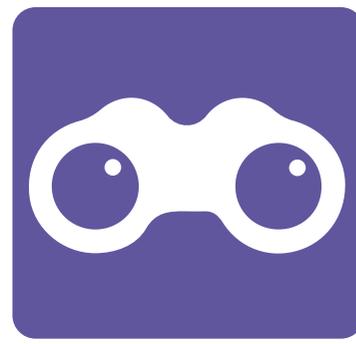
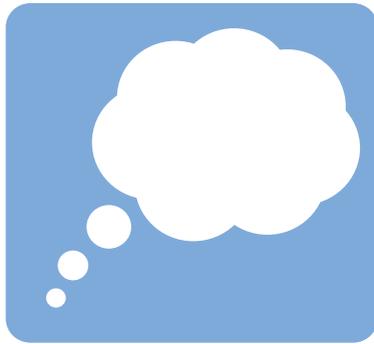


Giving patients **agency in healthcare**  
by constructing **actionable stories** from data

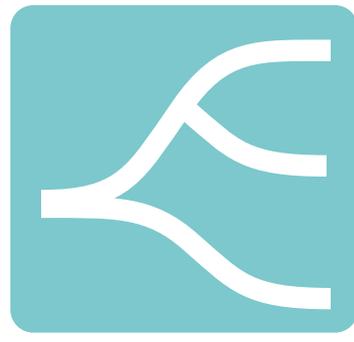
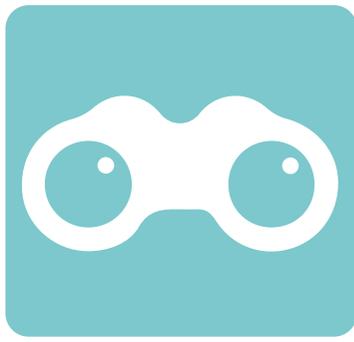


{narRecuperate}

Anna L. von Reden



Giving patients agency in healthcare  
by constructing actionable stories from data



A THESIS SUBMITTED TO THE SCHOOL OF DESIGN, CARNEGIE  
MELLON UNIVERSITY, FOR THE DEGREE OF MASTER OF DESIGN IN  
COMMUNICATION PLANNING AND INFORMATION DESIGN

---

CANDIDATE SIGNATURE:

---

ADVISOR: DAVID KAUFER, PHD  
PROFESSOR OF ENGLISH, CARNEGIE MELLON UNIVERSITY

{inarRecuperate}

Anna L. von Reden



## ● table of contents

0	abstract	2
1	introduction	4
2	research approach	8
3	contextualizing chaos	12
4	related products & systems	24
5	elucidating experience	27
6	synthesis	33
7	proposed system	36
8	from here	47
9	conclusion	51
*	acknowledgments	52
*	references	53



## 0 abstract

**{narRecuperate}** [*narrate + recuperate*] is a system that helps patients acquire proficiency articulating their own health concerns. It is born of the idea that the future of healthcare must lie in the hands of patients, while acknowledging that most people have neither the expertise nor the self-reflection skills necessary to manage their own care. The system harnesses the way people narrate their experiences: wrought with questions, discoveries, emotional pain, circular logic, and, at times, remarkable clarity. It then blends those tendencies with deep knowledge reservoirs and data structures only penetrable by physicians, creating an ecosystem of interactive visualizations aimed at increasing patient agency while not detracting from physician authority. The aim is to build a communication artifact, not to architect a battlefield.

The system is underpinned by insights gained from extensive face-to-face interviews with people—some with minimal health concerns, others suffering through unimaginable situations—and contextualized by what I have learned about American healthcare through working within the University of Pittsburgh Medical Center (UPMC): a top ranked but also heavily commercialized hospital system. The design itself is inspired by work in fields spanning anthropology, art, literature, film, information architecture, biomedical engineering, and behavioral psychology.

This document presents an early concept for an online, screen-based portal, but the ideas contained within the design do not rely on any particular technology. The vision is an ubiquitous patient-centered system that would continuously evolve with a person over the course of a lifetime: an ever-evolving record of self-and-health.

0

1

2

3

4

5

6

7

8

9

\*



# 1 introduction

## HEALTH IS A COMMUNICATION PROBLEM IN DISGUISE

While we possess health, we don't speak of it, don't address it, barely think about it. It is a natural part of our existence: an expectation that we will wake up each morning feeling approximately the same way we did the morning before. In this sense, health can be thought of as a component of identity, as it governs the activities in which we participate, our daily routines and rituals, and, ultimately our opinions of ourselves in a very deep emotional sense.

What happens, then, when you wake up one morning, and suddenly don't feel like yourself anymore? Perhaps you are suffering from decreased mobility and require a knee or hip transplant. Maybe you've recently been struck down by a heart-attack, and are still reeling in the aftermath. Perhaps you have recently been diagnosed with cancer, or multiple sclerosis. Or perhaps it's something slightly more nebulous: an anxiety disorder, post-partum depression, a strange food allergy—a chronic problem that has lingered for so long it has become a part of you, although nobody is able to tell you exactly what is wrong.

You ask your doctor; you ask multiple doctors. None of them can parse your opaque and psychologically loaded claim that 'something is wrong'. Eventually, you're hospitalized and scanned and poked and treated for all of the possibilities, however unlikely. All the while you have a vague, indescribable dread that this journey you've embarked upon is plotted on the wrong map, using a broken compass. Maybe the treatment helps one issue and causes another, or perhaps one set of instructions directly

0

1

2

3

4

5

6

7

8

9

\*

contradicts instructions given to you by another clinician. Maybe whatever you are being told to do simply doesn't feel right—emotionally, spiritually, morally, intangibly. You're pretty sure one or all of these things must be true, but you have no good way to validate your own instincts.

If you happen to count yourself among the self-motivated, perhaps you try to do some research, collect your thoughts, consult your friends, consult the internet. Maybe you begin using self-tracking technology to monitor your sleep, diet, heart rate, blood pressure, and other vitals. If you're the rare person who easily draws connections between disparate and decontextualized data sources, perhaps a larger picture of your situation begins to coalesce in your mind.

Then the moment comes for another conversation between you and your physician. You take a deep breath, sit down, and try to explain your discoveries and values. Your physician is not the enemy. He or she truly wants to help, but has limited time to comprehend your narrative, and even less time to decide whether your research is scientifically validated or purely anecdotal. Historical precedent suggests that they are the expert, and you are the novice. After all, you never began to educate yourself about your own body until this illness befell you—how could you have acquired enough insight to make wise decisions? The clinician's role—and mindset of the healthcare system—is to treat illness. They have a deeply ingrained sense of obligation (not to mention an economic incentive) to try anything and everything that might take what is broken and make it just like new again.

Rarely does it seem like anybody stops to reflect upon whether this goal makes sense. Illness changes a person, whether for

better or worse; it is a catalyst for emotional evolution. And yet, for some inexplicable reason, healthcare systems seem to be on a mission—and earnestly, not maliciously—to devolve you: to take you back to the way things were, as though that is the true definition of 'better'.

In the end you have little choice but to yield to medical authority, or refuse treatment altogether. In either scenario, you are sacrificing an element of your identity, forced to cope not only with the condition that led you to this moment, but with the consequences of decisions that were nominally 'yours to make', despite having been covertly made for you at the outset.

If there is illness to be treated, it lies within this model of healthcare. If there is something broken to be made new, it is the framework for conversations between physician and patient. And if there is one decision to be made by the patient, it must be the decision to be more reflective, and to be constantly aware of the intricacies and delicacies of our own bodies, long before illness or injury strikes.

However, it seems like we're going to need a little help.

### **TAKING A LOOK IN THE 'MIRROR'**

Consider an alternate scenario: a wild futuristic world where health continues to be a natural part of our existence, but is no longer a subconscious expectation. Instead of waking up in the morning and trusting your body to continue functioning with some resilient inertia, or being mystified and terrified when your internal Miss Clavel suddenly sits upright and cries,

“something is not right!”, you simply open your closet door. There, in your mirror, you suddenly have concrete means to monitor your wellbeing and explore physiological cause and consequence, all with input from trusted medical experts.

Before going about selecting an outfit for the day, you proceed through a routine that outfits you from the inside. Like something out of a recent *Iron Man* movie, your mirror shows you your organ systems superimposed upon your reflection, each one alive and kicking, and each one bearing a summary of its current condition.

You might ask: what are all the things I’m doing right now that are good or bad for my heart? Your mirror knows. Using data from an armband you’ve been wearing, and a diet app you’ve been using on your mobile device, it’s kept track of how many steps you’ve taken, the food you’ve eaten in the last month, the amount of sleep you’ve been getting, and your blood pressure at home versus at the office. It knows how upset you were at your next door neighbor for parking you in yesterday morning—it knows because you told it, through a blogging system, even though you were too afraid to tell your neighbor to his face. It knows what prescription you take for hypertension, the time your physician told you to take it, and—like some kind of Dr. Santa Claus—it knows how often you’ve been taking it two hours late... or not at all... or on an empty stomach instead of with food.

If this feels uncomfortably invasive, bear with me for a moment.

Not only does it know all of this, but the mirror is also constantly searching for connections. Using information supplied on the back-end from your physician, pharmacist, and vetted medical journals, it weeds out dangerous drug interactions, and contradictory instructions from multiple physicians. It

takes another look your inability to confront your neighbor and digs back through your writing for the last few years to find further evidence of communication failure (and communication success). It takes a moment to consider that your hypertension prescription might be helping your heart but inadvertently draining your body of electrolytes, affecting your central nervous system. And it realizes that the amount of coffee you drink each morning coupled with the Excedrin you take without realizing its caffeine content probably aren’t helping that situation any.

What your mirror doesn’t do is tell you what to do with this information. This hypothetical mirror is just a metaphorical extension of the mirror’s current purpose: reflection. It helps to centralize and make sense of the enormous amount of data we have at our disposal about lifestyle, anatomy, physiology, psychology, chemistry, and philosophy. This terribly invasive monster hanging on your closet door is really only trying to help you accomplish a task that you should really be doing with your own brain: carefully considering your behavior, understanding your own body, and grappling with cause and consequence. I would argue that, if the mirror feels uncomfortable and threatening, it is probably because we are currently uncomfortable and threatened by the idea of knowing, with certainty, what is going on inside these mysterious shells we wear.

There may be a far-flung future society where we are all incredibly adept at introspection, acutely self aware, and consistently make well-educated and meaningful decisions based on a summation of statistical factors. In that society, physicians and other medical experts would still hold valuable expertise, but would also be able to trust their patients to have a strong grasp on their health situation. This trust is the key to achieving the respect we as patients currently long for. But for a world where most of us take

- 0
- 1
- 2
- 3
- 4
- 5
- 6
- 7
- 8
- 9
- ★

less time to learn about the contents of our ribcage than we spend learning about the contents of our bank account, we'd have a much easier time parsing all the information when we have a little bit of technological help. 'The mirror' is a stopgap, a crutch for us to lean on while we strive to achieve better self-understanding.

Obviously, such a system is currently design fiction. However, it suggests a vision for the future of healthcare that is perhaps only a few years off.

## FROM FICTION TO REALITY

{narRecuperate}, the design concept presented in this document, harnesses much of the functionality of the fictional mirror, but situates it within contemporary screen-based technology. It also seeks a pragmatic perspective on the back-end infrastructure necessary to power such a system. This approach has crystallized the mirror into five key 'reflective modes' that I believe can help people engage meaningfully with their health data, and subsequently with their physicians:

1. **A RESPONSIVE BLOGGING PORTAL** that harnesses the power of natural language processing to track behavioral trends, link anecdotal information to clinical evidence, and add context to medical problems that, at first glance, may seem purely physical or purely emotional.

2. **A MEDICATION VISUALIZER** that neatly tracks how prescriptions function within the body, allowing a patient to spot issues and virtually adjust their regimen to see the consequences before swallowing a pill.

3. **AN 'ORGANIC' DISCOVERY SYSTEM**, which allows patients to explore what's happening in their own bodies in the way that we tend to understand our bodies naturally: in terms of individual organs. A systemic view of health is achieved gradually by connecting the dots.

4. **AN INTERACTIVE CAUSE & EFFECT NETWORK**, depicting possible health futures based on all of the above information. These futures can be altered by manipulating the pathways leading there, giving patients an ability to see how a behavior change or a new treatment would impact their entire health ecosystem.

5. **A CASE CONSTRUCTION TOOL**, allowing for the assembly of raw information from a variety of sources. This space allows patients to collect their thoughts before a physician visit, and acquire enough evidence to convincingly make a case for their own care.

These five ideas form the backbone of the {narRecuperate} system, and were chosen because they all have potential to both **illuminate opportunities for behavior change**, and **allow positive critical analysis of physician instructions**: elements that I believe are essential for us to be able to reach a new paradigm of healthcare.

The rest of this document describes the process and research that led to the selection of these subsystems.

## 2 research approach

### PERSONAL & PROJECT TRAJECTORY

This project is a natural synthesis of my two primary fields of interest: communication through creative narratives, and biomedicine & human health. During my undergraduate studies in biomaterials science, I became obsessed with how much technical information exists about medicine and healthcare that the public never sees. Part of my motivation to study communication design was to use my skills as a writer and visual designer to somehow decode and disseminate that information.

Meanwhile, I began to uncover another equally important but even more nebulous problem at the interface between people and medicine. Over and over again, I found myself encountering people coping with serious health situations. In all cases, the individual expressed deep-rooted concerns about the future, about 'whether the rest of their life would be like this', where 'this' was a physical and psychological state that felt alien compared to the routine that they had become accustomed to.

I was inspired by the work of Arthur Frank (see part 3 : contextualizing chaos), who talks about the types of stories generally told by people who are ill, and how sometimes, they don't follow a predictable linear pattern, or follow much of any structure at all. I wanted to collect these narratives from people who were suffering from chronic illness or recovering from acute medical events, and explore ways that design could help these people and their doctors understand their lives.

0

1

2

3

4

5

6

7

8

9

\*

However, I realized gradually that these special narratives, these chaos narratives, as Frank calls them, weren't confined to the critically or chronically ill. Nearly every person in the United States is struggling to tell an eloquent story about his or her health over time—a story that rings true within, and a story that will help their physicians provide better care.

At the same time, I was thrown headfirst into the true size and scope of the issue at hand as I began work at UPMC's Technology Development Center (UPMC | TDC). The American healthcare system is at a crossroads. We're moving from an economic model where physicians hand out mandates, order treatments, and run the show, to a model where these experts are supposed to work together with patients to provide care that aligns with their values. Technology is racing to bring medical data infrastructure up to speed and provide clinicians with comprehensive portraits of their patients. But that isn't enough. The portrait isn't complete without knowledge that only a patient can provide.

While working on countless wireframes for dozens of innovative clinical data applications, I couldn't shake the feeling that some system developers believe the goal is to centralize the data and simply make it visible to people. While this is a good start, I believe we can't hope for patients to be able to engage effectively with physicians using the current clinical data structure until they're properly informed and comprehend the implications of their actions. This requires more than just data presentation. It requires data contextualization and interaction.

To contextualize data meaningfully, I found myself returning to the questions I'd been asking at the very start of the project: what are the nuances in the way people tell stories about their lives and their health? How do we take the metaphors

and stylistic elements of those stories and use them to fuel elegant data visualization? And, perhaps most importantly: how do we use these techniques to help people acquire and assimilate health information in a way that seems natural—even subconscious—so that we can begin to shift our entire society toward self-and-health awareness?

## SCOPE & LIMITATIONS

As this project tries to integrate two enormous realms of content: healthcare and storytelling, it would be very easy to drown in the sheer amount of information available and challenges at hand.

It should be noted that I am not trying to tackle the enormous financial and political problems currently facing the American healthcare industry. I also make the optimistic assumption that the current technological nightmare of digitalizing and centralizing clinical data is surmountable sometime within the next decade. While I acknowledge that these issues exist, and are extremely pressing, it would be impossible, not to mention irresponsible, for me to claim I've addressed them thoroughly in this project. I do, however, believe that the concept proposed here fits nicely within the current paradigm shift from pay-per-procedure toward outcomes- and eventually values-based medicine. If the concept succeeds, it's reasonable to assume that a system such as **{narRecuperate}** could, as an additional benefit, have a significant impact on the cost of care.

I also acknowledge that my focus thus far has been on patients, and I have yet to interact heavily with physicians. As discussed later, I hope that presenting this work to UPMC | TDC will provide me with the opportunity to acquire essential doctor input.

## METHODS TO MATCH THE APPROACH

To achieve an intimate understanding of the stories patients tell, and to preserve their often subtle details and implications, I kept most of my design methods as unstructured as possible. My process is roughly outlined below, and the discoveries made with each strategy are discussed in more detail in the subsequent sections of the document.

### BUILDING CONTEXT

#### *A review of the literature surrounding patient-centered care, decision-making, and narratives in healthcare*

I strived to understand what doctors are trying to learn about their patients, what patients need to learn to make good decisions, and all of the communication strategies that sometimes muddy the water.

#### *A deconstruction of health narratives as portrayed in art, film and literature*

Many of the most interesting stories about health manifest in the form of art. I looked to several artists and their work to find commonalities in the way they address life, illness, and mortality.

#### *An analysis of related technologies and systems available or in development*

This includes electronic health records (EHRs), patient-facing health apps, and self-tracking.

## COLLECTING STORIES

### *Directed-storytelling sessions with patients and practitioners*

I conducted lengthy in-person interviews with four patients suffering from acute or chronic health problems. After acquiring a few basic pieces of demographic information, I simply asked each participant to tell me a story about their health, beginning wherever they wanted. I interrupted as little as possible, and when I did, my questions generally encouraged the participant to reflect on the past and project into the future. This tactic let me assess each person's storytelling style and perceptual limitations. The final question in each interview asked people to consider what they would change about their healthcare, and how they would make that change, if they possessed the agency to do so.

I conducted a fifth interview with a behavioral therapist who works primarily with cancer patients. The format of this interview was identical, except that the participant was encouraged to reflect upon the stories told by patients, and her strategies for making sense of those narratives.

I was also informed by dozens of other, shorter health-related anecdotes from friends and family, collected casually over the course of the year.

### *Observation of and casual conversation with healthcare professionals*

Much of my involvement in UPMC | TDC's interaction design work is under NDA. However, simply being immersed constantly in a healthcare-oriented environment, sometimes as a fly-on-the-

0

1

2

3

4

5

6

7

8

9

\*

wall, I was able to absorb tremendous amounts of information about how the industry works. Furthermore, I gained a better sense of how to present my own concepts to the medical technology community in order to increase their likelihood of adoption.

## ARCHITECTING A PLATFORM

### *Synthesis of patients' stories into repeating themes, and narrative elements*

I used a variety of methods to encapsulate the information I acquired via the previous activities, including: concept mapping to achieve a better understanding of the broad system context; image boards to distill common elements from prior art and designs, and close readings of the written transcripts of my interviews with patients to pull out similar experiences and idiosyncrasies. An affinity diagramming exercise related to decision making that I conducted as part of a UPMC | TDC research project also provided me with valuable data.

### *Wireframing and visual design for a system concept*

After the close-readings and concept mapping illuminated five major areas of opportunity to increase patient agency, I sketched several concepts for systems that could successfully fill those gaps. I then combined ideas from these pencil sketches into one cohesive system: **{narRecuperate}**, with several different 'windows' into the same data. The final design incorporated information architecture and visual design components observed within patient stories' themselves, such as redundancy, circular thought pathways, and contradicting and evolving perspectives.

### *Evaluation of initial concept*

I created a rubric that would quickly estimate how well the system ultimately met its goals as a communication artifact. The ideal system would provide a good balance of patient and physician authority, responsibility, activity and information generation, in order to encourage system adoption and foster trust from both parties over time. While different subsystems fared better or worse in individual categories, when viewed as a whole, an encouraging balance begins to emerge. This realization is what eventually led me to combine the different subsystems into a single portal, rather than picking one to develop. Initial reactions with industry professionals (both within large corporations and in the startup space) have been overwhelmingly positive. My next step is to formally present the design to UPMC | TDC colleagues and begin a discussion of how the concept could be built, or assimilated into other products currently in development. This presentation has been tentatively scheduled for the end of May, 2013.

### 3 contextualizing chaos

1. Robert Kinross, 'The Rhetoric of Neutrality' *Design Issues*, no.2(2), (1985), 18-30.

2. Kinross, "The Rhetoric of Neutrality," 18.

It takes very little observation or personal experience to realize that there is a gap in communication between doctors and patients. At it's extremes, the situations we perceive as extreme pain, with heavy implications for our routines and relationships, are represented as little more than cell-counts and chemical imbalances on a piece of paper, or a visual anomaly in a CT scan. That's not to say that medical practitioners are some kind of inhuman heartless automatons. They are simply following a highly rational mental model of medicine that is rooted in ideals of scientific accuracy and modernist simplicity.

It seems as though communication designers would be the ideal strategists to step into the doctor-patient schism and rethink this model of medical care. However, designers have a tendency to fall prey to precisely the same mental model. In his paper 'The Rhetoric of Neutrality', Robert Kinross describes a designer mindset where, to solve a communication problem, one must move it from a place of complexity to one of streamlined, universal simplicity.<sup>1</sup> As he puts it: "The idea was put forth [by modernists] that transactions might have the same order and essential simplicity as an electrical circuit. One may suspect here a desire for the human world to be as amenable to understanding and control and as free from unpredictability as an electrical machine."<sup>2</sup>

While society and design have moved on from the modernist approach, that desire for 'essential simplicity' is still quite alive in many instances of today's interaction and service design, and this is perhaps most evident in the realm of medical communication. As medical science continues

0

1

2

3

4

5

6

7

8

9

\*

to evolve into a shrine of sterility and precision, the communications involved—prescriptions, pill bottles, electronic records, information pamphlets, or recovery therapies—have followed suit.

However, this approach rather awkwardly ignores one glaring truth: that right now the human world isn't 'as free from unpredictability as an electrical machine'. And even if scientists were able to unravel the remaining mysteries of the human body and all biological unpredictability were miraculously removed, it is still highly unlikely that the everyday man—the patient—would perceive their own body with that level of understanding. The fact remains that the body sits within an ecosystem so vast and so full of choice that our brains are terribly unlikely to process all of the inputs and outputs in a systematic manner.

So, why, then, are we continually trying to design interfaces and move people through pathways as though we exist to calculate and compare rather than to experience? It's phenomenal that we have the technology on the back-end to analyze endless streams of data, and we can harness the information we gain to improve our lives. However, rather than insisting that people compress and manipulate their realities to align with our computational technologies, it seems wiser—or a very least like a refreshing change—to consider designing interfaces that reflect the way people actually understand the world.

In the context of medicine, that means stepping back from the white-blood-cell count and the EKG graph, and beginning our design process with a single data point—the only one that most people have at their disposal at the beginning of a health event: "Something is wrong."

Before we can begin to do anything productive with a sentence as oblique as that, we're going to need a little bit more understanding about what 'wrong' looks like to a person experiencing it firsthand. This is where a study of narrative becomes essential.

What follows in this section is an overview of one way of looking at illness narratives that grew from the observation of critically and chronically ill patients. I attempt to summarize that viewpoint and explore how it manifests across disciplines. I then take one step back and consider how this notion of narrative is applicable more broadly, for all patients, not just the sickest.

## RESTITUTION AND CHAOS

Arthur Frank, in his book *The Wounded Storyteller*, seeks to define the types of stories typically told by people suffering from illness or injury. His theories center upon the fact that most narratives are artifacts of the reflective process—that is, they are created after an experience has already concluded, and the author has achieved some critical distance from the material.<sup>3</sup> Frank classified many of these stories as **restitution narratives**, because they follow a traditional Aristotelian plot arc that sees a protagonist move from the emotional and physical lows of a challenge toward the eventual resolution of the challenge. The highly reductionist model of medical care currently adheres strongly to the restitution narrative. Patients are taken into care during a time of crisis and guided through a linear pathway that leads to recuperation and a return to normalcy.<sup>4</sup>

Frank gives several examples of statements made by care facilities and pharmaceutical companies—often in a marketing

1. Arthur W. Frank, *The Wounded Storyteller: Body Illness, and Ethics*. 1997. (75-114)

4. Frank, *The Wounded Storyteller: Body Illness, and Ethics*. 75.

5. Ibid., 79.

6. Ibid., 97.

7. Ibid.

8. Ibid., 99.

9. Ibid.

context—that showcase this mentality. The sentences “Harry now has a new immune system that gives him every reason to believe it’s a whole new ball game,” and: “Today, Mary has resumed her active, productive life—even adding a new pastime!” both bleed of happily ever after.<sup>5</sup> Resolution is an archetype that has become an expectation in our culture, but curiously, much as we aim for recovery, such sentences always ring trite. It’s as if we know, somewhere beneath the surface, that our own expectations are unrealistic. Harry doesn’t have every reason to believe in the future, and even if he does, it’s likely not completely because of his ‘brand-spankin’-new’ immune system. It’s a combination of factors: support from his wife, a decision to leave a stressful job, or excitement about his daughter’s wedding in six months.

Mary’s story is a little more encouraging. At least there is acknowledgement that pastimes are an important part of a meaningful life. But something still feels a little bit off. The sentence is somehow quantifying Mary’s pastimes, and the cold fact that the sum total of Mary’s pastimes now equals  $n+1$  is equated with successful patient care. How do we know Mary hasn’t taken up knitting as a new pastime because staying ‘active and productive’ is the only way for her to manage relentless anxiety post surgery?

Frank proposes a second set of patient narratives (there is actually a third, but it is less relevant for the purpose of this project). **Chaos narratives**, he says, are the result of a person trying to communicate coherently about an ongoing situation where no emotional or physical distance is possible.<sup>6</sup> Because there is no space for reflection, the stories tend to lack closure, plot-arcs, character development, and other qualities that most people can readily recognize in typical tales. These narratives stem from many situations: wars, natural disasters, oppression

and loss among them. But a large portion of these narratives are told by people suffering from serious illnesses, often in the form of autobiographies or memoirs. Many of the authors find the process of writing about their experiences therapeutic, even if finding a viable way to tell the story is a struggle.

## THE STRUCTURE OF CHAOS

According to Frank, there are a number of stylistic elements that help define a chaos narrative, among them **circular thought patterns, repetition** of words or phrases, **failure to make a concrete point**, and a **tendency to jump around in both space and time** in a way that feels more dreamlike than lucid. These stories also tend to **lack a discernable beginning and end**. The experience is always immediate and inescapable, as though all notions of a time before or after the event have fallen away.<sup>7</sup> Consider an excerpt from *The Wounded Storyteller* about a sick woman named Nancy who must also care for her aging mother:

“And if I’m trying to get dinner ready and I’m already feeling bad, she’s in front of the refrigerator. Then she goes to put her hand on the stove and I got the fire on. And then she’s in front of the microwave and then she’s in front of the silverware drawer. And if I send her out she gets mad at me. And then it’s awful. That’s when I have a really, a really bad time.”

Frank directs the readers’ attention to several pieces of this anecdote. The continual, waterfall-like usage of ‘and then’ moves the story along without really situating us in time or space.<sup>9</sup> This is something that happened to Nancy last night, tomorrow night, and every night. Likewise, Nancy’s mother moves around the kitchen in quantum leaps. She’s at the stove, at the refrigerator,

0

1

2

3

4

5

6

7

8

9

★

at the silverware drawer, all somehow without ever moving. She's a manifestation of all of Nancy's obstacles: always in the way, preventing progress.<sup>10</sup>

If we acknowledge that stories like Nancy's are real, then the next logical step is to ascertain just how common these stories are, and how we can engage them in a constructive way.

## THE ANTHROPOLOGICAL VIEWPOINT

The field of anthropology seems to be the primary—or at least the most vocal—champion of Arthur Frank's work. Since its publication, there have been a handful of attempts to a) encourage people to tell these difficult stories, and b) find a good way to record them. Sparkes and Smith use an unstructured interview format to draw out these stories from people with severe spinal injuries.<sup>11</sup> Their goal is to interrupt as little as possible, so as to allow the story told by the patient to assume its most natural form. They also ask their participants several questions about the past and the future, realizing that patients in chaos have trouble perceiving a larger context for their experiences. My own interviews heavily followed this format.

Less obvious is what can be done with these stories once they've been collected. Sparkes and Smith discuss the common and available responses to a chaos narrative; all options 'acknowledge that the person needs to move out of chaos', and guide the patient in changing their chaos narratives into various types of restitution narratives.<sup>12</sup> This is a noble approach, but seems to be highly steeped in the current scientific and medical paradigm: fix it, and fix it fast. Again, it is hard to argue that a person doesn't need to move out of chaos. It's not a desirable

nor sustainable cognitive state to live in. However, there are situations in which recovery is simply not an option—or at least not in the immediate future. In that situation, transforming the chaos narratives may not be as feasible, nor as valuable, as helping the patient embrace them. Even in circumstances where recovery is possible, allowing people to explore and recuperate in a more organic way could have significant benefits.

Arthur Frank himself argues that 'the need to honor chaos stories is both moral and clinical'. He further elaborates upon the cost of not doing so:

"To deny a chaos story [or try to fit it into the framework of a restitution narrative] is to deny the person telling this story, and people who are being denied cannot be cared for. People whose reality is denied can remain recipients of treatments and services, but they cannot be participants in empathic relations of care. The chaotic body ... cannot tell enough of its own story to formulate its needs and ask for help; often it cannot even accept help when it is offered."<sup>13</sup>

This begs the question, how exactly do we go about 'honoring' a chaos narrative? Admittedly, this seems like a difficult structure (or lack thereof) upon which to build a system for better healthcare. But if this is what Nancy's reality looks like, she probably won't benefit much from systems or interfaces that represent her life as straightforward and logically patterned. Seeking to understand what such an environment might look like, I turned my attention to another realm where chaos is often tackled in creative and aesthetically inspiring ways: the arts.

10. Ibid., 100.

11. A.C. Sparkes and B. Smith. "When narratives matter: men, sport, and spinal cord injury." *J Med Ethics; Medical Humanities*, 31. 2005. (81–88)

12. Sparkes and Smith. "When narratives matter: men, sport, and spinal cord injury." 83.

13. Frank, *The Wounded Storyteller: Body Illness, and Ethics*. 111-114.

14. Mark A. Runco and Ruth Richards, eds. *Eminent Creativity, Everyday Creativity, and Health*. 1997. (Google Ebook). (7-30)

15. Franz Kafka. *The Metamorphosis*. trans. David Wyllie. (Project Gutenberg Ebook). 2002.

16. Kafka, *The Metamorphosis*.

## THE ARTISTIC VIEWPOINT

There is often an element of artistry in chaos narrative. While the expression of chaos is at times limited to painfully un-edited spoken answers to interview questions, traces of chaos narrative frequently appear in literature, painting, music, and film. One can even make the argument that art stems from the struggle to express chaos—particularly if one believes the research that claims a genetic or environmental link between creativity and mental illness. An abundance of evidence exists on both sides of that argument, admittedly, and the issue is complicated by the wide spectrum of mental illnesses and their relative severities.<sup>14</sup> Yet regardless of whether one believes that mental illness is a prerequisite or a cofactor of creativity, the fact remains that many famous artists in history were diagnosed with either physical or mental illness, and their work often reflects their suffering, often in ways that can be considered ‘chaotic’ by Arthur Frank’s definition. In the search to create new type of interaction, we may be able to harness self-expression strategies, as well as the visual vocabulary of the arts.

### LITERATURE

#### *Franz Kafka’s The Metamorphosis*

Kafka’s short story *The Metamorphosis* begins with a memorable line: “One morning, when Gregor Samsa woke from troubled dreams, he found himself transformed in his bed into a horrible vermin.”<sup>15</sup> Inexplicably now an insect, Gregor’s round shell prevents him from getting out of his bed; he cannot eat his food, navigate his house, or go to work—at least not in the same way that he is used to. He does not perceive himself the same way,

and he cannot communicate to those people around him what in particular has changed. His family treats him like an alien, and moreover as though this sudden shift is somehow his own fault. Before long, he begins to treat himself the same way.<sup>16</sup>

Though entirely fictional, *The Metamorphosis*, is at its core, a polished literary example of a chaos narrative written long before the term was ever coined. It is not necessarily a story of illness—though it could be seen as a tale of mental illness—but it crystalizes two key elements of living with chronic or terminal illness that long to be better understood: 1) an inability to communicate what is wrong, and 2) a baffling lack of causality. Easily the most disturbing part of the entire tale is the nonchalance of that first sentence. Neither Gregor nor the audience has any idea what happened to transform Gregor into a bug. Was it a long time coming? Was it black magic? Will he be a bug tomorrow? Can he do anything to make himself *less* buglike? The narrative provides no answers.

Among the most valuable tools a healthcare interface could provide is a clear model of cause and effect. If we could find an accurate and parseable way to visualize the behaviors, genetic markers, and emotional triggers that led to a person’s descent into illness, not only could we alleviate some of the chaotic terror, but we could also prevent tales like *The Metamorphosis* from occurring at all.

#### *Ernest Hemingway’s theory of omission*

Hemingway’s prose itself—minimalist, distant, clinical, precise—is almost the antithesis of a chaos narrative. However, Hemingway’s theory of omission, also known as ‘iceberg theory’, has important

implications for the crafting of meaningful healthcare stories, chaotic or otherwise. Of the storytelling process, Hemingway wrote: “A few things I have found to be true. If you leave out important things or events that you know about, the story is strengthened. If you leave or skip something because you do not know it, the story will be worthless.”<sup>17</sup> Hemingway is essentially saying that any author must know exactly what is going on in every aspect of their story, even the pieces that don’t make it onto the page. Only by seeing the whole picture can one make an educated decision about what is truly meaningful. Applying this wisdom to a medical context, as we assemble health stories today, we omit pieces not by strategic decision, but because we don’t really *know* what is happening holistically. A specialist may ignore other organ systems because he or she has no expertise. A primary care physician may omit a patient’s emotional state because they can’t see how it relates to physical pathology—or, conversely, blame a physical illness on emotional state because all the puzzle pieces haven’t been assembled. Hemingway would likely consider the majority of current health stories ‘worthless’ in their myopia.

The solution to this value problem appears to be for the *patient* to become a master of every aspect of their health situation. Hemingway concluded his previous commentary by claiming: “The test of any story is how very good the stuff that you, not your editors, omit.”<sup>18</sup> Extending that wisdom again into the space of healthcare, the patient becomes the author and the physician the editor. In this scenario, we as patients can no longer rely on our physicians to parse the complicated tales of our lives and select what they think is relevant to a specific illness. We must be able to walk into our doctors’ offices with our narratives fully explored and pre-edited.

It follows that a good patient-facing healthcare interface would also have to allow people to fully explore their lives without censorship, and subsequently help them only present what is truly essential—in full awareness of what has been left behind.

#### VISUAL ART & FILM

Although countless examples of chaos narratives exist in writing, Frank, Sparkes and Smith all hint that the fraction of these stories that are written down is dwarfed by the number that are either a) never uttered, or b) expressed in other formats.<sup>19, 20</sup> The visual arts are an outlet for chaos narratives, but there has been less focus on these stories, likely because the visual conventions of a chaos narrative have not been well characterized or documented.

#### *Yayoi Kusama and Self-Obliteration*

One of Japan’s most renowned artists, Yayoi Kusama was a contemporary of Andy Warhol and a fixture of the New York avant-garde scene in the 1960’s. While her work also includes writing, sculpture, and film, Kusama is probably most well known for her paintings and installations where she proceeds to cover absolutely everything with polka-dots—a choice tied closely to her fascination with ‘self-obliteration’, or the sensation that she is slowly disintegrating and blending back into her environment. Kusama’s artwork at least partially stems from a mental illness she has suffered for much of her life, and the associated despair and paranoia.<sup>21</sup> In a discussion entitled Yayoi Kusama Between Abstraction & Pathology, Griselda Pollock makes an interesting observation about the way in which Kusama painted many of her polka-dotted pieces, including Infinity Net. “[Jackson] Pollock’s ‘action’ is oriented to detach the artist from the body of

17. Ernest Hemingway, “The Art of the Short Story”. In Benson, Jackson. *New Critical Approaches to the Short Stories of Ernest Hemingway*. 1990.

18. Ibid.

19. Frank, *The Wounded Storyteller: Body Illness, and Ethics*.

20. Sparkes and Smith. “When narratives matter: men, sport, and spinal cord injury.” 85.

21. David Pilling. “The world according to Yayoi Kusama,” in FT Magazine. (accessed January 20, 2012).

**Right:** View oversized plastic tulips in a white room filled with red polka-dots. Taken in the early afternoon of Thursday, February 2nd, 2012 at the Osaka National Museum of International Art. (From Wikipedia. Image by Samuel Mark Thompson. Used under Creative Commons Attribution-Share Alike 3.0 license.)



the painting; Kusama's continuous painting aspires to produce contiguity with her object... At the level of production, Kusama's brushstrokes do not 'finish' the relationship... In this process, to follow the 'self-obliteration' narrative, the self is not articulated but is continuous in connection with the body of the painting."<sup>22</sup> These comments strongly echo Frank's assertion that chaos narratives manifest when a person cannot achieve enough reflective distance from their own situation. Among many other things, Kusama's body of work is an embodiment of a chaos healthcare narrative.

However, in an interesting twist, commentary on the Tate Modern's website suggests that Kusama has "channeled this experience into a philosophy of 'self-obliteration' where being overwhelmed is a celebratory choice, not a feverish ordeal."<sup>23</sup> She's taken something inherently painful and confusing and sought to infuse it with beauty and some minimal structure.

Frank is very clear in his discussion of chaos narrative that there is nothing romantic about chaos.<sup>24</sup> It's not a state that any human being deserves to live within. I strongly agree with this sentiment in principle. That said, it also seems reasonable, if elements of chaos are more prevalent than we currently acknowledge, to borrow some of Kusama's more extreme modes of expression to create systems capable of achieving the same 'continuous connection' with the body as Pollock described.

### Migraine art

Less extreme than Kusama, but no less relevant, is artwork created by many people who suffer from migraines, including one of the professors at my undergraduate institution, Dr. Helen Donis-Keller. Her paintings try to communicate the pain and

distortion of a migraine, and are sometimes painted during the episodes. Some of her work combines painting with actual brain MRI imaging.<sup>25</sup> This sort of merger is fascinating in what it suggests about the techniques that people use, or *could* use, to better understand their minds and bodies. The MRI images provide the clinical viewpoint, while the paintings supply the other, more human perspective that is more difficult to articulate and often lost as a result. By intimately pairing paintings done during specific migraine episodes with medical images from the same time period, it may even be possible to better deduce where in the brain the migraine is occurring and what cognitive systems are being affected.

### Tarsim's *The Fall*<sup>26</sup>

A visually stunning film from start to finish, *The Fall* follows the story of a hollywood stunt man paralyzed from the waist down after falling from a horse. He tells a wild fictional story to a hospitalized little girl to manipulate her into acquiring him morphine from the hospital supply cabinet. The man's story shares almost all of the same structural elements as real-life chaos narratives collected from spinal injury patients by Smith and Sparkes: displacement in time and space, circular logic, and an inability to project into the future. The scenery and motives are ever shifting, and even the characters change name and face as the story progresses. The only stable piece of the tale is the assertion that the protagonist has lost *everything*.

The environments and cinematography of the film closely mirror this feeling of confusion and hopelessness, as the characters run up and down endless staircases that lead nowhere, chased by shadowy villains that turn out to be the child's vision of what doctors, nurses and radiologists look like.

22. Griselda Pollock, ed. "Yayoi Kusama between Abstraction and Pathology" *Psychoanalysis and the Image: Transdisciplinary Perspectives*. 2008. (147)

23. Rachel Taylor. "Kusama and Self-obliteration." Tate Modern Website. (accessed May 14, 2013).

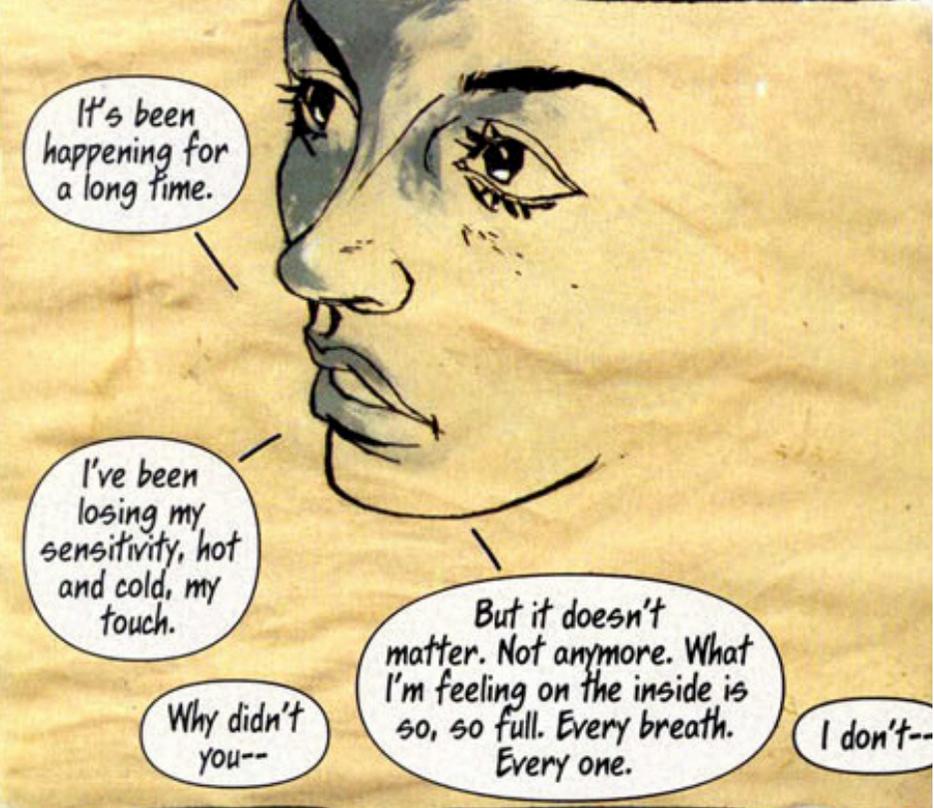
24. Frank, *The Wounded Storyteller: Body Illness, and Ethics*.

25. Klaus Podoll. "Helen Donis-Keller" (part of an online exhibition by The Migraine Aura Foundation). 2005.

26. Tarsim's *The Fall*. Directed by David Fincher. 2008.

**Right:** A fictional Charles Darwin looks out over an endless labyrinth of staircases swarming with an army of radiologists in Tarsim's *The Fall*. (Image captured from the DVD release of the film)





It's been happening for a long time.

I've been losing my sensitivity, hot and cold, my touch.

Why didn't you--

But it doesn't matter. Not anymore. What I'm feeling on the inside is so, so full. Every breath. Every one.

I don't--



She was trying to say something else but I couldn't, wouldn't hear it.

While the aim of an effective healthcare interface shouldn't be to recreate cinematic horror, and medical practitioners shouldn't be villified in reality, there are strong metaphors at play here that could be brought into a more pragmatic space. Consider the image on the previous page. Though current health interfaces tend to employ hierarchy intended to bring a patient efficiently from one discreet location to another, we could also envision a system architecture that allows the patient to navigate in redundant and revolving ways through data, encountering the same information again and again, each time with different nuances or new ways of taking action. This sort of system could be frustrating without a clear way to 'come up for air,' but if executed properly, it could prove therapeutic for patients who just need some time to explore and process information.

### Darren Aronofsky's *The Fountain*

Released both as a film and a graphic novel, *The Fountain* deals with the human struggle to accept mortality.<sup>27, 28</sup> In the present, a researcher scrambles desperately to find a cure for cancer while his wife slowly dies of the illness. But this is only one of three tales spanning several millenia. In each tale, the same man struggles to save the same woman, while the woman herself wonders whether she needs to be saved. We get the sense the man can never quite let go, and the woman has already made peace with death long before, perhaps in another lifetime. Similarly to *The Fall*, this story makes heavy use of visual redundancy and spatiotemporal displacement. From an interface design perspective, it hints that letting people revisit memories or data from other points in time based on content rather than chronology could aid in understanding and acceptance of difficult situations. This could manifest somewhat like the current trend of hashtags in Twitter or tag clouds in blogging portals, or

27. *The Fountain*. DVD. Directed by Darren Aronofsky. 2007.

28. Darren Aronofsky, and Kent Williams. *The Fountain*. 2005.

Left: A sequence from the 2005 graphic novel version of *The Fountain*, showing a situation where the doctor refuses to hear a patient's choice to let nature take its course.

29. Lisa Rosenbaum, "The Art Of Doing Nothing." *New England Journal of Medicine* 365, no. 9 2011. (782-785).

30. Lisa Rosenbaum, "The Art of Doing Nothing."

perhaps as something more immediate and lucid—past journal entries seamlessly intertwining with passages written in real time—plus an added layer of guidance to encourage reflection. The film also works well as a dramatized portrayal of a situation that happens frequently in everyday medical practice: one where a doctor feels obligated to try all possible options, even when a patient would rather let an illness run its course. This is a good segue from the metaphorical, highly stylized realm of the arts back to the modern reality we are currently facing in our hospitals and clinics.

### REVISITING EVERYDAY MEDICAL PRACTICE

Much of the literature and prior art covered in this review has focused on patients suffering through extreme situations, and the equally extreme modes of creativity that may provide comfort or insight. However, despite Arthur Frank's focus on the critically and chronically ill, I believe that aspects of the chaos story can be found throughout the current scenarios of patient care, regardless of whether a person is very ill, or ill at all. In fact, there is some chaos inherent simply in living our lives from day, and we currently struggle to express even those normal levels of confusion and anxiety to our physicians in a way that they can utilize meaningfully.

A number of articles in recent health journals discuss the difficulties not in treating patients, but in interacting with them pre- and post- treatment. Buzz-words abound: 'patient-satisfaction,' 'patient-care,' 'patient-outcomes,' 'patient-engagement' all of them similar and yet irritatingly different, and industry professionals spend a lot of time stressing that outcomes do not correlate to satisfaction, nor vice versa. One

thing, however, seems incredibly clear: patients are a trickier sort of beast than initially supposed, and new tactics need to be developed to engage with them successfully, care for them better, and create better outcomes, as linked or unlinked as those concepts are.

Some of the most compelling stories come from physicians who then find themselves in a role-reversal situation. Dr. Lisa Rosenbaum, a piece for *The New England Journal of Medicine*, writes about her epiphany after seeking attention for an injured knee.<sup>29</sup> Bound by her faith in the medical practice, her gut reaction was to seek advice from an orthopaedist immediately. But her primary care physician had other ideas, and simply told her to rest, and perhaps try swimming. "Telling a runner with an injured knee to swim is like telling an orthopedist with an injured hand to become a psychiatrist. He needed redirection," she initially concluded. But through a series of reflections and an ongoing dialogue with her dying grandfather—also a doctor—she has a change of heart, and learned about the 'art of doing nothing': the title of the piece.<sup>30</sup> Obviously, with so many incredible treatments available to us nowadays, it would be silly not to act when confident that the result will be better for the patient. But in order to know when to push forward and when to stand back, doctors need more information than MRI's and blood tests can provide. They need values-based information—like Lisa's dedication to running—as well as perhaps something a little bit more subtle: an understanding of how much the mere suggestion of substituting swimming could invoke fear, frustration, or mistrust in the relationship. Beyond values-based medicine, there is identity-based medicine.

Another doctor, based in Melbourne, sheds more insight into the breakdown of communication between patients and physicians,

- 0
- 1
- 2
- 3
- 4
- 5
- 6
- 7
- 8
- 9
- ★

this time in a situation where something undoubtedly *could* have been done, and wasn't. A breast-cancer patient slips through the cracks of follow-up care, and turns up in an examination room some time later showing strong symptoms of relapse. Why hadn't she called somebody? Nobody had called *her*. "To her thinking, no news was good news — [that is] not an uncommon belief among chronically ill patients who long for normality," says Dr. Srivastava.<sup>31</sup> The patient's conclusion is highly illogical to almost anyone with enough distance to reflect. But perhaps to the patient, during a "vulnerable time," the relief of being able to return to her life without having to ponder medicine or mortality was the only relief she wanted. She didn't want to remain so close to the chaos without any mechanisms in place to help her cope with it.

However, the mechanisms Dr. Srivastava suggests don't really aim to help her patient cope better with chaos, at least not directly. "Perhaps we can also learn from industries that manage vast numbers of goods and services by using active tracking systems that can locate products throughout their journey and provide alerts in case of mishaps," she says. The intention is noble, and there is something highly pragmatic about wanting to harness the technologies that track goods with extreme efficiency to also track people. I also don't doubt that medical mistakes would decrease, and lives would be saved. But if there were ever a sentence that more strongly echoed Kinross' assertion about post-war modernist design, I've never seen it. Is this really the best we can do to address the problem of patients longing for a sense of normalcy in a reality that cannot hope to be normal?

At this time, most people who are having trouble coping still have to seek help from psychotherapists. And despite their effectiveness in many cases, there is unfortunately still a large

stigma surrounding therapy for the mind, preventing many people who could probably benefit from ever seeking assistance.

#### SELF-EXPRESSION & THERAPY

Perhaps the most relevant form of therapy currently available, in keeping with earlier discussion, is art therapy. The American Art Therapy Association (AATA) explains on their website the value of creative expression in 'enhance[ing] recovery, health, and wellness,' and defines Art Therapy as "the therapeutic use of art making, within a professional relationship, by people who experience illness, trauma or challenges in living, and by people who seek personal development."<sup>32</sup> Through creating art and reflecting on the art products and processes, people can increase awareness of self and others cope with symptoms, stress and traumatic experiences; enhance cognitive abilities; and enjoy the life-affirming pleasures of making art."<sup>33</sup> The AATA's website claims that since the 1940s, art therapy has gradually been integrated with traditional behavioral and physical therapies, providing additional opportunities for insight.<sup>34</sup> However, therapies which harness creativity and still lie largely on the fringe of behavioral therapy, which in turn is still heavily sequestered from traditional medical infrastructure. There is much left to be done in the quest to unify treatment for mind and body.

31. Srivastava, Ranjana . "Denial." *New England Journal of Medicine* 360, no. 12. 2009 (1174-1177).

32. The American Art Therapy Association Webpage. (<http://www.americanarttherapyassociation.org>, (accessed January 2012).

33. Ibid.

34. Ibid.

35. "WebMD - Better information. Better health.." <http://webmd.com> (accessed May 14, 2013).

36. Microsoft HealthVault. "What Can You Do with HealthVault?" <https://www.healthvault.com/us/en/overview>. (accessed May 14, 2013).

37. Ibid.

## 4 related products & systems

### CURRENT PATIENT-CENTERED HEALTH PORTALS

#### *WebMD* <sup>35</sup>

*WebMD* receives a lot of criticism from doctor and patients, but honestly, its presence has probably done a lot to herald the changes we are now seeing in patient-centered care. The moment people realized that they could use the internet to find information about symptoms and treatments without having to spend the time, effort, and money to schedule a doctor's appointment, expectations subtly shifted. People realized they *wanted* more control over their healthcare. Unfortunately, they aren't quite adept enough to handle it. While *WebMD* excels at allowing people to explore medical information, it is such a highly depersonalized system that it can only tell us what is possible, not what is likely for *us*. Perhaps the largest problem with the system is how general some of the symptomology reads, often leading patients into a state of panicked hypochondria. This, in turn, makes it more difficult for doctors to ascertain the real problem, and might have the unfortunate effect of lowering the doctor's trust in the patient's judgment, perpetuating the imbalance of authority that the patient was originally trying to mediate.

#### *Microsoft's "HealthVault"* <sup>36</sup>

Microsoft's major contribution to the health-data space is *HealthVault*, a record organization system that functions as one might expect for an application containing the word 'vault' in its title. It is essentially one large storage repository for clinical records, including lab results, radiology images, and prescriptions. It also interfaces with many common health apps and devices for self-tracking, so patients can import and graph large amounts of raw data. Microsoft seems to assume that the user here is a 'manager' archetype; *HealthVault's* website has example scenarios that include 'sharing the care of an elderly family member,' 'being prepared for an emergency,' and 'managing family health information.'<sup>37</sup> All of these scenarios somehow imply that the system's purpose is to retain documentation like a file cabinet, so that patients can present it to their physician at the right time. However, it makes little mention of what

- 0
- 1
- 2
- 3
- 4
- 5
- 6
- 7
- 8
- 9
- \*

patients can do with those documents on their *own* time, and also leaves much of the document acquisition process up to the patient. Authority still appears to lie heavily with physicians, as they are the entities who ultimately make the records available, and interpret their content.

### *Carnegie Mellon University's "BodyTrack"* <sup>38</sup>

Approaching the problem of health data as an industry outsider, *BodyTrack* puts patients in control of their own health data. Interfacing with several devices for tracking everything from sleep to heart-rate to dieting patterns, *BodyTrack* gives patients tools to analyze their biological trends over large periods of time. It also has minimal capacity for people to share their discoveries with others using social media like Twitter and Flickr. However, the current interface relies on its users being highly self motivated, inquisitive and adept at making connections between data points without large amounts of context. Leaving out physician and industry-supplied data is a conscious design choice, but this seems to exclude users who have less experience grappling with quantitative data.

The model also currently relies heavily on patient having a 'health coach' who is not necessarily their physician, with whom they can discuss their hypotheses and plan lifestyle changes.

### *UPMC | TDC's "Convergence"* <sup>39</sup>

UPMC | TDC is developing a platform called *Convergence*, which is capable of sitting on top of electronic health records, and will provide clinicians with highly focused and actionable summaries of all of their current patients. The intent is for the system to become a central hub for medical data in both

inpatient and outpatient situations, and there are plans for it to interface with several other health applications, including others in development at the TDC. There are also preliminary plans for the portal to have a patient-facing side, so that the system could facilitate doctor-patient interaction rather than just being a reference tool for physicians.

Interestingly, one of the major achievements for *Convergence* is the implementation of an overarching timeline showing all of a patient's health events and records. Though a seemingly rudimentary concept, it's still relatively uncommon in current healthcare applications. While I support the idea of a timeline for the sake of information organization, I wonder if other, less linear visualizations may be more appropriate for a patient interface; to that end, it is my hope that the work done in this thesis will be able to impact the future trajectory of the patient-facing side of *Convergence*.

### *National Health Service's "How Are You?"* <sup>40</sup>

An app developed to work seamlessly within the United Kingdom's government subsidized National Health Service (NHS), *How Are You?* is one of the best examples of a comprehensive digital health portal I have come by in my exploration of the space. The makers of *How Are You?* have a strong grasp on the relationship between health data and context, and between doctor and patient. The app allows the patient to do a significant portion of the data entry, letting them configure the app to provide the most desired information. It's easy to discover more information about illnesses and therapies, and when one does have a question, it's easy to ask someone with the answer, whether that person is a doctor in your network, a friend, or family member. What it still seems to lack, however, is storytelling.

38. Carnegie Mellon University. "BodyTrack." *BodyTrack*. <http://www.bodytrack.org/> (accessed May 12, 2013).

39. Stein, Alicia. "UPMC's Analytics Project Uses Technology To Enhance Overall Patient Care." *XChange Events*. 2013.

40. Cambridge Healthcare. "How Are You?" *How Are You? : The Personal Health Record*. <https://en-gb.howareyou.com/patients> (accessed May 13, 2013).

# HEALTH APP COMPETITIVE ANALYSIS



- not present
- present in minimal capacity
- well executed

- 0
- 1
- 2
- 3
- 4
- 5
- 6
- 7
- 8
- 9
- \*

## 5 elucidating experience

I conducted four in-depth interviews with people of varying ages and with a wide range of medical problems, acute and chronic. Each patient interview lasted for an hour or more, and each contained elements of both restitution and chaos. For the purpose of this document I am including summaries of each story with what I feel were the major revelations from each. I acknowledge that in some respects this is slightly disingenuous, as my formulating these narratives into something more cohesive directly contradicts the idea of embracing chaos. However, I've tried to maintain the thematic elements of each story that embody a chaotic mindset.



## THE CATCH 22

The man before me was quiet, calm, and meticulous—a very well established scientist with a strong drive to figure out solutions to his own problems. And yet I left the interview with notes covered in arrows, asterisks and asides that I had trouble parsing only hours after I'd heard the story. Such is the nature of the chaos that this man had been through—and continues to experience. As procedural as he tried to be—and it was evident he was trying—his tale was fraught with phrases like 'well, let me back up' and 'I should also mention—'. I found myself continuously ricocheting back and forth between 2011 and 2012 as he tried to make connections between what he'd been through and where he is now, and not without good reason.

Everything started simply enough; he was having a routine biopsy to screen for prostate cancer. Because the biopsy pierces the wall of the colon, there is always a moderate risk of infection, and so an antibiotic is prescribed before the procedure takes place. However, the infection that this man acquired from the biopsy was among the worst that one could encounter: a rare antibiotic resistant strain of *E.coli*. It's unclear how it got there, but it lay dormant in his colon, waiting to strike. The *E.coli* entered his blood and brought him within hours of death. "My kidneys were shutting down, my liver was shutting down... my heart was going into V-tach... I was fortunate that the intensivist on call in the ER was doing all the right things to keep me alive. They did a blood culture, but those take 72 hours to come back."

After a week in the intensive care unit, doctors were able to pull him back from the brink, but he continued to be on intra-arterial antibiotics for weeks afterward (they couldn't keep using IV antibiotics because vein walls break down over time). Just when everything seemed like it was getting better, and the antibiotics had run their course, he ended up with a urinary tract infection (UTI) and was put on a new set of antibiotics.

Those antibiotics, in turn, wiped out all of the healthy bacteria in his colon, and without any competition, another vicious bacteria, *C. difficile*—which he likely acquired while in the hospital—overran his system. "They call it *difficile* for a reason: it's difficult to get rid of," the man explained. Doctors treated it with one set of antibiotics, which didn't work, and so he was given another, stronger type, a regimen he stayed on for

the next eighteen months. Needless to say, this is an incredibly unsustainable situation, as it both disrupts the body's biochemistry and also increases the chance of developing more drug-resistant bacteria like the *E. coli* that nearly killed him in the first place. Unfortunately, he couldn't get off the antibiotics, because every time he did, either the *C.difficile* or the UTI would re-emerge.

Therein lay the first catch 22.

As if this man's situation wasn't already complex enough, it was about to get much worse. Baffling "all the doctors he was talking to," given he was such an active person before his illness, he developed deep vein thrombosis: a clot in his ankle.

"I might've had something to do with the fact that I have cancer," he said then. Did he mention that the prostate biopsy came back positive?

But he couldn't weave that into the tale; not right then. There are too many other things going on. It turned out there wasn't just one clot, but many, and he was immediately placed on a blood thinner.

Not long after that, he started having excruciating headaches, which turned out to be a hematoma in his brain: bleeding caused by the blood thinner. He went back to the ER, and received a dose of steroids to stop the swelling. He also went off the blood thinners, but the headaches continued nevertheless. He wound up in the hospital yet again, and this time received a full craniotomy to relieve the pressure on his brain, and to

cauterize the blood vessels. While recovering from this surgery he began having seizures, and was put on anti-epileptic medication as well—a medication which he has remained on, and which interferes with his speech to a small degree.

Simultaneously, since it was evident that he could not be placed on blood-thinners, and still had a clotting problem in his legs, physicians opted to insert a filter in his inferior vena cava to make sure the clots didn't reach his lungs or heart. Such a filter needs exchanged for a fresh one every 6 months to a year, since they clog over time. Unfortunately, in order to perform the surgery to replace the filter, one needs to take blood thinners. Being unable to do so, he was unable to undergo surgery to replace the filter.

A second catch 22.

And so, as the initial filter began to clog, he began to pass out every time he tried to stand up. This is a problem that still plagues him, but through vigorous self discipline and exercise, he's been able to train his circulatory system to return his blood back to his heart through minor veins rather than the main venal pathway. Through all the chaos, the man is still completely determined to bicycle to work as much as he can. That is about as linear as the tale gets, and it is far from over. It includes asides about his ongoing battle with cancer (which is somehow the least of his worries), his battle with insurance companies, his battle to educate the obstinate physician who performed his biopsy about newer surgical methods that could have prevented

his initial infection, and his battle with addition to pain killers and anti-anxiety medications. He is still struggling to make sense of it all, and has been busy compiling research and contacting doctors at other medical institutions to try to approach his problems in innovative ways. Relentlessly applying the scientific method to himself seems to be his way of coping.

Toward the end of the interview, he voiced a mindset that somehow seemed to encapsulate simultaneously his resilience and his primary issue. "I'm just focusing on one problem at a time," he told me, which for one man with a lot of weight upon his shoulders, seems entirely reasonable. However, for the disparate set of physicians he works with—each one a specialist with only one organ to treat—this sort of mindset can lead to exactly the sort of systemic oversights that stacked the cards against him.

0

1

2

3

4

5

6

7

8

9

\*

## THE DENIALIST

A boy is born into a family of people with a long history of heart disease and heart attacks. He lived through both his mother and father suffering major heart attacks at a relatively young age—in fact, his father passed away by the time this boy had reached age 21. Yet, for some reason, he remained convinced of his own invulnerability, thinking somewhere in the back of his mind that he obviously was going to be the one to break the genetic trend in his family. Even though he was a runner, stress and the college lifestyle lead him down the path of poor diet and exercise, and he didn't think twice about it. He remained so convinced, that his first inclination when experiencing serious pain at age 47 wasn't to go to the ER, but to get some sleep, and when he finally did decide to get evaluated, drove himself to the ER.

At this point, he was brought into surgery and given stents, and has so far not suffered any complications either from the incident or the surgery. He has several medications to take, but that's fine, according to him. Although he was initially a little bit unsure what 'cardiac rehab' was or what it could do for him, he went after a bit of nudging from his doctor, and is now in what he describes as 'the best shape of his life'. He enjoys going to cardiac rehab to exercise now, even though he's technically 'graduated', because he genuinely enjoys the people he's met and the scaffolding that they've provided him.

In basically all respects, this man is a poster child for the American Healthcare system. He was fine, became ill, and made what seems to be a full recovery. And yet, there is something just a little bit strange about the story, if you think about it. The nature of the strangeness occurred to me when he said: "It's one of those really basic bits of wisdom people say like it's obvious until they're actually living the situation: if you ever think you're having a heart attack, or a stroke, don't drive yourself to the hospital!"

The thing is, this man didn't think he was having a heart attack. Despite the story he'd just told me about his past, the traumas he'd witnessed, and his own condition, his identity was not 'a person with a heart problem'.

He'd spent his whole life in denial.

## THE HIDDEN HOPE

A middle aged woman was diagnosed with breast cancer, underwent chemotherapy, and though it drove her cancer into remission, she reacted badly to a particular drug in the cocktail, and was left with substantial cognitive impairment on top of the nausea and the hair loss. By all accounts, before her treatment, she'd been a small but quick, fiery spirited woman, but the procedures left her dangling over an abyss. She lost her job, retreated into her home, and soon found herself in despair. No physician would really acknowledge the blunting of her mental acumen, because nobody undergoes a cognitive evaluation when they're healthy, so there was no baseline to contrast with her current condition. The only person who truly understood what had been lost was she herself. And she'd lost everything.

She explained to her therapist the other day that when a neighbor had treated her daughter poorly, she would have once gone over and set them straight. Now, she couldn't even bring herself to confront the neighbor on their behavior. "Why would anybody take me seriously?" she asked. "They'll just think I'm this crazy person ranting at them and it'll embarrass my daughter more."

This story can also be seen as an archetype of medicine, though a tragic one. And yet, there is interesting dissonance here too. Not long ago, the woman's cancer unfortunately came back, and her physician, despite her first reaction, insisted on putting her back on the same chemotherapy, and she listened for one round because she didn't know what else to do. Yet, when she reacted negatively again, she stopped treatment, did some research, found another doctor across several states who was doing a trial with a drug for her type of cancer. She picked up the phone, made a few calls, and got herself an appointment with the physician. People around her were baffled that she'd had the nerve and the perseverance to track the researcher down. "It's just a phone...!" she said, as though anyone would and could have done what she did.

And yet she couldn't confront her own neighbor.

0

1

2

3

4

5

6

7

8

9

\*

## 6 synthesis

My literature review, patient interviews, and constant conversations with friends, family and professionals eventually coalesced into a set of recurring themes. I used these themes in conjunction with the visual vocabulary and ideas for interaction that I'd acquired from my literature review in order to begin sketching concepts, shown on the facing page.

### FIVE PAINS OF PATIENT-CENTERED CARE

#### 1. CLINICIANS SEE LINEAR TIMELINES. PATIENTS LIVE NON-LINEAR LIVES.

When patients talk to doctors, their opinions are often invalidated because their hunches and feelings aren't easily substantiated. And because people don't try to learn about themselves until they are already sick, they rarely have good points of comparison. Many maladies have root causes hidden in a patient's past that aren't immediately evident to the patient or the doctor.

#### 2. WHEN IT COMES TO MEDICINE, MOST PEOPLE ARE SHEEP.

Provided with prescriptions or other medical instructions, most people will fall into one of two camps: those who strictly follow every rule, dreading what might happen if they fail, and those who find following the rules difficult, out of forgetfulness, lifestyle patterns, or a lack of understanding. In both cases, people are missing a fundamental 'why', leading to confusion and frustration.

#### 3. IN SCHOOL WE ARE TAUGHT ABOUT ORGANS, NOT ABOUT THE BODY.

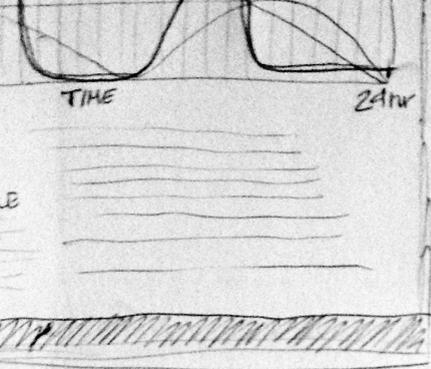
We break everything down into buckets to make things easier to understand. Specialists take this to an extreme, becoming experts at ear, nose & throat problems, or gastro-intestinal problems, or mental illness. This is essential on the clinical side to achieve depth of understanding. But each patient doesn't come with one organ. We come with entire bodies, and have to understand how our systems overlap, but trying to see all the connections can be overwhelming, for us, and for our doctors.

#### 4. WE CAN NEVER SEE PAST CHOICES WE DON'T UNDERSTAND.

We choose to be constantly sleep deprived, to take on an extra project, to try herbal alternatives to prescription medication, to eat less fatty foods, but we have very little idea how those choices impact our bodies at a grander scale. Sometimes, the interconnectivity can be so overwhelming that living in denial becomes a preferable alternative.

#### 5. WE WALK 10,000 STEPS, SLEEP 7.5 HOURS, AND LOG THOUSANDS OF DECONTEXTUALIZED DATA POINTS DAILY.

There are all sorts of monitors to help with weight, heart health, stress, breathing, sleeping. Most of them will give you a stream of data that falls nicely into the linear clinical concept of health. But the vast majority of it is also noise without context. We are not trained to pick out the signal.



TYPE DOSAGE

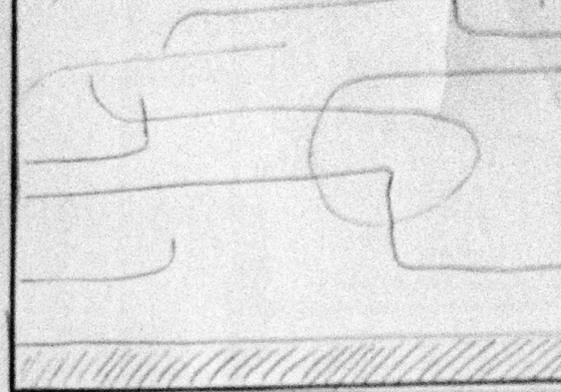
TYPE SPECIAL INSTRUCTIONS

GO

# NARRATIVE RECOVERY

BUILDING STORIES TO REBUILD A HEALTHY, WHOLE LIFE

ENTER



## VS - COMPARE

What do you want to compare?

Actual Day to Ideal Day

Tell A Story!

- Different Medication options
- Active in Blood vs other organ

TIME 24hr

## INTERNAL STATUS - (CONCEPT 1)

## CONTEXTUALIZE

THOUGHTS

RECENT BLOOD WORK

ENTER TEXT

ADD TO STORY

## MEDICATIONS

MARCH 31ST

8AM

MEDICATION CARDINAL

WHAT'S GOING ON?

↑ CREATE HYBRID VIEW

## STATUS - (CONCEPT 2)

PAIN

SKELETAL

LIVER

## INTERNAL STATUS - INDIVIDUAL ORGAN

BRAIN

MEDICATIONS

PERSONAL OBSERVATIONS

LONG-TERM CONDITIONS

ADD +

ADD +

## PUZZLE PIECES

JOURNAL OF ALL MED.

STOMACH PAIN IMPORTANT BREAKTHROUGH AT BOSTON U.

ABSTRACT

SEARCH

STOMACH PAIN

MEDICAL JOURNAL

WEB MD

SOCIAL MEDIA

GO

## SHARING

WHO KNOWS WHAT?

D1 D2 D3 D4

SEND THIS

(articulate issues)

(learn new info / v)

(archive and research)

(communicate)

# {narrRecuperate}

Telling & re-telling the story of your health  
doesn't have to become the story of your life.

Let's tell the story well the first time.

Where did we leave off?

*username*

*password*

*sign in*

## 7 the proposed system

{narRecuperate} begins with the same basic functionality as many other health-related applications currently on the market or in development. These capabilities include but are not limited to:

- Access to an electronic medical record,
- A timeline view of a patient's health incidents and documentation
- Mechanisms for sharing information with a team of medical experts, family and friends, and
- Support for a variety of self-tracking devices, and the ability to import information from external apps.

But it doesn't stop there. The true value in the system is the window it provides into the story behind all this raw data. It combines five overlapping but strategically different data visualizations to **illuminate opportunities for behavior change**, and **allow positive critical analysis of physician instructions**. Each begins with an observed patient behavior or perspective, then augments that way of looking at the world with data supplied from clinical sources, transforming internalized experience into an externalized and collaboratively generated artifact. This artifact can then be used to facilitate face-to-face, doctor-patient interactions. The visualization techniques borrow from the arts, leading to a few non-traditional system workflows, high levels of redundancy, and illustration styles not typically seen in reductionist healthcare portals. The rationale is simple: chaos is bright and bold, and at times startlingly intuitive in the way it wanders, so why not embrace some of that wanderlust and subtly manipulate it to our advantage?

0

1

2

3

4

5

6

7

8

9

\*



## DEMYSTIFY THE ABSTRACT

### WITH A RESPONSIVE BLOGGING PORTAL

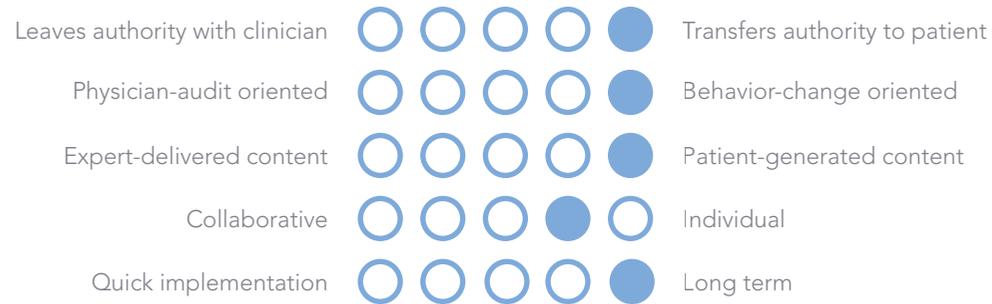
At first glance, the blogging functionality of **{narRecuperate}** is much like any other. But dig a little deeper, and it becomes a powerful tool for turning abstract thought and emotion into valuable information. The system scans each entry for key words, tone, and repeating structures. It then presents the connections it finds, so you can see repeating thoughts and behaviors you may not have fully understood. The tool doesn't treat each connection it finds as a rigid, meaningful truth, it just encourages you to take a second look, sometimes through another lens.

#### *Employed elements of chaotic narrative*

The ability to **move freely through time** based on shared context, **no prompts** or guidelines for what to write, highlighting of **repetitive words or themes**.

#### *Who it would help most*

**The Hidden Hope** could use this portal to realize that she does have the internal strength to confront her neighbor. **The Denialist** might also discover lifestyle habits or mindsets that are leading him down an unhealthy road.



BLOG HISTORY

MAKE A NEW POST

REFLECT

SORT BY:



Enter a title for this post

[Redacted content area with horizontal bars and some colored highlights]

FEBRUARY		
02.03.2013	[Redacted]	[Icons]
02.04.2013	[Redacted]	[Icons]
02.10.2013	[Redacted]	[Icons]
02.14.2013	[Redacted]	[Icons]
02.17.2013	[Redacted]	[Icons]
02.18.2013	[Redacted]	[Icons]
02.22.2013	[Redacted]	[Icons]
MARCH		
02.03.2013	[Redacted]	[Icons]
02.04.2013	[Redacted]	[Icons]
02.10.2013	[Redacted]	[Icons]
02.14.2013	[Redacted]	[Icons]
02.17.2013	[Redacted]	[Icons]
02.18.2013	[Redacted]	[Icons]
02.22.2013	[Redacted]	[Icons]
02.03.2013	[Redacted]	[Icons]
02.04.2013	[Redacted]	[Icons]
02.10.2013	[Redacted]	[Icons]
02.14.2013	[Redacted]	[Icons]
02.17.2013	[Redacted]	[Icons]
02.18.2013	[Redacted]	[Icons]
02.22.2013	[Redacted]	[Icons]
02.22.2013	[Redacted]	[Icons]
APRIL		
02.03.2013	[Redacted]	[Icons]
02.04.2013	[Redacted]	[Icons]
02.10.2013	[Redacted]	[Icons]
02.14.2013	[Redacted]	[Icons]
02.17.2013	[Redacted]	[Icons]
02.18.2013	[Redacted]	[Icons]
02.22.2013	[Redacted]	[Icons]
02.22.2013	[Redacted]	[Icons]

"I couldn't make myself **confront** my friend about what she said, even though it upset me. I was just so **exhausted**."

"**CONFRONTATION**" and its various forms have shown up a total of **24** times in **21** entries.

02.03.2013	[Redacted]
02.14.2013	[Redacted]
02.19.2013	[Redacted]
03.12.2013	[Redacted]
04.01.2013	[Redacted]

"**EXHAUSTION**" and its various forms have shown up a total of **46** times in **30** entries.

02.03.2013	[Redacted]
02.14.2013	[Redacted]
02.19.2013	[Redacted]
03.12.2013	[Redacted]
04.01.2013	[Redacted]

THOUGHT OF THE DAY:

In today's entry (and 10 others) you spoke of confrontation in a negative sense (couldn't). However, in your entry on **APRIL 3, 2013**, you succeeded in confronting your sister. How did you feel then? What was different about that situation? What was the same? Is there anything you can do to replicate that success?



## UNCOVER THE 'WHY' WITH A MEDICATION VISUALIZER

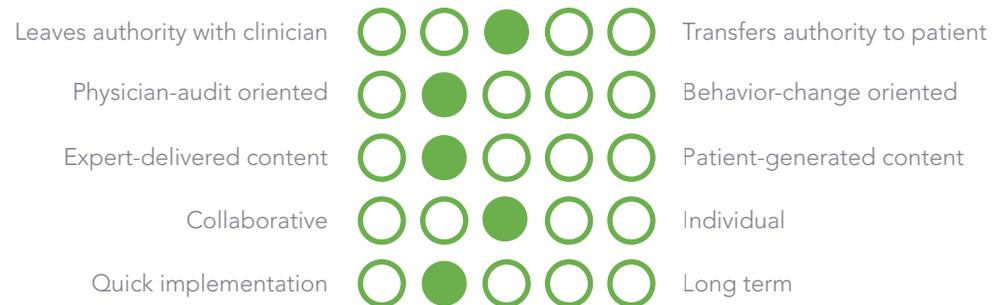
This tool is an interactive visualization of pharmaceutical information. Aside from providing the instructions that every medication already comes with, the portal lets you set a regimen for yourself from all your medications, displays the concentration of each medication in your blood over the course of the day (a standard indicator of effectiveness & safety). It then lets you compare your ideal regimen with your actual behavior each day, and provides a place to experiment with generics, alternatives, and different dosages to see their effects before you medicate.

### *Employed elements of chaotic narrative*

Admittedly not many in this portal, though visualizing all medications in a single location could lead to a very complex portrait.

### *Who it would help most*

**The Catch 22** can check to see if a medicine he's taking for one condition will negatively affect the treatments he's receiving for another. **The Puzzle** can better manage her pain medications and better understand the necessity of adherence. **The Hidden Hope** might uncover a medication with dire cognitive consequences.



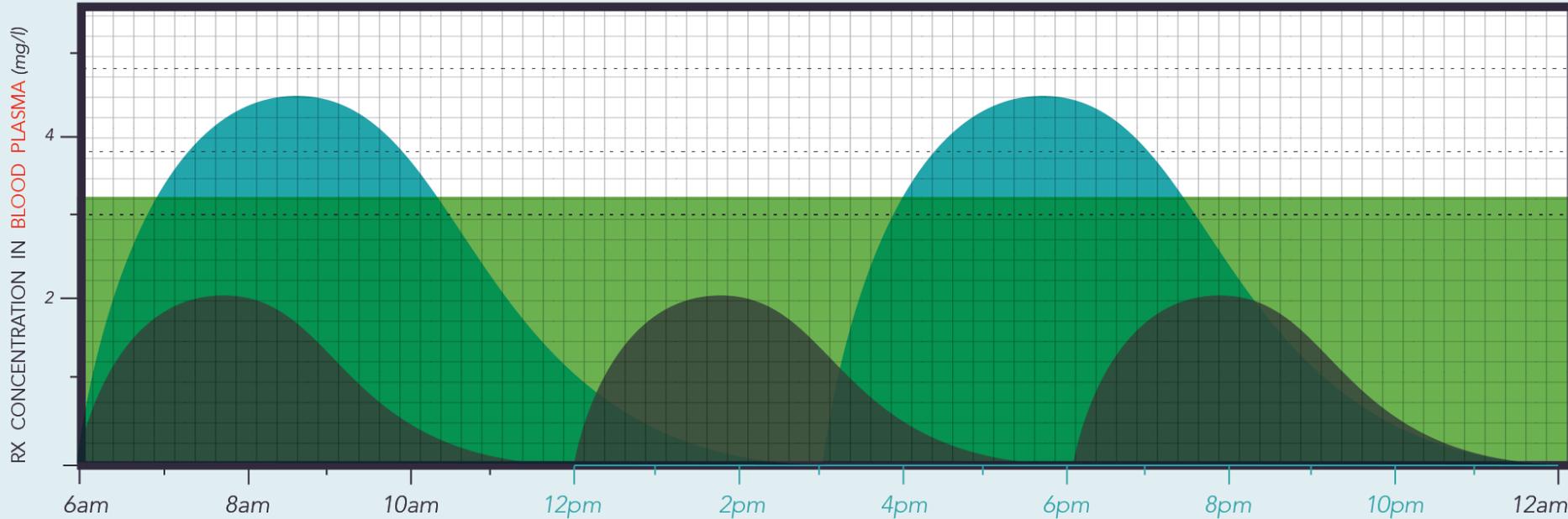
LEARN

TRACK

PLAN

COMPARE

### Your Daily Regimen



## HYDROCHLOROTHIAZIDE

### About this medication

**WHAT DOES THIS MEDICATION TREAT?**

This prescription is used to treat **high blood pressure**.

[HYPERTENSION](#) ▶  
[HEART/CIRCULATORY](#) ▶

**HOW DOES THIS MEDICATION WORK?**

Hydrochlorothiazide, abbreviated HCTZ, HCT, or HZT, is a diuretic drug of the thiazide class that acts by inhibiting the kidneys' ability to retain water. This reduces the volume of the blood, decreasing blood return to the heart and thus cardiac output and, by other mechanisms, is believed to lower peripheral vascular resistance...

### How do I take this medication?

**YOUR CURRENT DOSAGE**

1 50mg tablet, Twice Daily [SEE HISTORY](#) ▶

**SPECIAL INSTRUCTIONS**

Take tablet with food or thick beverage (like a smoothie).

Do not take less than 6 hours apart, and do not exceed 2 tablets in 24 hours.

### Warnings & side effects

**SIDE EFFECTS**

**Dehydration:** This medicine works by removing water from your blood, so make sure you drink lots of water to make up for the loss.

**Potassium Depletion:** Hydrochlorothiazide is a calcium sparing thiazide, which means it leaves your body's calcium supply alone. However, it can **severely impact potassium levels, affecting the nervous system**. Make sure you are getting enough potassium while taking this medication, or consider [a potassium supplement](#).

## MED BROWSER

**SORT:**

- ALPHABETICALLY
- BY PRESCRIBE DATE
- BY CONDITION TREATED

**NAME:**

**SHOW?**

BAYER (ASPIRIN)	<input type="checkbox"/>
ATENOLOL	<input type="checkbox"/>
CITALOPRAM	<input checked="" type="checkbox"/>
EXCEDRIN (ASPIRIN / PARACETAM...)	<input type="checkbox"/>
HYDROCHLOROTHIAZIDE	<input checked="" type="checkbox"/>
TYLENOL (PARACETAMOL)	<input checked="" type="checkbox"/>
ZYRTEC	<input type="checkbox"/>



## SHIFT PERSPECTIVE WITH AN 'ORGANIC' DISCOVERY SYSTEM

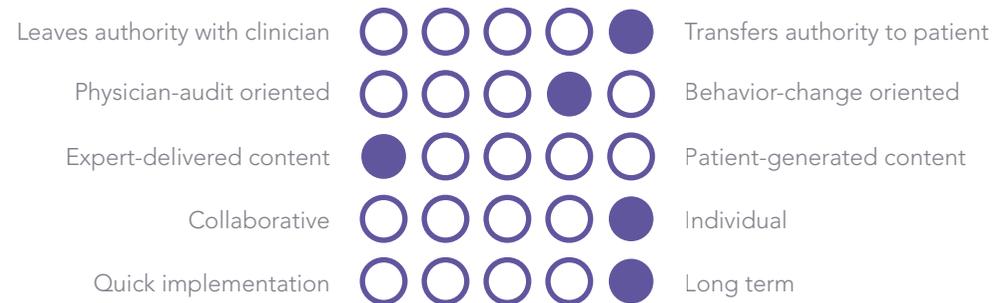
Travel through your body, organ by organ, and begin to understand how interrelated everything is. Follow a single medication through every organ and learn how a prescription you're using to treat a heart problem is simultaneously harming your kidneys. Or, stick with an organ system, and understand how everything in your life stacks up to paint a bigger picture. Every bit of information comes with links to the other subsystems, so you can take notes, and take action as you learn.

### *Employed elements of chaotic narrative*

The the organ-by-organ view **keeps the patient extremely close to the information** with no attempt at tackling a bigger-picture, all of the information is **highly redundant**, just approached, recontextualized, and reapproached.

### *Who it would help most*

**The Puzzle** could cycle quickly through all possible organ systems that might be the root cause of her pain. **The Catch 22** may take comfort in being able to stay focused on one problem at a time without losing track of the connections between systems.



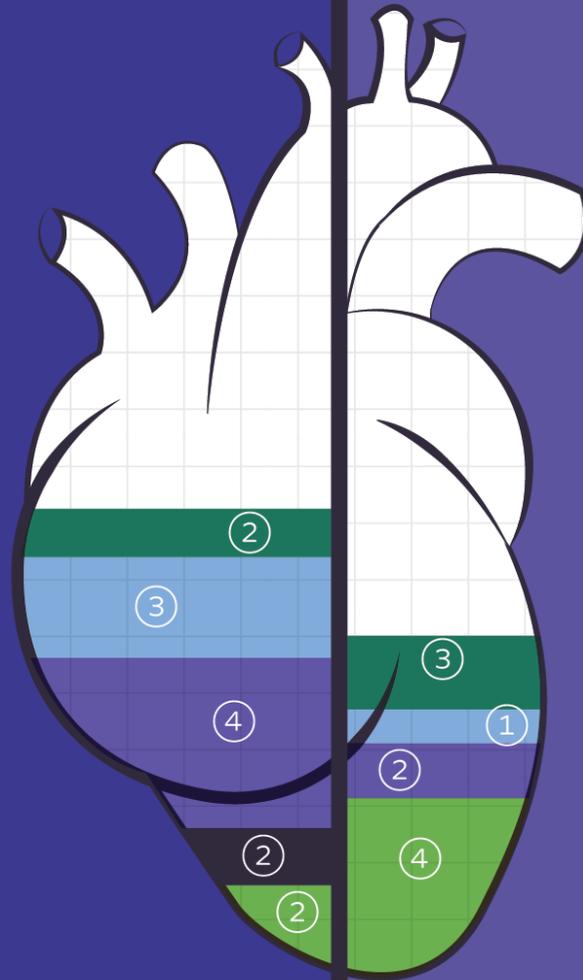
MENTAL & EMOTIONAL FACTORS AFFECTING THE HEART / CIRCULATORY SYSTEM

THE BAD NEWS

THE GOOD NEWS

- GENERAL ANXIETY ?
- DEPRESSION ?
- JOB LOSS ?
- VISITING HOUSEGUESTS ?

- RUNNER'S HIGH ?
- YOUR BIRTHDAY ?



GENERAL ANXIETY



ABOUT

**WHAT IS THIS?**  
Generalized anxiety disorder (GAD) is an anxiety disorder that is characterized by excessive, uncontrollable and often irrational worry about everyday things that is disproportionate to the actual source of worry. For diagnosis of this disorder, symptoms must last at least 6 months... [\(READ MORE\)](#)

**HOW DOES THIS AFFECT MY KIDNEYS?**  
Any feeling of anxiety causes the adrenal glands in your body to release more cortisol. Cortisol alters kidney function, acting as an anti-diuretic, which increases blood pressure, worsening the effects of hypertension. It may also increase heartrate... [\(READ MORE\)](#)

**HOW ELSE DOES THIS AFFECT MY BODY?**  
Generalized Anxiety also affects these systems:

- KIDNEYS ▶
- ENDOCRINE ▶
- BRAIN/NERVOUS ▶
- DIGESTIVE ▶

RUNNER'S HIGH



ABOUT

**WHAT IS THIS?**  
A publicized effect of endorphin production is the so-called "runner's high", which is said to occur when strenuous exercise takes a person over a threshold that activates endorphin production. Endorphins are released during long, continuous workouts, when the level of... [\(READ MORE\)](#)

**HOW DOES THIS AFFECT MY HEART?**  
Exercise is already good for the cardiovascular system, but the release of endorphins is an added boost. Endorphins produce a sense of well-being in a person's brain--happiness, painlessness and relaxation--that can help ease other conditions like anxiety, depression, and hypertension... [\(READ MORE\)](#)

**HOW ELSE DOES THIS AFFECT MY BODY?**  
Generalized Anxiety also affects these systems:

- ENDOCRINE ▶
- BRAIN/NERVOUS ▶
- DIGESTIVE ▶



## MEDDLE WITH FATE

### WITH AN INTERACTIVE CAUSE & EFFECT NETWORK

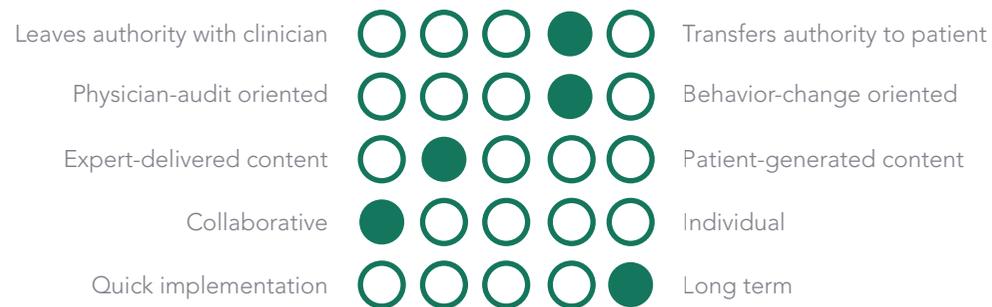
It's easy to figure out that a cup of coffee at 8pm might make sleeping difficult, but maybe a little bit harder to figure out how many things in your life are slowly causing your stents to fail. When everything we do seems to have consequences that are both dire and vague, intelligent choices can be difficult. By combining patient and physician supplied information into an interactive tree chart, you can start to take informed steps toward an improved lifestyle. Turn on and off any assortment of nodes and watch what happens to your prognosis.

#### *Employed elements of chaotic narrative*

Aside from the liberal use of dots reminiscent of a Kusama painting, this portal essentially tries to show the biggest picture possibly, which is invariably chaotic. There is no immediate solution or linear pathway of change. The patient is left to meddle freely, adding and removing components until some ideal or satisfactory compromise is met.

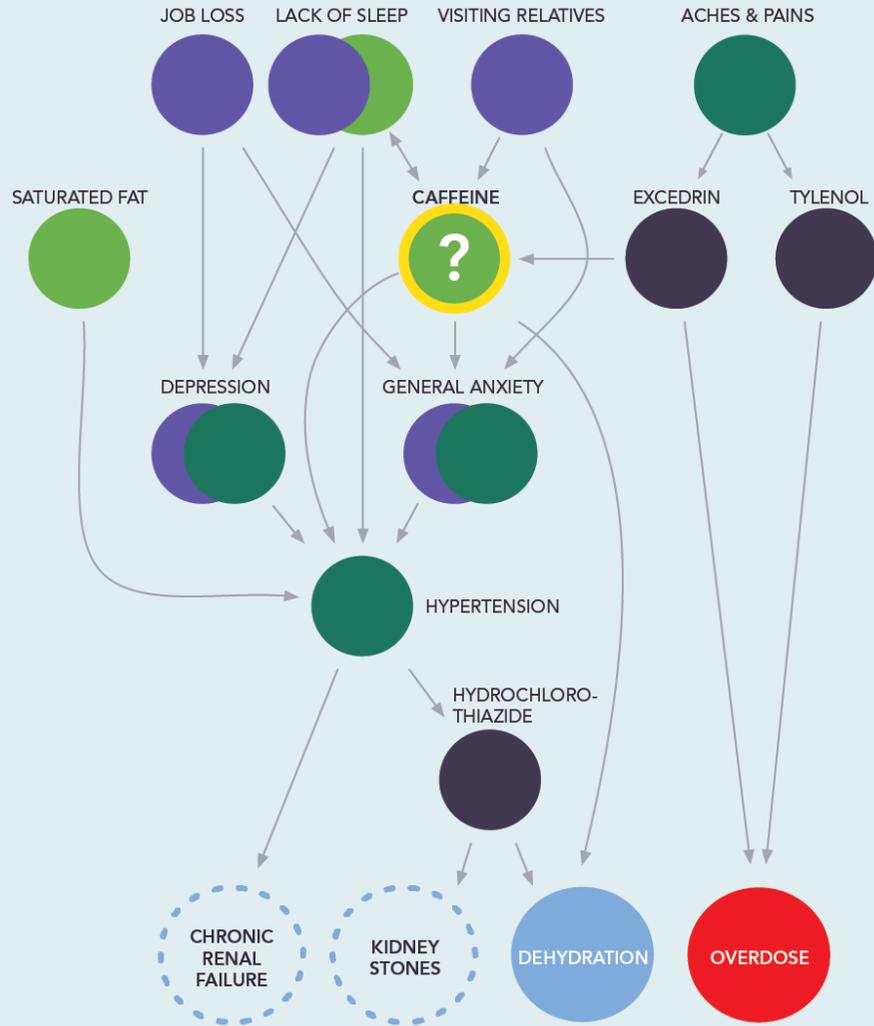
#### *Who it would help most*

**The Puzzle** and **The Catch 22** could both probably find some answers as to what is causing their current discomfort, while **The Denialist** could learn to avoid choices that set him on a road to another heart attack.



## CAUSE AND EFFECT CHART

### BEFORE



### MAKE A CHANGE

Select which caffeine-related items you would like to learn more about, adjust, or remove.

COFFEE	?	edit	remove
EXCEDRIN MIGRAINE	?	edit	remove
ENERGY DRINK	?	edit	remove

### CAFFEINE



### ABOUT

#### WHAT IS THIS?

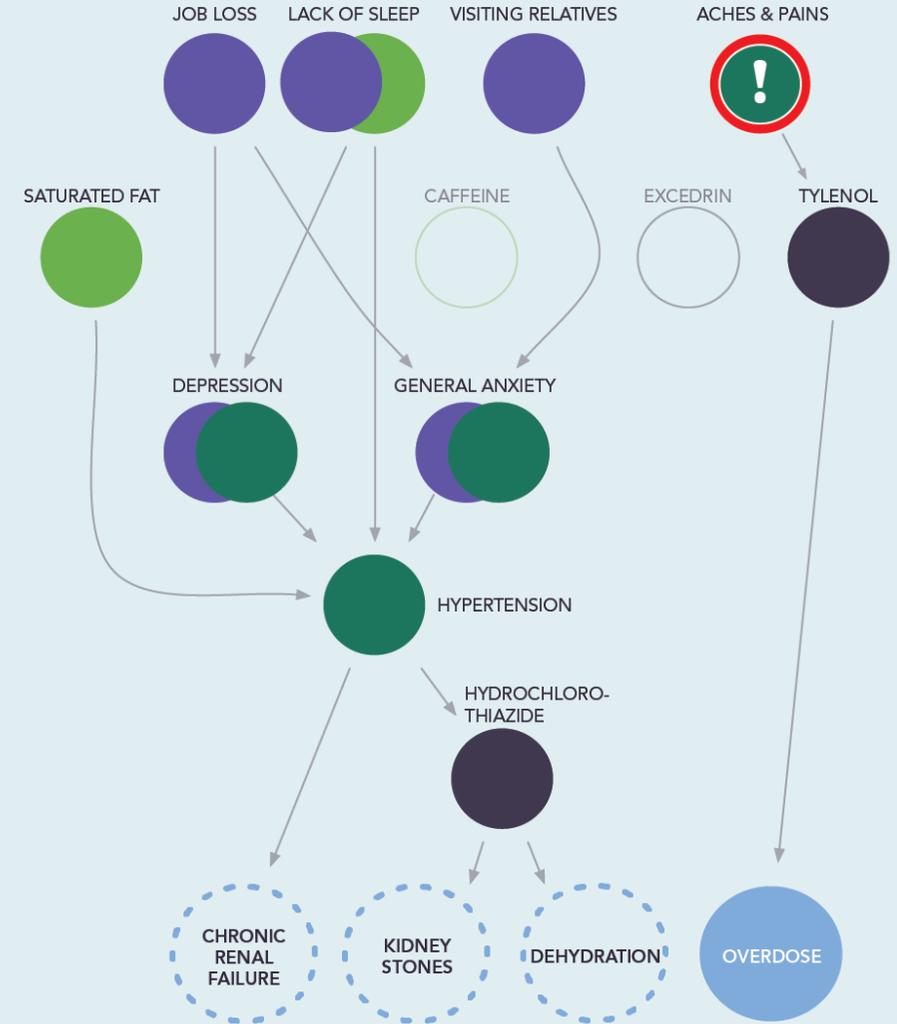
Caffeine is a bitter, white crystalline substance that acts as a stimulant drug. Caffeine is found in varying quantities in the seeds, leaves, and fruit of some plants. In humans, caffeine acts as a central nervous system stimulant, temporarily... [\(READ MORE\)](#)

#### HOW DOES THIS AFFECT MY KIDNEYS?

Caffeine can have an effect on your kidneys through the pathways below:

- | SHOW                  | PATHWAY   |
|-----------------------|---|
| <input type="radio"/> | By acting as a <b>diuretic</b> , causing your kidneys to filter more water from your blood, possibly leading to dehydration.                                  |
| <input type="radio"/> | By acting as a <b>stimulant</b> , keeping you awake when you should be sleeping, and therefore worsening conditions that are impacted by your sleep schedule. |
| <input type="radio"/> | By increasing your risk of <b>hypertension</b> , which in turn affects your kidneys by harming the blood vessels within them.                                 |
| <input type="radio"/> | By stimulating the central nervous system, leading to increased <b>anxiety</b> .  |

### AFTER





## MAKE PESUASIVE POINTS WITH A CASE CONSTRUCTION TOOL

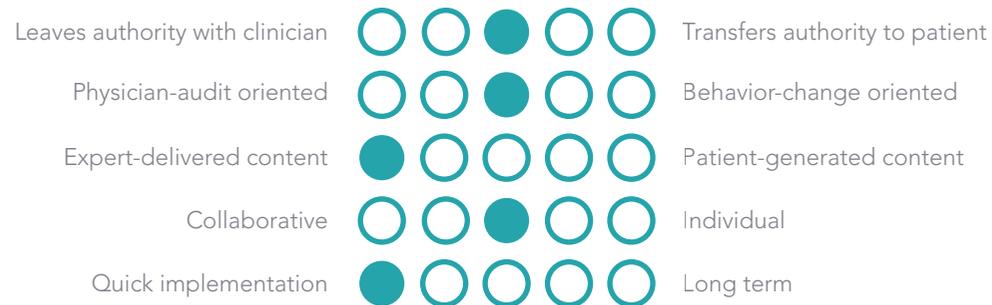
This is a place for all of your medical records, insurance documents, lab results, self-tracking data, and prescription orders. In addition, it allows you to access numerous top level medical journals, blogs, and other media. Find information about your condition that is a) at the right level for you, b) save- and sortable, and c) verified by a community of experts as well as other patients. But this isn't just a vault. Combine your own experiences with cutting edge research and reports from the community, crafting crystal clear narratives for yourself and your doctors.

### *Employed elements of chaotic narrative*

This portal is the point at which chaos begins to turn a corner toward progress. After sufficient exploration of the problem from many perspectives, a patient can begin to strategically omit the irrelevant details, crafting a tale that would please Hemmingway.

### *Who it would help most*

**The Puzzle** could quickly recap with a new specialist everything she has learned about her own condition from multiple doctors. **The Catch 22** meanwhile might finally be able to convince his doctor to stop performing risky biopsies. **The Hidden Hope** could research new cancer treatments, and **The Denialist** could track his exercise patterns.



CASES

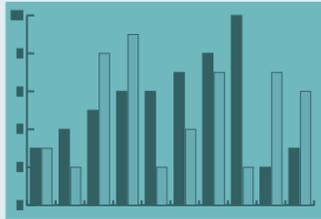
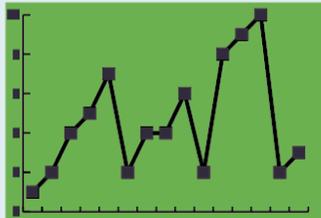
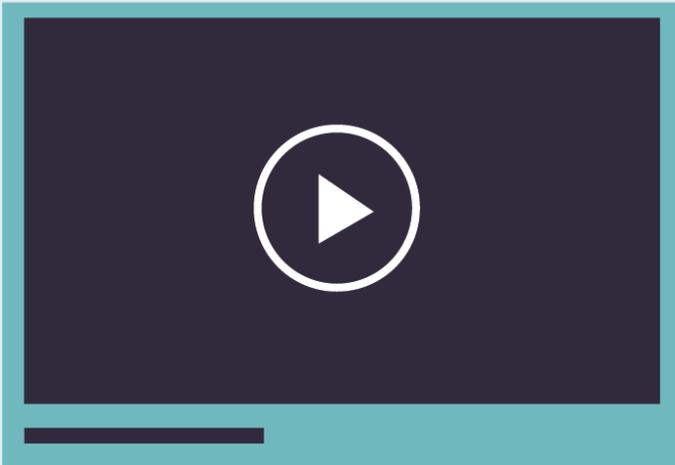
DOCS

DATA

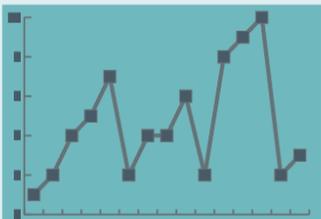
RESEARCH

This is the case you have built around: **IMPLANTATION OF STENTS**

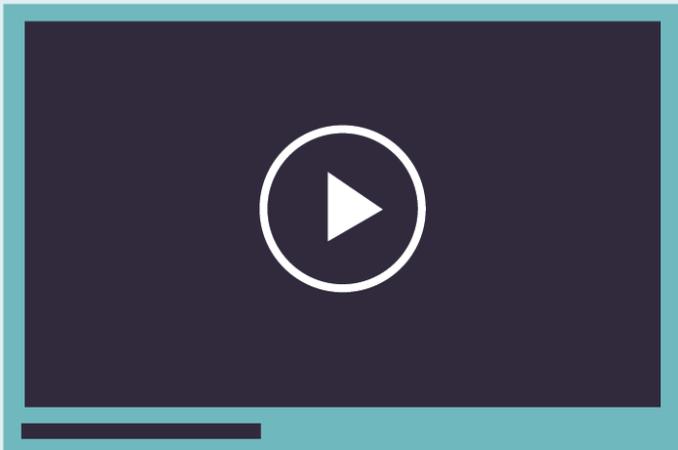
IT CONTAINS **5** DOCUMENTS, **25** PIECES OF EXTERNAL RESEARCH, AND **3** DATA SOURCES



Placeholder for text content, represented by horizontal bars.



Placeholder for text content, represented by horizontal bars.



Placeholder for text content, represented by horizontal bars.

SEARCH YOUR ARCHIVES

ENTER KEYWORD  **GO**

[MORE OPTIONS...](#)

DOCUMENTS

██████████		
██████████		
██████████		
██████████		
██████████		
██████████		
██████████		
██████████		

EXTERNAL RESEARCH

██████████		
██████████		
██████████		
██████████		
██████████		
██████████		
██████████		
██████████		

DATA

██████████		
██████████		
██████████		
██████████		
██████████		
██████████		
██████████		
██████████		

CASE BROWSER

**+**  
**ADD NEW**

**KIDNEY HEALTH**  
3 DOCS  
13 EXT. RESEARCH  
4 DATA

**GLUTEN-FREE**  
3 DOCS  
13 EXT. RESEARCH  
-- DATA

**PANIC ATTACKS**  
1 DOCS  
43 EXT. RESEARCH  
4 DATA

**GOOD CHOLES...**  
2 DOCS  
19 EXT. RESEARCH  
23 DATA

## 8 from here

Although presented in high resolution in order to communicate a specifically desired visual style, the concept in this document is a very early stage prototype—almost a design fiction—that requires substantially more research and development before it could be put on the market. However, given early reactions from both everyday people and industry professionals, the idea appears to at very least capture imaginations and provoke important conversations about the future of healthcare. It points to a bigger picture of patient care—a world that comes after we’ve successfully digitalized health records, granted, but a world that we should still be considering now.

In the previous section, the subsystem concepts were each ranked according to a brief rubric. The scores on that rubric correspond to factors which I believe will be key in determining whether this system stands a chance of large-scale adoption. Among all the issues still yet to be tackled, below are the five which, given my reading and contact with medical professionals, are the most pressing.

### **ENCOURAGING PATIENT & PHYSICIAN ADOPTION**

ENSURE THAT THE SYSTEM IS CLINICALLY VETTED.

Dismissal of current patient education portals—particularly those online, stems from an uncertainty about where the information comes from. Doctors and patients alike mistrust information gathered on the internet because so much of it is misinterpreted, exaggerated, or false. Not only does the system have to make sure it uses accurate information, it also

has to make that fact transparent to the users. A patient or doctor should be able to trace a piece of information easily back to its source, ascertain how much weight should be given to each fact accordingly.

This issue is also partially resolved in the system design by somewhat limiting the information available to content generated by the patients and by his or her specific network of caretakers. Instead of being able to search the entire internet for anything that could be wrong, exploration is guided by careful analysis of the patients' history and current complications. Such data should be readily available by the time medical records are fully digitalized in the next decade.

#### TAILOR CONTENT TO VARYING DEMOGRAPHICS.

Healthcare has been struggling for some time to successfully communicate medical information to people without much education. A successful system will have to make health as basic and engaging as possible, without losing crucial details. Achieving this balance will not be elementary.

I acknowledge that the people from whom I collected stories were all from a middle- to upper-class demographic, and tended to be highly self-motivated. One was a chemist, and another a bio-engineering student, both more than capable of parsing clinical data that might baffle the average person—even one with comparable education in a non-technical field. This is obviously not a complete picture of what it means to be a patient. I myself am also biased by a bio-engineering background.

I do believe, however, that the concept presented here could begin as a tool for patients with strong initiative and health-

literacy, and then be adapted over time to meet the needs of people who need more encouragement, or more explanation. This adaptation process would probably rely partially on physicians using the system to engage with less-motivated or surefooted patients more regularly. This brings me to the next key to the success of such a system, this one a do-or-die:

#### SHOW DOCTORS THE SYSTEM WON'T TAKE MORE TIME.

Doctor behavior is extremely difficult to influence. At least in the current economic model of care, schedules are packed and likely to remain so. If physicians believe that engaging with their patients using this tool will take more time per visit, they will likely ignore it before ever trying it. Many a health app has failed for this exact reason.

As of now I am not certain that this concept passes the test. However, there are many methods one could try in order to make sure the workflow of the design matches physician needs. There needs to be more user research on the clinician end to determine how frequently and how intensely a doctor is able to interact with the system, compared to the ideal engagement needed to make it a productive tool for patients. I am hoping that by introducing this concept to UPMC | TDC, I will acquire access to physicians who can provide me with better answers to these questions.

#### ACHIEVE A BALANCE IN POWER.

Physicians are hesitant to trust in the ability of a patient to make complex choices, and rightly so. They go to school and practice for years to acquire knowledge and experience that a layperson doesn't have. Meanwhile, patients likely won't

- 0
- 1
- 2
- 3
- 4
- 5
- 6
- 7
- 8
- 9
- ★

engage productively with a system that spits out more rules sans discourse. In other words: physicians have to believe on a visceral level that this system is not trying to put them out of a job. Patients have to believe that they are not being mollycoddled. A successful system has to mediate control and distribute it wisely according to context. I expect this will have less to do with any system functionality and instead with subtle nuances in presentation, vocabulary, semiotics and experience.

#### SHOW AN IMPACT ON HEALTHCARE COST.

At the end of the day, healthcare is run as a business, and likely will be for a long time to come. Clinician portals and decision support tools are gaining traction when they can prove that they decrease billing errors, prevent unnecessary treatment, decrease hospital re-admissions, and generally lower the staggering cost of care. In-depth analysis will have to be conducted to determine whether the care-benefits of this system translate into hospital savings, but I'm confident that with proper execution, they could.

#### FROM FICTION TO REALITY : HOW FAR?

At some point in the not too distant future, we could easily be opening our closet doors and taking a whole new look at ourselves in 'the mirror' speculated at the beginning of this document. However, at this very second, there are still some substantial technical hurdles preventing this system gracing even a standard laptop or mobile device. Among the items on the laundry list:

#### FINISH BUILDING THE INFRASTRUCTURE FIRST.

The process of digitalizing current medical records is far from complete. Many hospitals and clinics still rely on pen and paper for their transactions and book keeping. President Obama has been very adamant about fully digitalizing medical records by 2014. He recently signed into law the Health Information Technology for Economic and Clinical Health (HITECH) Act, allocating close to \$20 billion to promote the wider use of electronic medical records, partially through incentives to doctors who make good use of them.<sup>41</sup> It's unclear whether this goal is truly achievable within such a short time frame, even with federal investment. Nevertheless, digital health records that are not only online but interoperable and highly malleable are a must before any system like **{narRecuparate}** could become a reality.

#### IMPROVE NATURAL LANGUAGE PROCESSING.

Natural language processing (NLP) has made leaps and bounds over the last decade, with computer AI now capable of quickly parsing our sentences and drawing out meaningful data from documents. For proof, one needn't look further than Siri on the Apple iPhone or IBM's Watson, a computer that beat two Jeopardy champions at their own game last year. NLP has already made a large impact in healthcare, with companies such as Nuance and M\*Modal both working right here in the Pittsburgh area to develop health applications capable of turning EMR data into actionable stories.<sup>42, 43</sup>

That said, NLP technology is far from perfected, and it will be at least a few years before such systems are reliable enough to be trusted as the primary method of clinical data analysis (i.e. without people double checking records behind the

41. United States House of Representatives. "Health Information Technology for Economic and Clinical Health Act or HITECH Act." [waysandmeans.house.gov/media/pdf/110/hit2.pdf](http://waysandmeans.house.gov/media/pdf/110/hit2.pdf) (accessed May 4, 2013).

42. "For healthcare - Medical Voice Recognition & Dictation Software | Nuance Healthcare - Nuance." [Nuance.com](http://Nuance.com) (accessed May 10, 2013).

43. "M\*Modal | Transcription, Speech Recognition & Clinical Documentation." [MModal.com](http://MModal.com). (accessed May 10, 2013).

scenes). Additionally, NLP is still relatively poor at analyzing emotional meaning and tone. This will need to change before many aspects of **{narRecuperate}** can reach their full potential, particularly the blogging functionality, since it relies so heavily on an AI that would make meaningful connections not merely between keywords, but between abstract behaviors, themes, and motivations. Beyond mere textual analysis, what **{narRecuperate}** really needs is Natural *Subtext* Processing.

#### MOVE OFF DESKTOP

Although presented here as a sequence of wireframes for a standard desktop or laptop, a system like **{narRecuperate}** would really benefit from a multi-device approach to storytelling. The blogging portal works well in a laptop setting, but the cause and effect network could use a much larger space (like a wall). The organic discovery tool, meanwhile, could be breathtaking in a tangible format, either with haptic technology or augmented objects, and the medication visualizer would be useful on a mobile device for easy access on-the-go. Some of these technologies are already in development, but others—particularly tangible interactive environments—are still largely academic and built as one-time installations rather than for mass-production and household use. As these technologies develop, they will undoubtedly open doors but also pose new design challenges for healthcare systems that will significantly alter the proposed content and hierarchy of **{narRecuperate}**.

0

1

2

3

4

5

6

7

8

9

★

## 9 conclusion

We are living in a tumultuous but incredibly exciting time in American healthcare, on the brink of accepting or rejecting major changes to the way our care is financed, structured, and delivered. This includes closing the gap between healthcare information technology and the technology currently available to consumers. Finally moving medicine away from fax machines and clipboards and into the 21st century by itself could save our country upwards of \$8.3 billion a year.<sup>44</sup>

As enormous and broadly impactful as many of these changes are, however, I live in constant fear that we are making tactical decisions with our blinders on. At times, we are so narrowly focused on the goal of making data accessible, portable and transparent that we're sacrificing the opportunity to think critically and creatively about how we are going to present and interact with such a vast amount of information once we can easily get our hands on it. If we don't pause for a moment and strategize a bit better—not as businessmen or engineers or doctors, or even designers, but as *humanists*—I worry that we are going to miss our opportunity to inject meaning into this data for people without a clinical background. Though the healthcare industry may be saved by economic investment and technological restructuring, the *health* of people in this country will continue to lag behind other countries until we invest considerable effort into helping people master navigating, not a maze of hospital corridors, but the labyrinth of their own biology. Despite the work left to be done, I believe **{narRecuperate}**, more than anything, is a promise to people that we will not forget one important truth:

**We live a powerful story, not a powerful data set.**

44. Byron Acohido.  
"Hospitals lose \$8.3 billion  
using old technology."  
USATODAY.com.  
(accessed May 14, 2013).

## acknowledgements

I would like to sincerely thank all of the people I interviewed for this project for being so willing to share their experiences. So much of this project relies upon understanding how people cope with illness, navigate medical infrastructure, and form relationships with others; all of these experiences can be frustrating, terrifying, distressing, or a combination of all three. I recognize that it takes a certain degree of strength and trust to share some of these stories with a stranger or casual acquaintance, and so I deeply appreciate those that decided to place that trust in me. I hope this project will eventually lead to innovations in healthcare that make all of your lives a little bit easier.

I would also like to thank my coworkers at UPMC's Technology Development Center for giving me a better understanding of how healthcare works from the inside, and for helping me situate my research in a pragmatic framework.

Lastly, thank you to my advisor, David Kaufer, for continually encouraging me to pursue my love of narratives and helping me shape that interest into a systematic design method.

0

1

2

3

4

5

6

7

8

9



## references

- Aronofsky, Darren, and Kent Williams. *The Fountain*. New York: D.C. Comics, 2005.
- Acohido, Byron. "Hospitals lose \$8.3 billion using old technology." USA TODAY: Latest World and US News - USATODAY.com. <http://www.usatoday.com/story/cybertruth/2013/05/07/healthcare-technology-cybersecurity-privacy-patient-care/2142739/> (accessed May 14, 2013).
- Cambridge Healthcare. "How Are You?" How Are You?: The Personal Health Record. <https://en-gb.howareyou.com/patients> (accessed May 13, 2013).
- Carnegie Mellon University. "BodyTrack." BodyTrack. <http://www.bodytrack.org/> (accessed May 12, 2013).
- Frank, Arthur W. *The Wounded Storyteller: Body Illness, and Ethics*. Chicago, IL: The University of Chicago Press, 1997.
- "For healthcare - Medical Voice Recognition & Dictation Software | Nuance Healthcare - Nuance." Nuance - Home. <http://www.nuance.com/for-healthcare/index.htm> (accessed May 14, 2013).
- Hemingway, Ernest. "The Art of the Short Story". In Benson, Jackson. *New Critical Approaches to the Short Stories of Ernest Hemingway*. Duke University Press, 1990.
- Kafka, Franz. *The Metamorphosis*. Translated by David Wyllie. Project Gutenberg Ebook, 2002.
- Kinross, Robert. "The Rhetoric of Neutrality," in *Design Issues*, 2(2), 1985.
- Microsoft *HealthVault*. "What Can You Do with HealthVault?" <https://www.healthvault.com/us/en/overview>. (accessed May 14, 2013).
- "M\*Modal | Transcription, Speech Recognition & Clinical Documentation." M\*Modal.com. [mmodal.com/](http://mmodal.com/) (accessed May 10, 2013).
- Pilling, David. "The world according to Yayoi Kusama," in *FT Magazine*. <http://www.ft.com/cms/s/2/52ab168a-4188-11e1-8c33-00144feab49a.html#axzz1uQqW7gmD>. (accessed January 20, 2012).
- Podoll, Klaus. "Helen Donis-Keller" (part of an online exhibition by The Migraine Aura Foundation). [http://www.migraine-aura.org/content/e24966/e22874/e23331/index\\_en.html](http://www.migraine-aura.org/content/e24966/e22874/e23331/index_en.html). March 14, 2005 (accessed January 20, 2012).
- Pollock, Griselda, ed. "Yayoi Kusama between Abstraction and Pathology" in *Psychoanalysis and the Image: Transdisciplinary Perspectives*. John Wiley & Sons, 2008.
- Rosenbaum, Lisa. "The Art Of Doing Nothing." *New England Journal of Medicine* 365, no. 9 (2011): 782-785.
- Runco, Mark A., & Richards, Ruth, eds. *Eminent Creativity, Everyday Creativity, and Health*. Greenwich, CT: Ablex Publishing Corporation, 1997. (Google Ebook).
- Sparkes, A.C., & Smith, B. "When narratives matter: men, sport, and spinal cord injury." *J Med Ethics; Medical Humanities*, 31. 2005.
- Stein, Alicia. "UPMC's Analytics Project Uses Technology To Enhance Overall Patient Care." XChange Events. [www.xchange-events.com/newsletter-articles/upmcs-analytics-project-uses-technology-to-enhance-overall-patient-care/](http://www.xchange-events.com/newsletter-articles/upmcs-analytics-project-uses-technology-to-enhance-overall-patient-care/) (accessed May 4, 2013).
- Srivastava, Ranjana . "Denial." *New England Journal of Medicine* 360, no. 12 (2009): 1174-1177.
- Tarsim's *The Fall*. DVD. Directed by David Fincher. Culver City, Calif.: Sony Pictures Home Entertainment, 2008.
- Taylor, Rachel. "Kusama and Self-obliteration." Tate Modern. Tate Museums. <http://www.tate.org.uk/context-comment/blogs/kusama-and-self-obliteration>. April 3, 2012. (accessed May 14, 2013).
- The American Art Therapy Association Webpage. <http://www.americanarttherapyassociation.org/> (accessed January 2012).
- The Fountain. DVD. Directed by Darren Aronofsky. Burbank, CA: Warner Home Video, 2007.
- United States House of Representatives. "Health Information Technology for Economic and Clinical Health Act or HITECH Act ." Health Information Technology for Economic and Clinical Health Act or HITECH Act . [waysandmeans.house.gov/media/pdf/110/hit2.pdf](http://waysandmeans.house.gov/media/pdf/110/hit2.pdf) (accessed May 4, 2013).
- "WebMD - Better information. Better health.." WebMD - Better information. Better health.. <http://webmd.com> (accessed May 14, 2013).

