

HAPI

# Agency Preservation in Healthcare

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*Restoring Human Participation Under Illness, Fear, and Institutional Complexity*

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Human Agency Preservation Infrastructure

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***Core thesis: Healthcare should not only treat the body. It should preserve the patient as an agent under pressure.***

Status: Working research manuscript. This paper develops a governance and agency-preservation framework for healthcare systems. It is not medical advice, clinical protocol, or a substitute for professional medical judgment.

## Abstract

Healthcare is one of the clearest domains where human agency matters most and is most easily weakened. Illness, fear, pain, time pressure, specialist language, financial stress, fragmented records, and institutional complexity can reduce a patient from a participating person into a managed case. This paper applies Human Agency Preservation Infrastructure (HAPI) to healthcare. It argues that agency-preserving care requires more than informed consent, patient portals, or access to options. It requires the preservation of clarity, authority, refusal, revision, memory, contestability, capacity, and accountability at the points where medical decisions become consequential.

The paper defines healthcare agency loss, explains why crisis narrows agency, distinguishes clinical authority from patient agency, and proposes a HAPI healthcare model for restoring meaningful participation without undermining medical expertise. It also examines diagnosis shock, cancer care, chronic illness, family caregiving, AI-assisted medicine, and institutional governance. The central claim is that good healthcare should not only ask whether the patient was technically informed, but whether the patient had enough restored capacity to meaningfully participate in what happened to their body, future, family, and life.

Keywords: human agency, healthcare governance, patient autonomy, informed consent, medical decision-making, agency restoration, care coordination, AI in healthcare, HAPI

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# 1. Introduction

Healthcare is not only a biological intervention system. It is an agency environment. A patient enters healthcare because something about their body, mind, function, future, or family has become uncertain. That uncertainty can create fear, dependence, confusion, and urgency. At the exact moment when a person needs the ability to understand, choose, refuse, revise, remember, and remain accountable, the system can become too complex for meaningful participation.

This creates a core HAPI problem: healthcare can preserve human life while weakening human agency. It can treat disease while leaving the patient disoriented, overruled, unheard, undocumented, or dependent on a system they cannot understand. The goal of HAPI is not to reject medicine, expertise, or institutional care. The goal is to make powerful healthcare systems more capable of preserving the person inside the process.

***The patient is not a passive site of intervention. The patient is the human agent whose life, body, family, and future are being acted upon.***

This paper develops a theory of agency preservation in healthcare. It does not propose that every patient must make every technical decision. Rather, it argues that the patient must remain meaningfully present where decisions affect bodily integrity, risk, identity, long-term burden, family responsibility, and life direction.

## 2. The Healthcare Agency Problem

Agency loss in healthcare occurs when the patient remains physically present but loses meaningful participation in what is happening. This can happen even when legal forms are signed, appointments are attended, and instructions are followed.

Common healthcare agency-loss patterns include:

- The patient is given information but cannot understand it under stress.
- The patient is asked to consent but has no realistic time or support to deliberate.
- The patient is told options but not helped to understand tradeoffs.
- The patient is assigned responsibility for adherence while lacking capacity, transportation, money, energy, or memory.
- The patient is moved between specialists without anyone preserving the whole story.
- The patient is treated as noncompliant when the system has not made participation possible.
- The family is either excluded from context or overloaded with responsibility.
- Records exist, but the patient cannot use them as memory or decision support.

This is not primarily a blame claim against clinicians. Many clinicians are themselves trapped inside overloaded systems. The HAPI claim is structural: healthcare systems should be audited for whether they preserve agency under pressure, not merely whether they deliver procedures, visits, documentation, and billing events.

### 3. Agency Under Illness and Fear

Illness narrows agency. Pain narrows attention. Fear narrows interpretation. Fatigue weakens memory. Medication, sleep loss, grief, and uncertainty can make ordinary decisions feel impossible. A person who appears calm may still lack the capacity to integrate information or make durable choices.

This means healthcare cannot treat agency as a constant. Agency is dynamic. It can expand or collapse depending on the patient's condition, environment, support, and timing.

#### Healthcare Agency Principle

The more pressure a patient is under, the more the system must restore capacity before asking for consequential decisions.

A signature is not enough when the patient lacks clarity, memory, time, or support.

The system must ask not only, "Did we give information?" but also, "Was the person capable of using that information?"

### 4. Informed Consent Versus Meaningful Participation

Informed consent is necessary, but it can become agency theater if it is reduced to disclosure and signature. A patient may be legally informed while practically unable to participate.

Meaningful participation requires several conditions:

- Clarity: the patient understands the situation in plain language.
- Alternatives: the patient sees real options, including delay, second opinion, or refusal when appropriate.
- Consequences: the patient understands likely benefits, risks, uncertainties, and burdens.
- Time: the patient has enough time for the decision type, unless emergency conditions truly prevent it.
- Support: the patient has access to help from trusted family, advocates, interpreters, or care coordinators.
- Refusal: the patient can say no without humiliation, retaliation, or abandonment.
- Memory: the patient can review what was decided and why later.

***Consent is not meaningful unless the person can understand, refuse, revise, and remember.***

This distinction is central to HAPI. Healthcare should not merely document that the patient was told something. It should preserve the conditions that let the patient participate as a person.

### 5. Diagnosis Shock and the Collapse of Capacity

Diagnosis can be an agency shock. A serious diagnosis changes the patient's future in one sentence. The body becomes uncertain. The future becomes unstable. Family roles shift. Work, money, identity, parenting, faith, and mortality can all enter the decision space at once.

During diagnosis shock, the patient may retain formal decision rights while losing practical capacity. A patient may nod, agree, sign, and schedule while absorbing very little. HAPI treats this as a predictable agency-risk moment.

Agency-preserving diagnosis practice should include:

- A plain-language summary of what is known, unknown, urgent, and not urgent.
- A written decision map showing the next few steps.
- A pause point for questions after initial emotional shock when clinically safe.
- A named contact or care coordinator for follow-up clarification.
- A record the patient can share with family or advocates.
- Explicit permission to ask, repeat, slow down, or seek a second opinion.

The goal is not to remove clinical urgency. The goal is to prevent urgency from becoming unnecessary agency collapse.

## 6. Cancer Care as an Agency Stress Test

Cancer care is one of the strongest tests for HAPI because it combines uncertainty, fear, specialized language, time-sensitive decisions, multiple clinicians, staged treatment, side effects, imaging, labs, family worry, financial strain, and existential meaning.

A patient may face surgery, chemotherapy, radiation, immunotherapy, targeted therapy, surveillance, palliative care, fertility concerns, work disruption, child care, pain control, and end-of-life fears. These are not only medical facts. They are agency burdens.

HAPI does not claim a universal cure or simple protocol. Instead, it claims that a patient's agency can be preserved even when the disease is frightening and complex. The system can help the patient understand which gates failed biologically, which options exist clinically, which decisions are urgent, what tradeoffs matter, and how to stay meaningfully involved.

### **Cancer Care HAPI Claim**

The goal is not to make the patient carry the whole system.

The goal is to build an agency-preserving support structure around the patient so they can participate without being crushed by complexity.

This is why HAPI has healing relevance. It gives patients a way to regain participation when life feels governed by forces they cannot control.

## 7. Clinical Authority Without Agency Capture

Doctors, nurses, specialists, pharmacists, therapists, and care teams need real authority. Expertise matters. HAPI is not anti-expert. The question is whether clinical authority serves patient agency or captures it.

Clinical authority preserves agency when it:

- translates complexity without manipulating the patient
- names uncertainty honestly

- protects the patient from false choices and unsafe shortcuts
- supports refusal and second opinions
- helps the patient align treatment with values and capacity
- accepts accountability for recommendations and documentation

Clinical authority captures agency when it:

- treats questions as resistance
- uses fear to pressure agreement
- hides uncertainty behind confidence
- frames the patient as noncompliant before checking capacity barriers
- confuses institutional convenience with patient best interest
- makes the patient responsible for outcomes the system controlled

***The clinician is not the replacement for patient agency. The clinician is a steward of agency under biological and institutional pressure.***

## 8. Family, Caregivers, and Shared Agency

Healthcare decisions often involve more than one person. A patient may depend on a spouse, parent, adult child, friend, pastor, advocate, or caregiver. This creates shared agency. Shared agency can preserve participation or create new forms of pressure.

Family support preserves agency when it helps the patient remember, ask questions, manage logistics, process emotions, and stay connected to values. Family support becomes agency capture when the family speaks over the patient, hides information, pressures decisions, or makes the patient responsible for everyone else's fear.

HAPI treats caregivers as agency-support partners, not automatic decision owners. The patient's voice remains central unless the patient has clearly delegated authority or lacks decision capacity under appropriate legal and ethical standards.

## 9. Medical Records, Memory, and Continuity

Memory is a core component of agency. Healthcare often produces large amounts of documentation, but documentation is not the same as usable memory. A record preserves agency only if it helps the patient and care team understand what happened, what was decided, what remains uncertain, and what comes next.

Agency-preserving records should answer:

- What was the problem?
- What was known and unknown?
- What options were discussed?
- What decision was made?
- Who made or supported the decision?
- What risks or tradeoffs mattered?
- What should happen next?
- What should the patient watch for?

- How can the patient contest, clarify, or update the record?

This directly connects HAPI healthcare to the broader HAPI infrastructure thesis: receipts preserve memory after consequence. In healthcare, every major decision should leave behind a usable trail, not merely an administrative trace.

## 10. AI in Healthcare and Delegated Clinical Support

AI systems will increasingly summarize records, triage messages, draft notes, recommend workflows, flag risks, generate patient instructions, schedule follow-ups, and support clinical decisions. These tools can amplify agency or strip it away faster.

AI preserves healthcare agency when it reduces complexity, improves memory, supports clinicians, clarifies options, and keeps humans meaningfully involved. AI erodes agency when it hides uncertainty, automates decisions without contestability, turns patients into scores, or makes clinicians rubber stamps for machine-generated recommendations.

The HAPI question for healthcare AI is not only, "Is the model accurate?" It is also:

- Can the patient understand how the AI influenced the process?
- Can the clinician contest or override the AI?
- Can the patient contest or clarify AI-shaped records?
- Is authority still held by accountable humans?
- Does the system preserve a receipt of how the recommendation entered the workflow?
- Does automation reduce load without removing meaningful participation?

***AI in healthcare should amplify clinical and patient agency. It should not become an invisible governance layer over the body.***

## 11. The HAPI Healthcare Audit Model

A healthcare system can be audited for agency preservation across ten dimensions:

1. Clarity: Does the patient understand what is happening?
2. Authority: Who has the right to decide, recommend, approve, or refuse?
3. Refusal: Can the patient say no or slow down when clinically appropriate?
4. Revision: Can decisions be revisited when context changes?
5. Memory: Can the patient and care team reconstruct what happened?
6. Contestability: Can errors, misunderstandings, or disputed decisions be challenged?
7. Capacity: Does the system restore decision capacity under stress?
8. Continuity: Does the patient experience one coherent path or fragmented handoffs?
9. Dependency Risk: Does the system support the patient or make the patient helpless without it?
10. Accountability: Are responsibility and authority aligned?

This audit model turns compassion into infrastructure. It gives healthcare organizations a way to ask whether their systems preserve personhood under pressure.

## 12. Agency Restoration Pathways

Agency restoration in healthcare is practical. It can be designed into intake, diagnosis, consent, treatment planning, discharge, follow-up, records, and AI workflows.

### Restoration Pathway 1: Translate

Convert clinical complexity into plain-language understanding without hiding uncertainty.

### Restoration Pathway 2: Sequence

Separate urgent decisions from decisions that can wait. Do not overload the patient with everything at once when staged understanding is possible.

### Restoration Pathway 3: Anchor

Tie decisions to the patient's values, goals, family responsibilities, tolerance for risk, and desired quality of life.

### Restoration Pathway 4: Preserve Memory

Give the patient usable records, decision summaries, next-step maps, and ways to revisit what was decided.

### Restoration Pathway 5: Protect Refusal

Make refusal, questioning, second opinions, and clarification legitimate parts of care rather than signs of disobedience.

### Restoration Pathway 6: Coordinate

Reduce fragmentation by preserving continuity across specialists, institutions, and time.

### Restoration Pathway 7: Audit

Measure whether agency is preserved across real workflows, not merely asserted in policy.

## 13. Risks and Failure Modes

HAPI healthcare also has risks if misunderstood.

- Over-romanticizing patient control: Some decisions require clinical urgency and expertise.
- Undermining expertise: Agency preservation should not flatten technical knowledge.
- Administrative burden: Agency-preserving documentation must be usable, not another bureaucratic layer.
- False empowerment: Portals and forms can create the appearance of agency without restoring capacity.
- Family capture: Involving caregivers can help or pressure the patient.
- AI opacity: Automated summaries and scores can shape care without meaningful visibility.
- Equity gaps: Patients with fewer resources may need more agency support, not more blame.

The design principle is balance: preserve patient agency without denying medical reality, clinical expertise, or emergency constraints.

## 14. Conclusion

Healthcare is one of the most important domains for Human Agency Preservation Infrastructure because it places people under biological, emotional, institutional, and informational pressure. A patient may be alive, treated, documented, and compliant while still losing meaningful participation. HAPI exists to prevent that failure.

Agency-preserving healthcare restores clarity, authority, refusal, revision, memory, contestability, capacity, and accountability. It does not replace medicine with vague empowerment language. It gives healthcare systems a structural way to keep the person present inside the process.

***The measure of humane healthcare is not only whether the system treated the condition, but whether it preserved the human agent living through it.***

This paper supports the broader HAPI claim: governance is the product of agency preservation. In healthcare, that means good governance emerges when the patient, clinician, family, institution, and tools are aligned around restored participation rather than procedural compliance alone.

## Appendix A: Healthcare Agency Preservation Checklist

- Did the patient understand the situation in plain language?
- Were the patient's real options explained?
- Was refusal or delay possible where clinically appropriate?
- Was the patient given a usable record of the decision?
- Was uncertainty named honestly?
- Were family or caregivers included only in ways that supported the patient's agency?
- Were capacity barriers identified before labeling the patient noncompliant?
- Was the care path coordinated across handoffs?
- Could the patient contest or correct the record?
- Were AI tools, if used, accountable to human authority?
- Did the system preserve the patient's dignity and participation under pressure?

## Appendix B: Key Propositions

11. P1. Healthcare is an agency environment, not only a treatment system.
12. P2. Illness, fear, pain, and uncertainty can collapse practical agency even when formal rights remain intact.
13. P3. Informed consent becomes theater when the patient lacks capacity to understand, refuse, revise, or remember.
14. P4. Clinical authority preserves agency when it translates, supports, protects, and remains accountable.
15. P5. Clinical authority captures agency when it pressures, obscures, dismisses, or substitutes for patient participation.
16. P6. Medical records preserve agency only when they function as usable memory, not merely institutional documentation.
17. P7. AI in healthcare should amplify patient and clinician agency, not become an invisible authority layer.
18. P8. Cancer care is a high-pressure test case for agency preservation because it combines fear, uncertainty, complexity, and consequential decisions.
19. P9. Family and caregivers can preserve agency or capture it depending on whether they support or override the patient.
20. P10. The goal of HAPI healthcare is restored participation under pressure.