

Parallel Patient Narrative Streams

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Background

Professional

- Academic: ETH Zurich, Harvard University
- Machine learning engineer and data scientist (worked while sick)
- Pharma, biopharma, R&D, health startups

New path

- Founder, Emancipation Health
- Environmental Health / Root Cause health startup

Patient

- Environmentally-acquired illnesses
- Over a decade in the Swiss healthcare system
- Diagnostic and treatment errors
- Medical gaslighting
- Took charge of my health
- 3,000+ hours reading expert literature and learning from fellow patients
- Significant improvement through root cause approaches

Questions for You

What is the purpose
of the healthcare system?

Questions for You

How do researchers decide
what to research?

Implicit Assumptions in the System

That researchers know what to research to serve patients' health, and to what priority

That physicians objectively and accurately record patient health

The health and lives of patients are at stake.

We finance the system via insurance and taxes.

Despite having all skin in the game, patients have been silenced about our own health.

Medical Records: The Physician's Filter

When clinicians document, they filter through their own knowledge, biases, and prejudices. No systematic mechanism exists to surface these.

Availability bias

Physicians document what's mentally available to them. ~10,000 diseases exist. No physician can recall a significant fraction.

Topol, Deep Medicine

Confirmation bias

The tendency to embrace information that supports one's beliefs and reject what contradicts them.

Topol, Deep Medicine

Overconfidence

"Endemic in medicine." Physicians "completely certain" were wrong 40% of the time.

Kahneman via Topol

Probability blindness

80% of doctors don't think probabilities apply to their patients.

Redelmeier via Topol

These are structural cognitive limitations. Human nature. No good intentions can overcome them.

Medical Records: The Physician's Filter

Records shaped by the desire to present a coherent narrative or limit legal risk rather than reflect truth.

Correa Soto, Celi et al., BMJ 2025

Error propagation

Office notes are routinely copied forward. Mistakes propagate from one visit to the next, from one physician to another.

Topol, Deep Medicine

50%

of records contain errors in medication lists and key background information.

Makary, Unaccountable

Previous providers' notes contain "implicitly biasing descriptions or language" that lead the next provider to approach the patient with suspicion.

Shapiro & Hayburn, Current Psychology 2024

"Doctor-reported outcomes are notoriously biased in all studies." — Makary, Unaccountable

My Experience

The most critical information was left out of my file because the physician didn't have the knowledge to recognise what I told them.

Symptoms were selected and adapted based on what the physician considered relevant.

My health record has been distorted on several occasions.

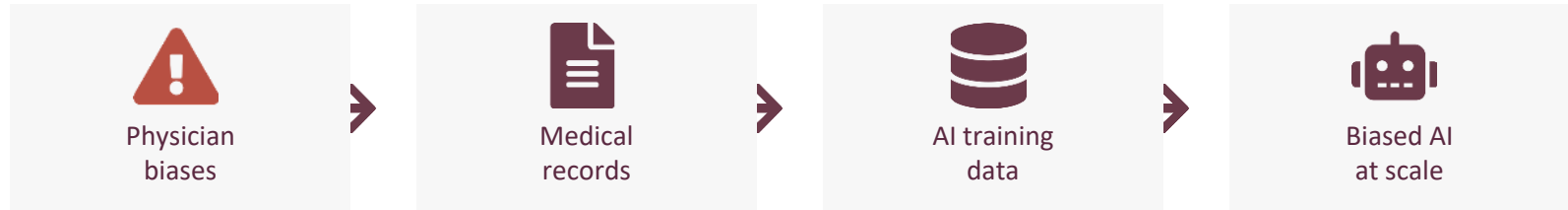
"Patient expertise about their own lives constitutes essential knowledge that no amount of medical training can replace."

Patel, Celi et al., npj Digital Medicine 2026

AI Amplifies the Problem

"The hierarchical structure of medicine creates a theatre of authority where performance often supersedes accuracy."

Correa Soto, Celi et al., BMJ 2025



Patients have essential knowledge the system doesn't have and doesn't accurately capture.

I propose a new framework

Parallel Patient Narrative Streams

Systematically capturing the patient voice alongside physician records



The Parallel Patient Narrative Stream in Practice



A dedicated portal space where patients write their narrative in their own words



Patients can read the physician records



If they consider them correct and complete, they don't have to write



If they see inaccuracies or incompleteness, they document those or write their full narrative



Alternative: AI scribe records the patient narrative with consent. Patient checks and amends the transcription



Patients may add thoughts that come to mind after the appointment



The physician can read the patient narrative, but not edit it

What Changes for the Physician?

The physician continues their work and practice of medicine as they are used to and consider best.

- Anonymised data from both streams is systematically analysed
- Discrepancies between physician and patient records are identified and patterns detected
- Patterns are mapped to patient outcomes, including patient-reported outcomes and experiences
- Insights inform research priorities, clinical practice, and public health initiatives

Preventing Human Harm, Reducing Costs, Enabling Healing



Reducing Human Harm

Diagnostic errors, wrong treatments, and iatrogenic harm affect a substantial proportion of patients. Two narrative streams surface discrepancies the current system cannot see, dramatically reducing preventable harm.



Reducing Costs

Fewer diagnostic errors, fewer wrong treatments, fewer patients cycling through the system without answers or getting worse. And research investment informed by rich data.



Root Cause Understanding

Patient narratives at population scale reveal root cause patterns invisible in physician-only records. Understanding root causes allows healing, not only managing conditions with medications.

Examples in Practice

The Textbook Trap

When a condition presents differently from what guidelines describe, physicians may not recognise it. If symptoms don't match the textbook, the condition is ruled out rather than the textbook questioned. A parallel patient narrative stream would capture these presentations at scale, revealing that "atypical" may be more common than assumed.

The Rarity Trap

Physicians tell patients a condition is very rare, suggesting they don't have it. They don't test or appropriately consider it. But if the condition is actually more common than physicians learned, and physicians don't consider it, they keep thinking it's rare. A parallel patient narrative stream would break this self-reinforcing cycle.

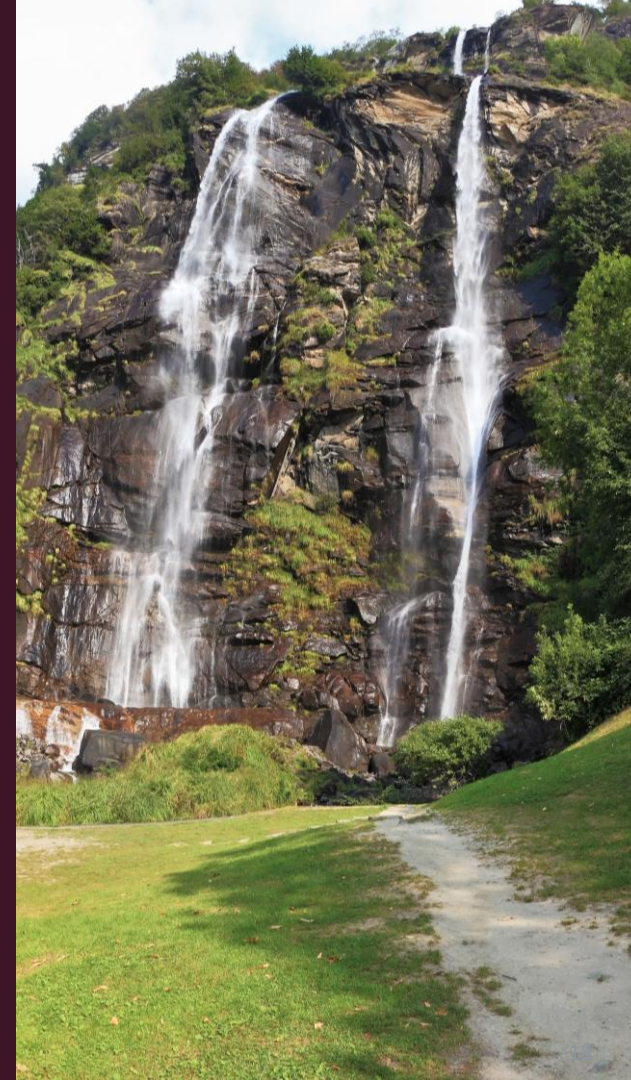
The Translation Gap

Invisible conditions with high disease burden have been neglected for decades, and patients have been gaslit. A parallel patient narrative stream would surface these conditions at population scale far earlier.

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Questions are welcome

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