthcare innovation.

*"You fall asleep fine but you wake up feeling like you didn't sleep at all and **nobody gets it unless they've been through it.**"*

Patient | non-restorative sleep | Reddit

Marcello Patané | Common Synapse | October 2026

commonsynapse.com

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ABOUT THIS REPORT

The question and the data

This report starts from a single question: **when people can get answers from GenAI, what value do spontaneous conversations between patients still have, and what can research learn from them?**

To answer it, Common Synapse brought together **more than 3,800 narratives** from six studies run in 2026, across eight conditions, from multiple sclerosis and Alzheimer's disease to ADHD, depression and menopause. They were written by patients, caregivers and clinicians, mainly on Reddit, YouTube, Facebook and TikTok, and in specialist communities such as HealthUnlocked, the MS Society forum and Mumsnet. The patient-journey framework used to code them was built by Common Synapse from the studies themselves, as they progressed: each study added stages, needs and tensions, and the full corpus was then coded again against the final version.

Each post was coded for its stage in the health journey, the sources it names, what the author looks for in other people's experience, stated expectations and decisions, how clinicians appear, narrative tension and lived signals. Findings are reported pooled, by study and by type of source, so that a pattern carried by one platform or one condition can be told apart from one that holds across them.

The full scope, the breakdown by source and the method appear at the end of the report.

3,800+

narratives from public online communities

8

conditions: **multiple sclerosis, optic neuritis, Alzheimer's and MCI, ADHD, autism, depression, sleep disorders, menopause**

5

types of source: **Reddit, YouTube, Facebook, TikTok, specialist forums**

ABOUT COMMON SYNAPSE

Common Synapse is an independent consultancy based in Basel. It turns unprompted patient, caregiver and clinician language from public online communities into structured, source-traceable evidence for early development decisions: which construct to test, which population to study, which outcomes matter and how to position a therapy.

HOW TO READ THIS REPORT

Unprompted means a post written outside any question asked by a researcher. Percentages describe the posts analysed and estimate no prevalence in a patient population. One author can contribute more than one post. S1 to S6 refer to the six studies described in Part 4.

Executive summary

Anyone can now get a fluent answer from AI in seconds, and more than 230 million people ask ChatGPT health questions every week [1]. Yet two in three US adults still get health information from people with a similar health issue [3]. **This continued reliance on peer experience is worth studying.** Online conversations show how people build meaning, expectations and decisions along their health journey, and they surface needs and signals that can guide research before its hypotheses are fixed.

Across 3,835 posts from six studies:

61%

of posts turn to other people's experience. **82% of those look for more than an explanation.** Share of all posts: practical advice 24%, recognition 14%, inspiration 10%, comparison 8%, validation 4%, help deciding 4%.

51% → 34%

What people need changes along the journey. **Before diagnosis, 51% seek an explanation.** At the treatment decision, help deciding leads at 34%; on treatment, practical advice leads at 27%.

47%

describe the condition in **concrete everyday terms** that a clinical label or score would flatten. It appears in every study and every type of source.

1 in 5

posts (19%) hold **two competing meanings at once**: sleeping without feeling restored, stable scans with a harder day, a treatment that helps and costs.

The corpus was built around conditions, and only 7 of 3,835 posts name GenAI as a source. In those few, the AI answer is brought back to other people to share and test. Sources [1] to [3] are listed on page 5.

INTRODUCTION

Anyone with a symptom can now get an explanation in seconds. People still spend hours reading and writing about their condition in public communities. This report asks what they find there that an answer cannot give them, and what research can learn by paying attention.

The question behind the report

A health journey can now begin with a question to GenAI. More than 230 million people ask ChatGPT health and wellness questions every week [1], and a third of US adults used AI for health information or advice in the past year [2]. Yet two in three US adults get health information from people with a similar health issue, and only 18% of those who use chatbots for health rate the answers as highly accurate [3]. If explanation were all people needed, communities of patients would matter less every year.

The posts analysed here point the other way. Most of what people write to each other concerns things an explanation leaves open: whether someone else has felt this, what happened to them, whether it is worth starting a treatment, how to get through the next week.

Why it matters for research

For close to twenty years I led global digital intelligence and insights work across biopharma, consumer goods and media technology. In biopharma, patient insight often reached teams once a programme was in late-stage development, when its design was largely set.

The conversations analysed here hold signals that matter much earlier: how people describe an experience before it has a clinical name, what they count as benefit, which trade-offs they weigh before starting a treatment. Read while a programme is still deciding its construct, population and endpoints, those signals can shape the hypotheses themselves.

How the report is organised

Part 1 describes how people put their health journey together today from search, communities, clinicians and GenAI. **Part 2** shows what people look for in each other's experience, and how that changes along the journey. **Part 3** sets out what these conversations make visible to research, from early signals in discovery to the experience of treatment. **Part 4** sets out, study by study, the hypotheses generated, the uses clients documented and the applications proposed. **Part 5** describes how the practice of patient intelligence changes as a result.

Marcello Patané
Common Synapse, Basel

Sources

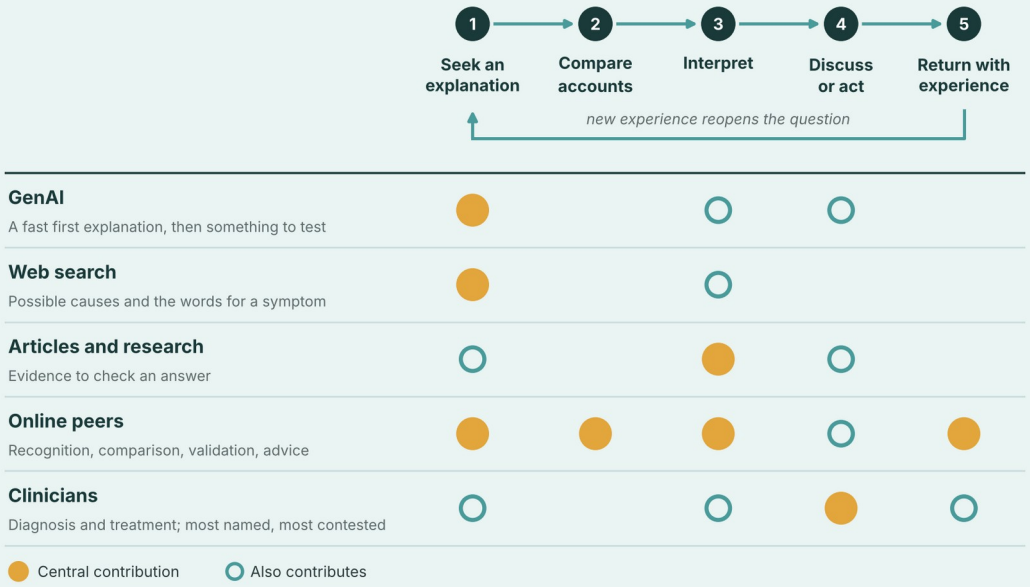
[1] OpenAI, Introducing ChatGPT Health, 7 January 2026
[2] KFF, Tracking Poll on Health Information and Trust: Use of AI for Health Information and Advice, 25 March 2026
[3] Pew Research Center, Users of social media and AI chatbots for health information are more likely to say they are convenient than accurate, 7 April 2026

The patient journey today

People assemble their understanding from search, communities, clinicians and, increasingly, GenAI. No single source carries them through.

FIGURE 1

How information sources contribute across the patient journey



Source: Common Synapse patient-journey framework, built from the studies. Roles overlap: the marks summarise where the posts describe each source contributing, and show no measured prevalence or sequence.

*"I **asked chat gpt** why I kept waking up at 2am. It said that maybe my levels dipped at that time."*

Patient | menopause, sharing what worked with a peer forum | Mumsnet

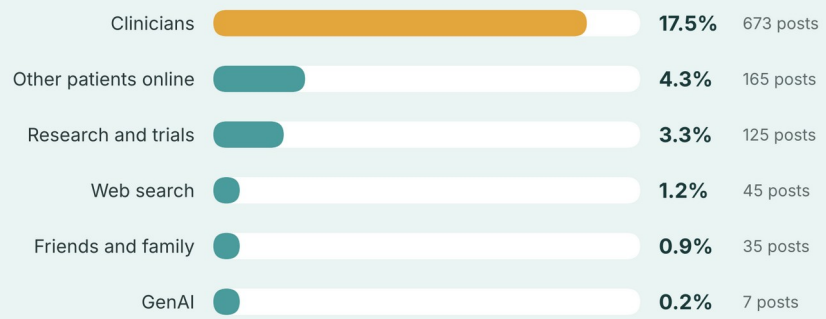
A symptom, a diagnosis or a change in function reopens a question. People look for an explanation, compare it with other people's experience, interpret what it means for them and bring that interpretation into a consultation. Then they return with new experience and start again.

What people name as a source

Across the corpus, people rarely say where information came from. When they do, clinicians dominate: 18% of posts name one. Other patients online are named in 4.3%, research and trials in 3.3%, web search in 1.2%. The community itself is the unstated source: the posts are written to other patients and draw on their replies.

FIGURE 2

Sources people name in their own posts



Source: 3,835 posts. Each bar shows the posts in which patients name that source of information or advice; clinicians, the most named, in amber.

Clinicians are also the most contested source. Of the 981 posts that describe a clinician, 22% describe feeling dismissed or unheard and 16% describe a gap between what the clinic measured and what the person lives with. 14% describe feeling supported.

What the posts say about AI

Only 7 of 3,835 posts name GenAI as a source of health information, and 16 mention AI in any form. The corpora were built around conditions and were never designed to measure AI use; the low count reflects what people choose to write in a patient community. The few posts that mention AI bring an answer to the group to test it, or describe it as a tool that compensates for what the condition has taken. Several come from the Alzheimer's study, where people interpret their own blood-test and genetic results. [S6]

PATIENT VOICES | GENAI IN THE COMMUNITY

An answer, then the people who have lived it

> *"I already use chatGPT a lot [...] I also gave it a lot of my OSCAR reports [...] but eventually,* ***nothing of what chatGPT preconized turned out to solve my issues****"*
>
> Patient | non-restorative sleep and sleep apnoea | Reddit r/SleepApnea

> *"****I had AI do an in depth analysis based on my symptoms over time****, I had a journal with notes, and the fact that I have significant disease burden in my spine."*
>
> Patient | secondary progressive MS | Reddit r/MultipleSclerosis

> *"I get glimpses of myself again! I am remembering words!* ***I can write emails without ChatGPT!****"*
>
> Patient | perimenopause, after starting oestrogen | Reddit r/Perimenopause

> *"****I don't think we have anything to worry about****, my final score, Im guessing like yours, was 0.00622 [...] from chatGPT: p-tau217: A newer biomarker"*
>
> At-risk adult | Alzheimer's blood test, replying to another commenter | YouTube

In each case the AI output becomes material for the conversation with people who have lived it.

For generative engine optimisation (GEO), answer engines respond to questions in patients' own words, and these communities record those words first.

What people look for in each other

Six in ten posts turn to other people's experience. Most look for something beyond an explanation.

*"Is **anyone else** always tired even after full 8 to 10 hour of sleep and 2 cups of coffee?"*

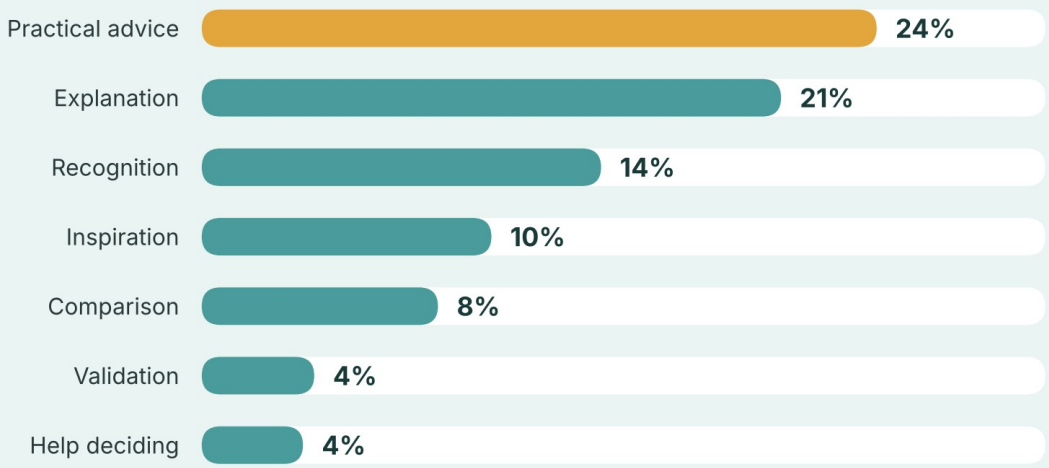
Patient | ADHD | Reddit
r/adhdwomen

In 61% of all posts, the author is doing something in relation to other people's experience: asking, recognising, comparing, reassuring or advising. Of those 2,325 posts, 82% go beyond seeking or offering an explanation.

The pattern is stable across very different conditions. The share of posts that turn to others varies little from one study to the next.

FIGURE 3

What people look for in other people's experience



Source: 3,835 posts. One post can carry several functions.

Explanation

21%. People ask what is happening and why. The question often arrives already shaped by experience: "*What is it when I can sleep several hours and still feel exhausted?*" (Patient, ADHD, Reddit). [S2]

Recognition

14%. "Anyone else?" is one of the most frequent openings in the corpus. Recognition works in both directions: "*this is exactly how my vision was when I had my first major relapse. Hang in there*" (Patient, optic neuritis, Reddit). [S3]

Comparison

8%. People compare courses, treatments and outcomes. Comparison is most frequent in the ketamine study, where commenters set their own sessions against the creator's: dissociation, number of treatments, whether it worked. [S5]

Validation

4%. Validation is the request to be believed, and it rises where clinicians have dismissed the person, as in progressive MS and optic neuritis. [S3, S4]

Inspiration

10%. Success stories and encouragement carry hope across the group: "*I'm sleeping like a teenager now and I feel like myself again after so many years*" (Patient, menopause, YouTube). [S2]

Practical advice and help deciding

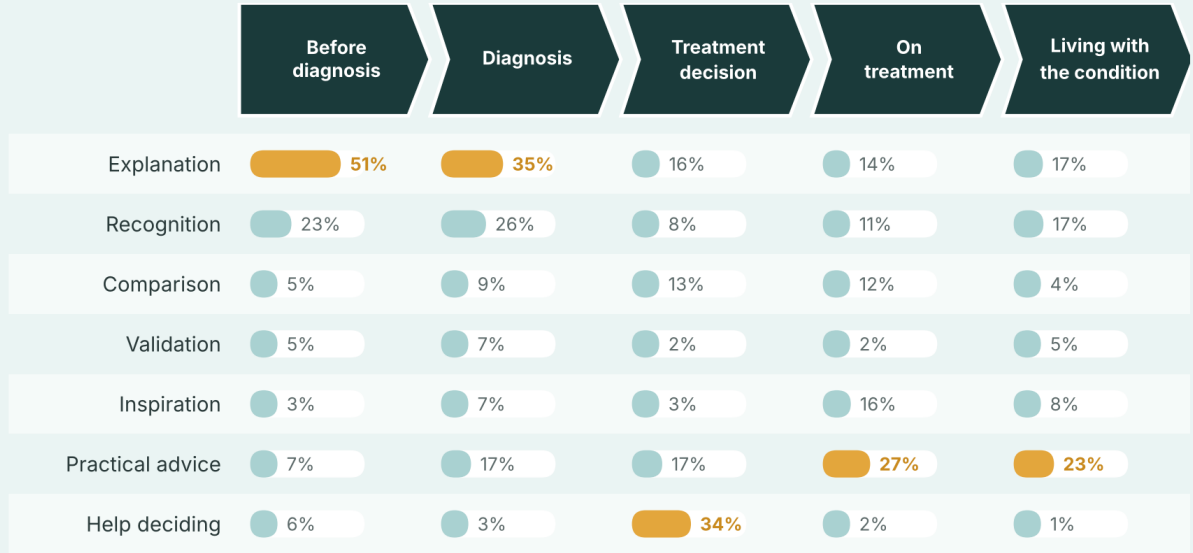
Practical advice is the most common function overall at 24%: workarounds, routines, what to ask the doctor. Help deciding is rarer at 4%, and concentrated at one moment of the journey.

The journey changes what people need

Reading the same functions by journey stage shows a clear progression. Explanation dominates before a diagnosis. Recognition stays high through diagnosis. At the treatment decision, people ask for help deciding and compare options. On treatment, they trade practical advice and hope. Living with the condition, recognition returns alongside the most detailed descriptions of daily life.

FIGURE 4

What people look for at each stage of the journey



Source: Share of posts at each stage carrying each function; the amber bar marks the leading need. 262 posts with no clear stage are excluded.

Expectations, decisions and tension by stage

Stage	Expectation stated	Decision in play	Narrative tension	Clinician dismissed or gap
Before diagnosis	23%	41%	22%	20%
Diagnosis	23%	39%	14%	26%
Treatment decision	43%	94%	40%	10%
On treatment	12%	35%	23%	7%
Living with the condition	14%	8%	15%	10%

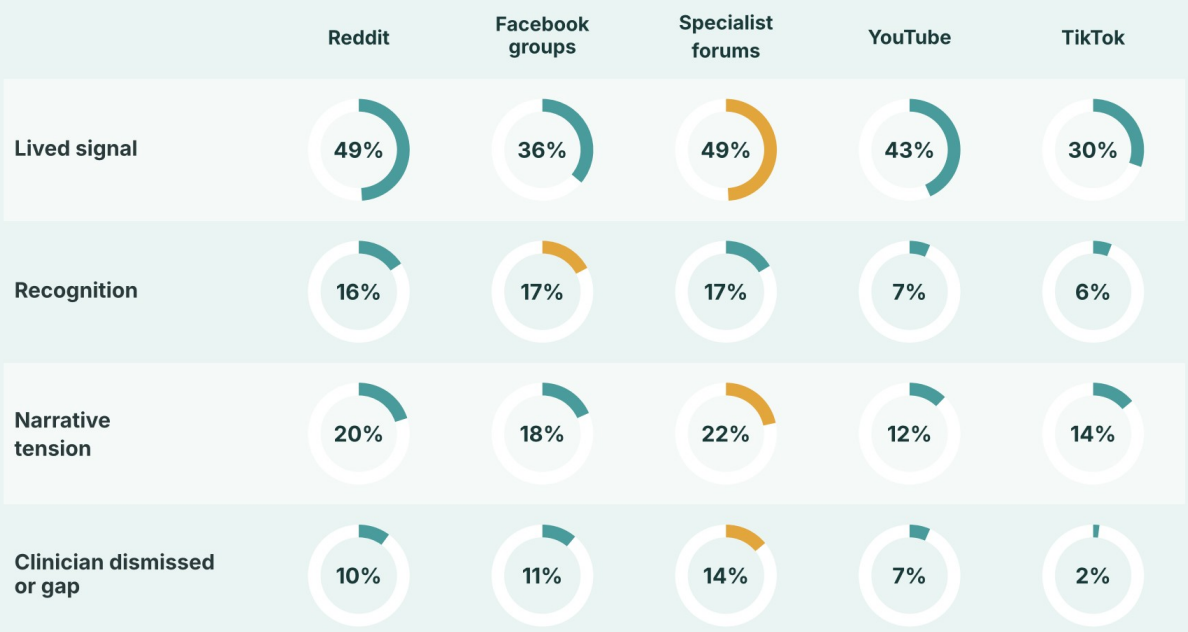
Share of posts at each stage.

The pattern holds across sources

Following the source-diversity principle, every measure was compared across five families of source: Reddit, Facebook groups, specialist forums, and comments under YouTube and TikTok videos. Lived signals, recognition, narrative tension and reports of clinical dismissal appear in all five, so none of the findings rests on a single platform.

FIGURE 5

Four measures across five families of source



Source: Share of posts in each family: Reddit 2,674, Facebook 180, specialist forums 315, YouTube 515, TikTok 151.

Where patients still talk to each other

As social media turn into interest media, with feeds built by recommendation more than by people talking to each other, Reddit and specialist forums gain relevance as the places where patients still answer one another. The posts show the difference. Recognition appears in 16% of Reddit posts, 17% of forum posts and 17% of posts in Facebook groups, against 7% on YouTube and 6% on TikTok, where people mostly respond to a creator. For research, the community platforms are where recognition, comparison and validation can be observed directly.

What these conversations make visible to research

From early signals in discovery to the meaning of benefit during treatment, the posts carry evidence that clinical framing often flattens.

*"That feeling of being half-lost in my own world, **like my brain is running a few seconds behind.**"*

Patient | menopause | Reddit r/Menopause

Three properties make these posts useful to research. 47% describe the condition in concrete everyday terms. 19% hold two competing meanings at once. And 26% involve a health decision being weighed or taken. Each points to a different research use.

Early signals and hypothesis testing in discovery

A lived signal names an experience in the terms people use to live with it: a task, a time of day, a role, a sensation. 47% of posts carry one. Lived signals appear in every study and every type of source, and are least frequent where authors have no symptoms and write about tests, genes and prevention. Before diagnosis, 43% of posts already describe the experience this way, while it still has no clinical name.

For discovery teams this is the material of a hypothesis. Patients in the sleep studies separated sleeping from feeling restored before the construct appeared in a protocol; in progressive MS, they described decline their scans did not show. Both were handed to the teams involved as hypotheses to test (Part 4).

Narrative tension: when the contradiction is the finding

Coding can erase meaning when contradictory language is forced into clean themes. Across this corpus, one post in five holds two competing meanings at once, and the type of tension follows the condition. That makes tension a direct guide to what a programme should measure.

Tension	Posts	Where it concentrates
Sleep without restoration	169	Sleep and cognition, ADHD, menopause, autism
Clinically stable, lived decline	138	Progressive MS, optic neuritis
Treatment helps and costs	217	All conditions
Hope against scepticism	59	Progressive MS
Fear of treatment, fear of disease	42	Optic neuritis, sleep, ketamine
Control against dependency	42	Sleep and cognition, ADHD, menopause, autism
Other double binds	54	Several conditions, including relief that costs identity
All narrative tensions	721 (19%)	Share of all posts

Each post is coded with one tension type at most, so the rows add up to the total.

What benefit and change mean in daily life

Living with a condition, 63% of posts describe it in lived terms: the highest of any stage. These are the posts that tell a team what meaningful change would look like.

PATIENT VOICES | DAILY LIFE

What change looks like from the inside

Four posts from four studies, each naming an activity a standard measure would score only indirectly.

> *"My AHIs are down to the mild range now, but **I'm battling brain fog. I'm about to lose my job.**"*
>
> Patient | sleep apnoea, after treatment | Reddit r/SleepApnea

> *"**I write important things down in a notebook.** My memory is terrible at times but then other days it's perfect"*
>
> Patient | perimenopause | Mumsnet

> *"blurry with floaters and I'm scared that my vision won't be able to be corrected so **I'll have to give up driving.**"*
>
> Patient | optic neuritis | Reddit r/MultipleSclerosis

> *"**My disability continues to progress even as my disease process does not.**"*
>
> Patient | primary progressive MS | MS News Today forum

Expectations and decisions before treatment starts

At the treatment decision, 43% of posts state an expectation or fear about what treatment will do, and 40% hold a narrative tension: the highest of any stage. This is where concerns that never reach a consultation become visible.

> *"I'm scared about the dissociation. **When I was younger, I had a bad trip on acid.**"*
>
> Prospective patient | esketamine | YouTube

In the ketamine study, people still considering treatment wrote about fear of losing control; people in maintenance wrote about cost, travel and clinic time. The same treatment raised different questions at different stages. [S5]

In optic neuritis, newly diagnosed patients described choosing a disease-modifying therapy under pressure: "*Truthfully I am scared on going on any medication but I am strongly urged to do so*" (Patient, HealthUnlocked). [S3]

In the Alzheimer's study, the first decision comes before any treatment: whether to take a test at all. Comments weigh or report a health decision more often here than in any other study. Some refuse a test that comes without a cure: "*No way I'm having this test. Life is stressful enough as it is*". Others want to know so they can plan: "*It gives me a chance to fight it through lifestyle changes*" (At-risk adults, YouTube). [S6]

Where clinical and lived views part

A clinician appears in 26% of posts. Before and at diagnosis, 24% describe dismissal or a gap between clinical and lived views, and progressive MS shows it most often. The gap is a research question in itself: what does each post capture that the assessment misses, and what does the assessment capture that the post cannot? [S4]

What the six studies informed

Each study began with a different question, at a point where the answer could still change a decision.

Each study is reported on three levels, kept apart on purpose. **Hypothesis**: what the posts suggested. **Documented use**: what the commissioning client did with the findings, as stated in a case study the client approved or in its feedback at the readout. **Proposed application**: what the study recommended, still to be confirmed. S5 and S6 were run independently, so they carry hypotheses and proposals only.

S1

Sleep and cognition
Commissioned

Hypothesis. Patients describe sleep that fails to restore as a problem distinct from trouble falling asleep, in their own words, and link it unprompted to named cognitive domains such as memory and focus.

Documented use. The client reviewed the findings with its leadership team at a live readout and commissioned a follow-on study (S2).

Proposed application. Build the construct and the positioning around restoration, in the space patients place between sedation and restoration.

"This is like a gold mine. There's so many more questions to ask." CEO, commissioning biotech

S2

ADHD, menopause and autism
Commissioned

Hypothesis. ADHD shows the clearest sleep-driven subgroup; menopause posts name the most measurable cognitive domains; autism is feasible, with cognition described more vaguely.

Documented use. The comparison went into the client's internal indications review.

Proposed application. ADHD as the lead population, with a sleep-driven subgroup pre-specified at screening; a quantifiable cognitive endpoint in menopause, stratified by hormone therapy; autism as a later exploratory arm.

S3

Optic neuritis
Commissioned

Hypothesis. Many patients describe residual visual deficits after an episode considered clinically resolved, with driving, reading, work and screens as the activities affected.

Documented use. In the case study it approved, the client reports tracing fundraising claims to verbatim patient evidence, and using the findings to inform endpoint selection in its MS programme and the framing of physician communications. It then commissioned a second study (S4).

"The patient data told a different story." CEO, commissioning biotech

S4

Progressive MS
Commissioned

Hypothesis. Patients describe stable scans alongside declining daily function, and follow repair-oriented candidates by name.

Documented use. At the readout, the client said the work let it add patient voice to the competitive comparisons investors ask for, alongside the scientific ones.

Proposed application. Which residual functional burden to measure beside imaging in a repair-oriented programme.

"We went in with a mechanism story we believed in. We came out knowing exactly where patients feel the gap." CEO, commissioning biotech

S5	**Ketamine treatment for depression** Independent	**Hypothesis.** Fear of losing control comes mostly from people still considering treatment; people in maintenance raise cost, travel and clinic time. **Proposed application.** What to ask before a first dose, and which expectations a trial or information plan should address.
S6	**Alzheimer's disease and MCI** Independent	**Hypothesis.** For adults at risk, the first decision is whether to take a test at all: some refuse a test without a cure, others want to know in order to plan, and APOE4 carriers trade prevention protocols and lab values. **Proposed application.** Which questions a test result raises before any clinical contact, and where an information plan for testing should start.

What the studies have in common

In each study the posts reached a question while it was still open. They generated hypotheses at a stage when a team could still act on them; confirming those hypotheses takes methods built for confirmation.

How patient intelligence changes

When explanation is available to everyone, the value of listening moves to what people do with each other, and to reading it early enough to act.

Capture what people do with each other, alongside what they talk about.

1. From topics to functions

Topic and sentiment coding describe what a conversation is about. Function coding describes why it happens: explanation, recognition, comparison, validation, inspiration, practical advice, help deciding. The second view shows where in the journey a need sits and what kind of evidence will meet it.

2. Source diversity as research design

No single platform represents patient reality. Sources are chosen because they illuminate different parts of the question, and findings are checked for convergence across them. Where sources diverge, the difference is reported and interpreted. As social media turn into interest media, Reddit and specialist forums carry more of the exchange between patients, and they weigh more in the design.

Research question	Sources to weight
What does this symptom feel like?	Reddit and specialist patient forums
What language is emerging?	TikTok and Reddit
How does the experience unfold over time?	YouTube, forums and long-form posts
What do caregivers notice?	Facebook groups and association communities
Why do people stop or switch treatment?	Treatment-review sites, Reddit and HealthUnlocked
How informed are patients about the pipeline?	Condition publications and dedicated communities

Adapted from the Common Synapse source-diversity framework.

3. Automation in tiers, with human review

Explicit facts such as a named treatment, a platform or a cognitive domain can be coded at scale with periodic checks. Interpretive codes such as sentiment, causal attribution and functional burden need machine support plus human review of uncertain cases. Ambiguity, archetypes and strategic interpretation stay with the analyst. This report used the same structure: language-model coding of every post against a fixed codebook, a second model pass on a 400-post sample to measure consistency, and a human review of a 140-post sample to check accuracy.

4. A narrative tension layer

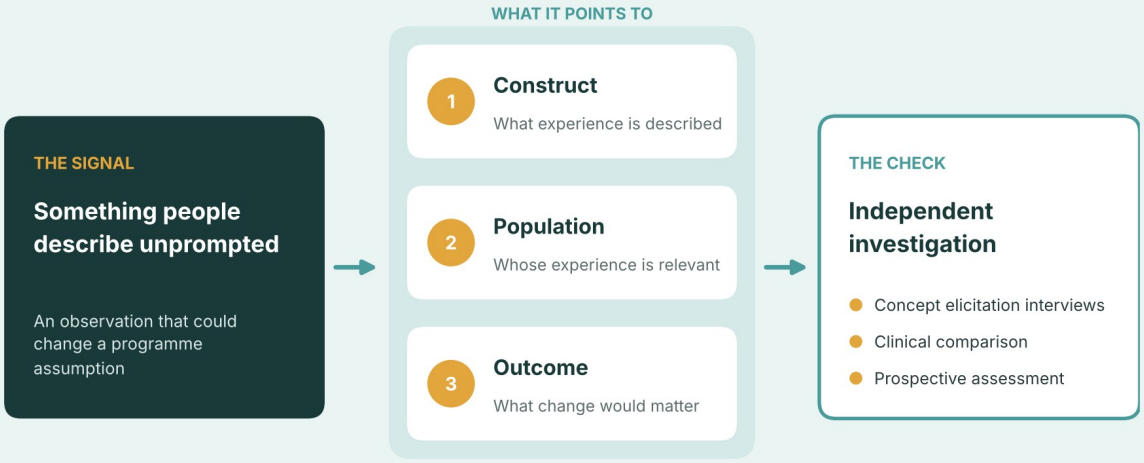
A label such as ‘mixed sentiment’ describes without explaining. Naming the tension, such as stable scan and declining function, or relief at night and grogginess the next day, explains the trade-off behind it, and points to what a programme should measure.

5. Earlier in development

The signals in Part 3 are most useful while a construct, a population or an endpoint is still open. Common Synapse calls this designing patient reality in: bringing unprompted patient language into a programme early enough that the next question a team investigates already reflects how people live with the condition.

FIGURE 6

From a signal in the posts to an independent investigation



Source: Common Synapse framework. A signal points to a construct, a population or an outcome; each is then confirmed with a method designed for confirmation.

6. GenAI as a subject of study

As AI answers become part of the journey, they become part of what patient intelligence studies: which questions people bring to AI, which answers they test in communities, and where answer engines and lived experience diverge. A design that searches health communities for AI talk and AI communities for health talk can measure this directly.

What this means for leaders in early development

Role	Question to put to patient posts
Biotech CEO	Does the patient story we tell investors match what patients describe, before the next raise or IND?
Discovery and scientific leadership	Does the experience our mechanism targets have a recognisable expression in daily life, and in which population is it clearest?
Clinical development	What would meaningful change look like in the activities people describe, and does our outcome measure reach it?
Commercial and medical affairs	Which concerns hold people back before the first dose, and which emerge during maintenance?
Medtech and diagnostics	How do people recognise the problem, and where does the pathway stall at home?

CONCLUSION

What patient assumption is your programme making?

Validate patient reality before it is validated for you.

GenAI has made explanation abundant. Confirmation is still scarce, and people still look for it in each other: someone who has lived it, a comparison with people further along, a clinician who knows their case. In doing so they record how they build meaning, expectations and decisions.

For research, that record holds early signals, lived definitions of benefit and the tensions a programme will eventually have to measure. Its value depends on timing: it is most useful while the construct, the population and the endpoints are still open.

Where to start

Start with one assumption whose resolution could change the programme. Name the decision that depends on it and when you need confidence in it. A focused engagement can then show how people describe the experience, what their posts suggest and which further evidence would change the decision.

A useful first conversation starts with three things

01 The decision you need to make

02 The assumption you want to test

03 When you need confidence by

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ABOUT COMMON SYNAPSE

Patient narrative intelligence for biotech and medtech

Validating the science with patient reality.

COMMON SYNAPSE

Common Synapse turns what patients, caregivers and clinicians write in public online communities into structured, source-traceable evidence. The method is social listening and narrative coding: every finding can be traced back to the posts behind it.

The work is built for pre-market decisions, when a construct, a population, an endpoint or a narrative is still open. Clients have used it to trace the patient story they tell investors to verbatim evidence, to feed an indications review, and to inform endpoint selection.

Focus areas

Neurology, rare neurology, neuropsychiatry and ophthalmology, with work extending into immunology and rheumatology.

Who runs it

Marcello Patané runs Common Synapse from Basel, after close to twenty years leading global digital intelligence and insights across biopharma, consumer goods and media technology.

METHOD, SCOPE AND DATA

How the cross-corpus analysis was done

Corpus

All coded posts from the six studies with text available: 3,835 in total. 105 rows that held only a placeholder were excluded. Some studies contribute coded excerpts, others full posts or comments.

Codeframe

One shared codebook: journey stage; sources named; functions in relation to others (explanation, recognition, comparison, validation, inspiration, practical advice, help deciding); expectation; decision; clinician experience; narrative tension and its type; lived signal; one exact supporting quote.

Coding

Every post was coded by a language model working to the fixed codebook, in batches mixed across studies; AI mentions were also checked with a rule-based search. A second model-based pass, run blind to the first, re-coded a stratified random sample of 400 posts from the first five studies; the sixth was screened and coded later with the same codebook. Agreement was 87% on journey stage (Cohen's kappa 0.81) and 88% or higher on functions, sources, clinician experience, narrative tension and lived signal (kappa 0.64 to 0.92 for codes present in at least 1% of the sample). This measures the consistency of the coding. To check accuracy, the analyst reviewed a stratified sample of 140 posts from all six studies against the source text and confirmed the coding.

Reporting

Every measure is reported pooled, by study and by family of source (Reddit, Facebook, forums, video comments). Pooled figures describe this corpus; Reddit contributes 70% of posts, which is why source-level checks accompany each finding.

Limits

The corpora were assembled for different questions, by condition-specific searches, so the pooled corpus is a purposive sample. Identities and diagnoses are self-described. The low count of GenAI mentions reflects how the corpora were built and is no measure of AI use. Figures are reported at whole-percent precision and describe the posts analysed.

Salience over prevalence

The analysis looks for what people raise unprompted and how precisely they describe it. Frequencies describe the posts analysed and estimate no prevalence in a clinical population.

Scope and data

The corpus holds 3,835 public narratives from six Common Synapse studies run in 2026, covering eight conditions: multiple sclerosis, optic neuritis, Alzheimer's disease and mild cognitive impairment, ADHD, autism, depression, sleep disorders and menopause.

Source	Narratives	Share	Communities
Reddit	2,674	70%	r/MultipleSclerosis, r/Menopause, r/ADHD, r/insomnia, r/AutismInWomen, r/MOGAD, r/Alzheimers and others
YouTube	515	13%	Videos by patients, creators and clinicians
Specialist forums	315	8%	MS Society forum, My MSAA, MS News Today, HealthUnlocked (including CHADD and RLS-UK), Glaucoma UK, Eye Conditions Support Group, an NAION group, Sleep Matters, National Autistic Society, Mumsnet, Drugs.com, Inspire, Mayo Clinic Connect
Facebook	180	5%	Patient groups and pages on MS, MOGAD, autism and sleep apnoea
TikTok	151	4%	Videos by patients and creators
Total	3,835	100%	Six studies, 2026