

How Do Patients Visualize Their Own Health Stories?

Ryan Smith (PhD Candidate, Computer Science, University of British Columbia)
PI: Tamara Munzner (Professor, Computer Science, University of British Columbia)
Industry Partner: Diane Tam (VP of Product, Thrive Health)



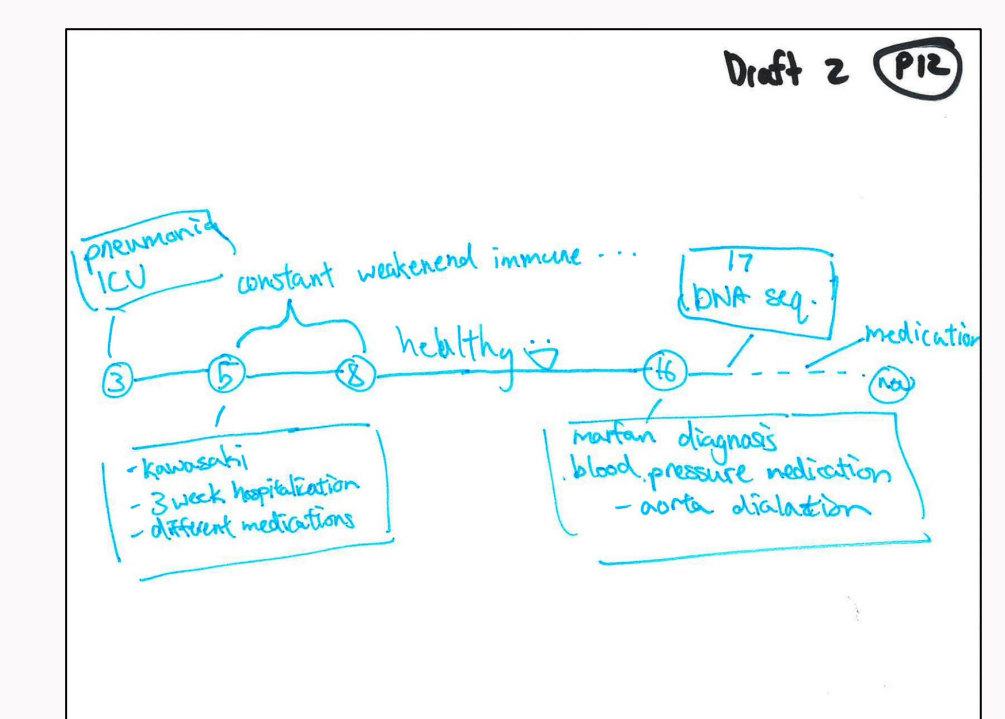
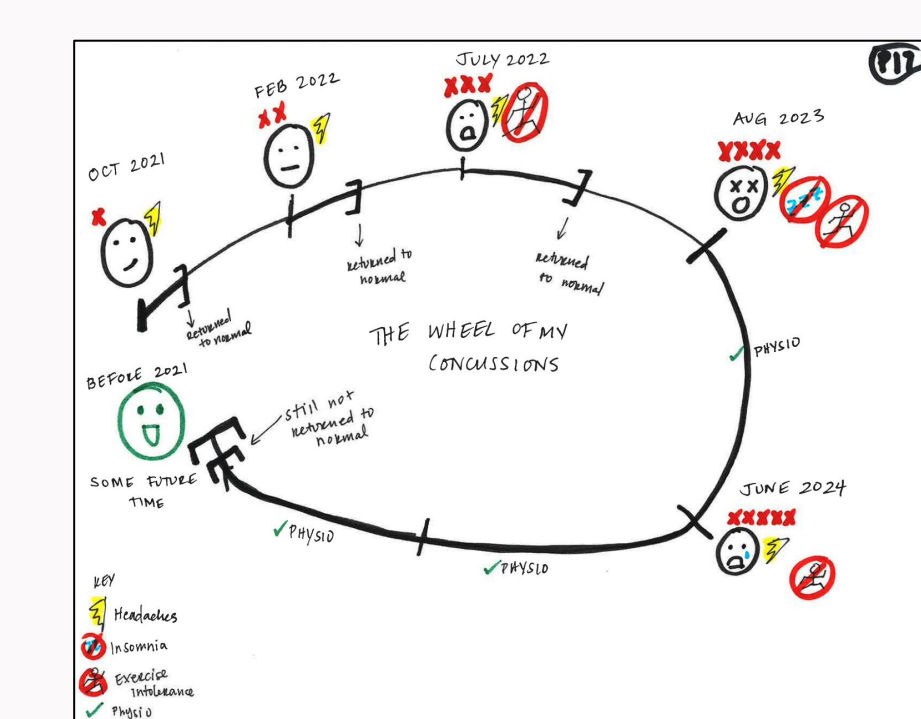
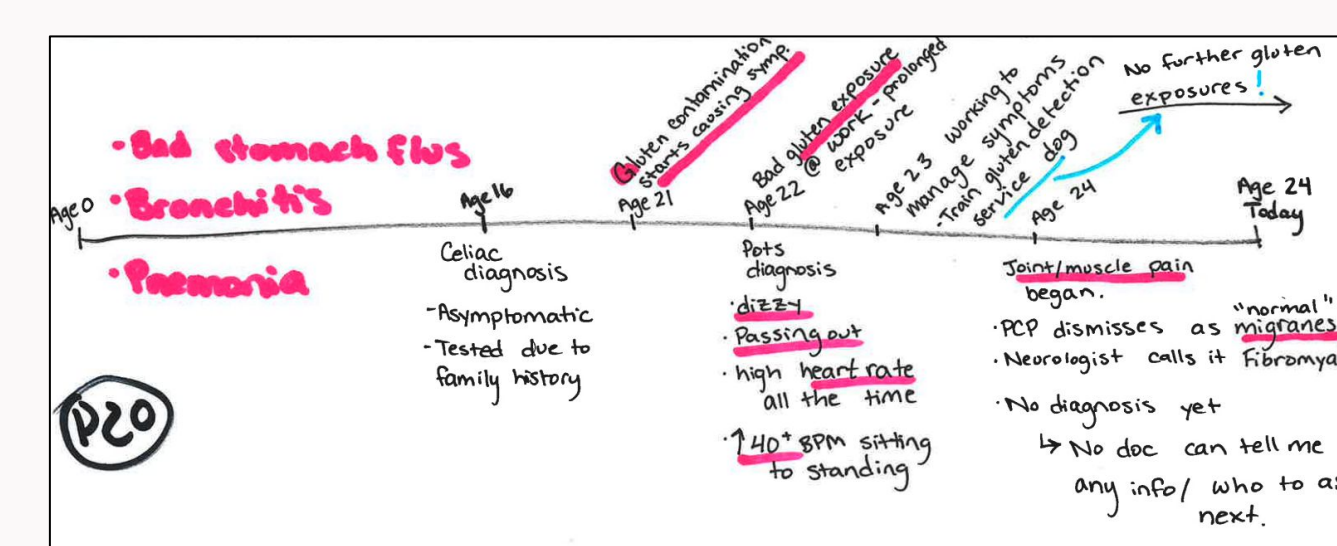
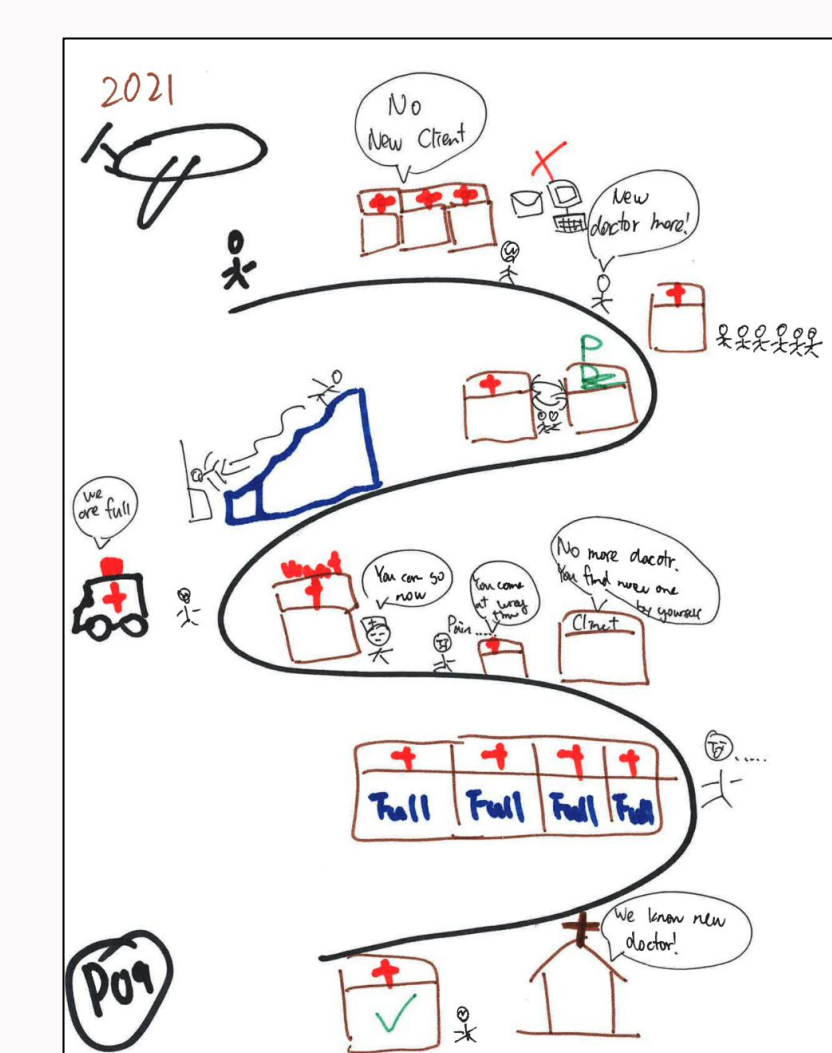
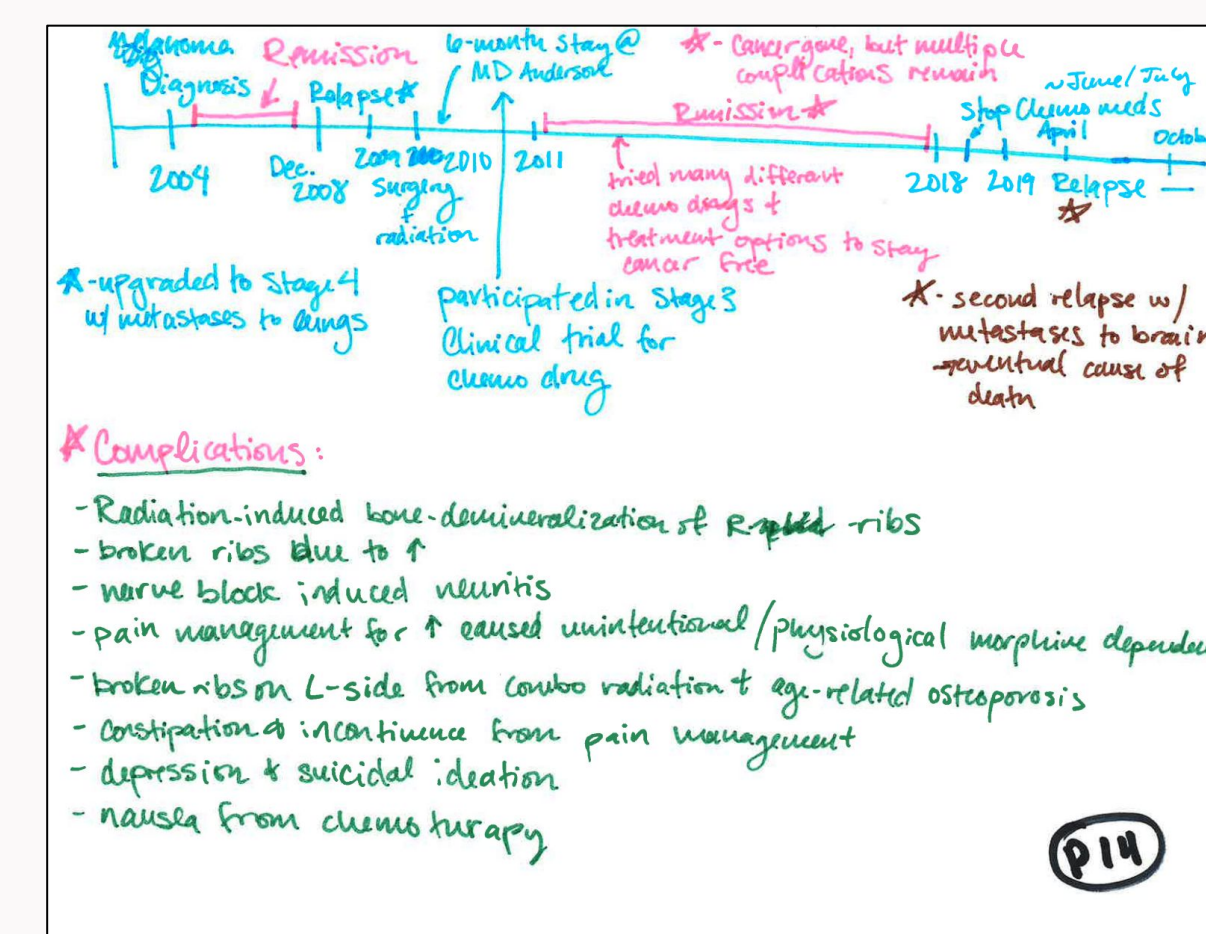
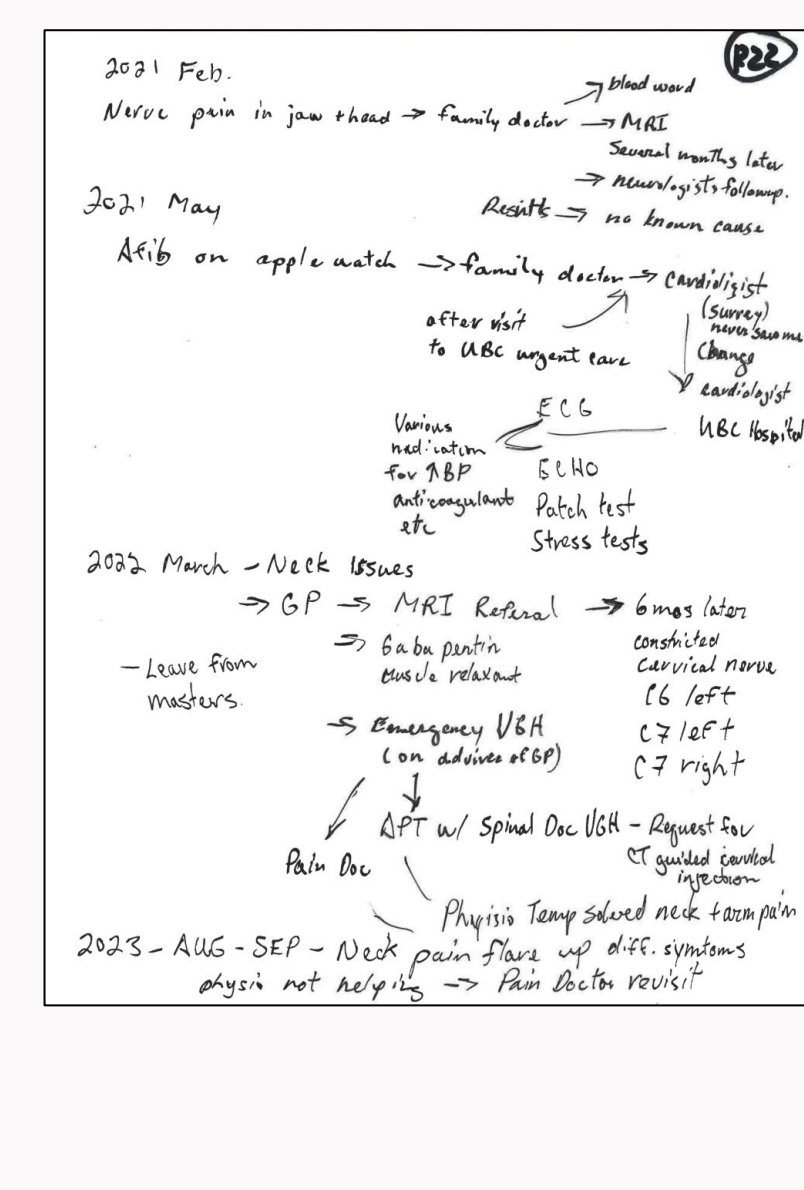
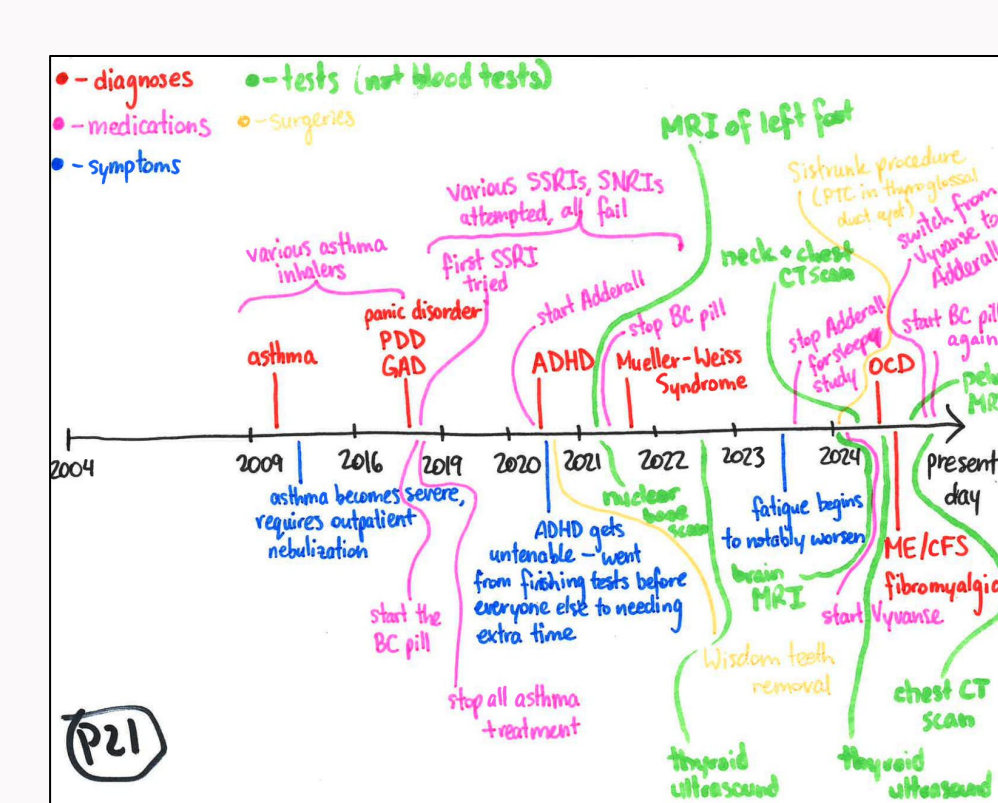
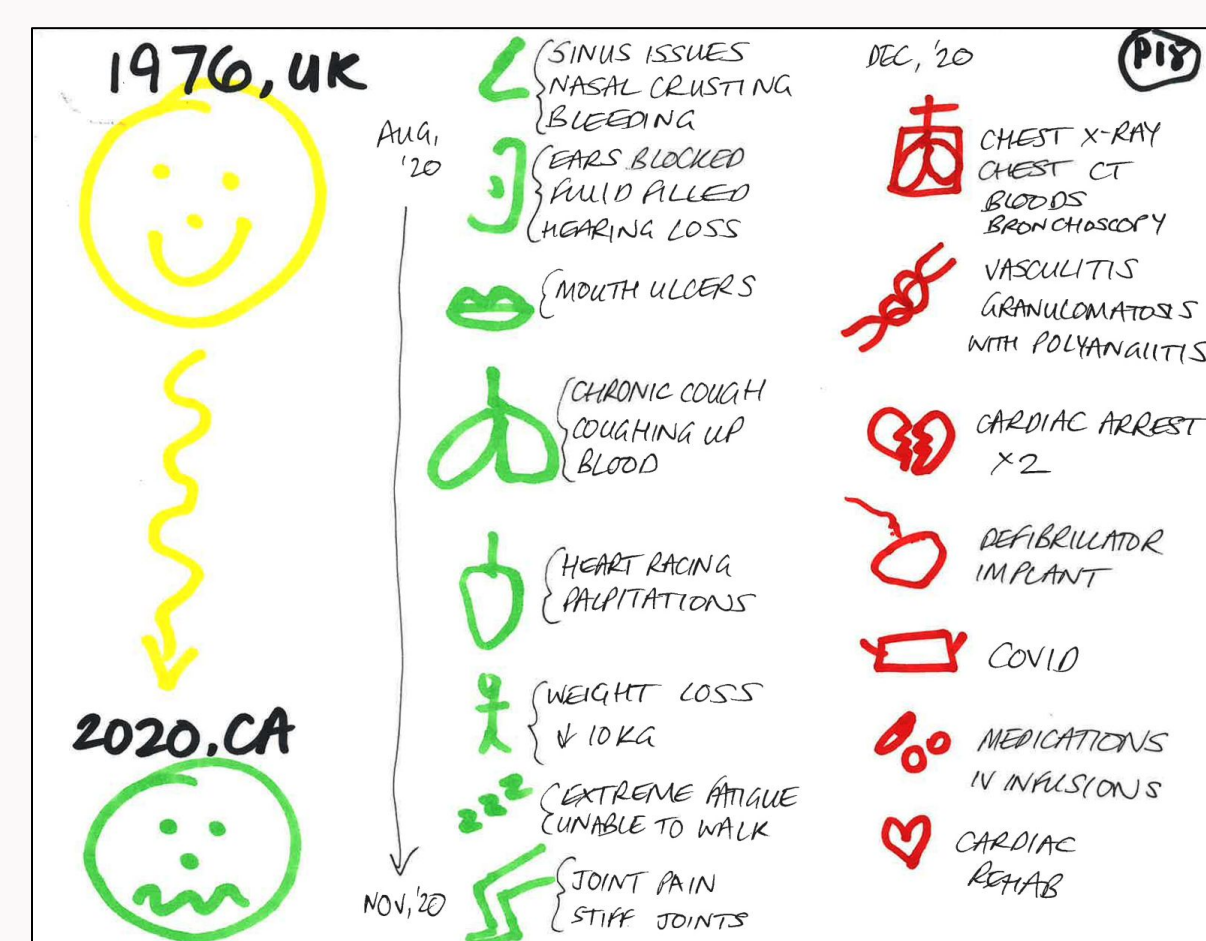
What is a health story?

A personal account of one's health, combining medical facts with personal context and experiences

Experimental Design

- Ran elicitation study to understand how patients build and use mental models of their health stories
- 22 participants created two versions of their health story: **sketch** and **written text** (counterbalanced)
- Analyzed story artifacts and interviews to identify **elements** and **strategies** in how people think and talk about health stories
- Created **design space** of these elements & strategies

How do patients sketch their health story?



How do patients write their health story?

P18 Written

I was a perfectly healthy 44 year old until 2020 when I first started experiencing symptoms. These were sinus issues including nose, ears and associated facial pain. I saw 3 different doctors via telehealth who prescribe different antibiotics and my symptoms were attributed to chronic sinusitis. The medications did not alleviate my symptoms and I continued to worsen with a chronic cough and then started to cough up blood. At this point the doctors thought it might be pneumonia but I did not respond to those medications either. By this point I was constrained to the house. I couldn't hear which made me feel disoriented, I was very weak having lost almost 10kg. I also had ulcers in my mouth and found it difficult to eat. I was on the waiting list for an ENT doctor for 2 months, when I saw them they also had sinusitis and advised me to wait a few months at which point they could drain the fluid in my ears. I continued to worsen during this time, relying on my partner for everyday tasks like washing and cooking. I also started experiencing chest palpitations and my joints were stiff and I was unable to move freely. My mother (who is a nurse) requested that I get a full blood panel and some additional tests. These test results came back and I was admitted to hospital immediately for further investigation.

I was initially isolated, at the time it was the pandemic and the doctors did not know the cause of my illness at this point. They ruled out Covid and TB and performed a bronchoscopy to take a biopsy. A couple of days later they diagnosed me with Vasculitis (Granulomatosis with Polyangiitis), a rare autoimmune condition. They started me on a treatment program of medications which involved an initial course of treatment followed by ongoing maintenance treatments for up to 4 years. No sooner had I started the treatment I woke up with chest pain which progressively worsened and unfortunately I suffered a cardiac arrest. I was resuscitated twice and spent the next week in the ICU. I was then diagnosed with heart failure with a reduced ejection fraction of 32%. On account of this it was thought best that I was fitted with an ICD (defibrillator) but unfortunately whilst waiting for surgery I caught Covid in hospital and had to be isolated again in ICU.

I recovered from the surgery and returned home, joining a cardiac rehab program. I continue to receive lifelong medications, currently 20 different types in total, including IV infusions every 3 months. In 2021 shortly after I was discharged I developed an LV thrombus which means having blood clots. This was initially warfarin which meant regular blood work and dose adjustments with my nurse as well as bridging with injections every time I needed further surgery. I am now on a DOAC type which saves a lot of this. I still have monthly blood work to monitor my condition. Unfortunately the damage caused to my lungs pre-diagnosis means that my always are narrowed and my lung frequently collapses.

Mental health:

- Diagnosed with persistent depressive disorder, panic disorder, and generalized social anxiety, late 2018
- Diagnosed with ADHD, late diagnosis as a result of high performance in school as a child and adolescent, mid 2020
- Diagnosed with OCD, mid 2024
- Consistently attending therapy since 2018

Physical health:

- Chronic blood asthma (ages 5-13 or so)
- Diagnosed with Mastoiditis Syndrome (avascular necrosis of the left foot), fall 2021
- Chronic symptoms of general fatigue, brain fog, sleepiness, and widespread nonspecific pain for several years now, slowly getting worse -> diagnosed as ME/CFS (not in the context of a post-viral syndrome) mid 2024, suspected misdiagnosis as a result of uncertain presence of PMS
 - Also received a diagnosis of fibromyalgia at that time
- Chronic joint pain, several hypermobile joints (including but not limited to, both knees, both hips, right ankle and toes), pain seems to be mostly alleviated with usage of soft joint braces/supports
 - Frequent lower rib slippage
- Chronic iron deficiency (low ferritin levels consistently tested since 2019)
- Diagnosed POTS, diagnosed with orthostatic intolerance, symptoms include posturally-affected tachycardia and hypotension
- Cardiac symptoms also include arrhythmias, PACs have been noted on 24-hour holter monitors, suspected PVCs as well but occur rarely enough (maybe once a week) that they have not been picked up on holter monitors yet
 - Frequency of arrhythmias has increased since starting the antiarrhythmic

Surgeries:

- Wisdom teeth removal, summer 2020
- Sistrunk procedure, early 2024

Medications:

- Including (dosages), currently on Adderall (for ADHD), amitrifonyne (for sleep), LBN (for ME/CFS), vitamin D (for noted deficiency), iron (for noted deficiency), hormonal birth control (for managing period pains), and spylum husk fiber laxative powder (for managing side effects from iron supplement)

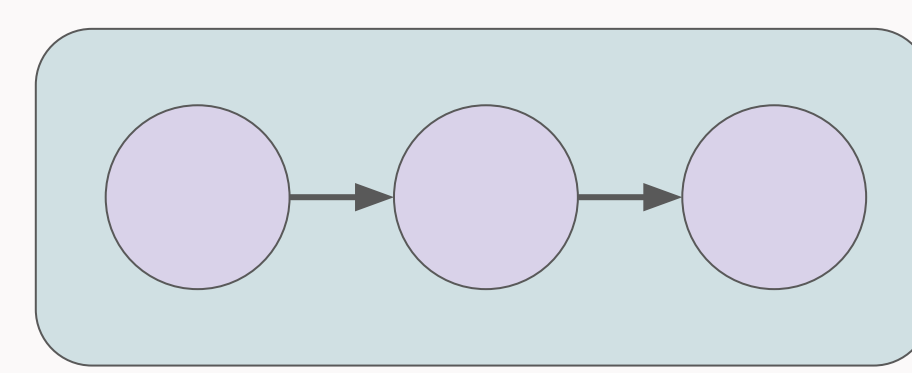
Elements of a health story

- Events:** lowest level elements of a health story
 - Events may have **Time** information
 - Several **Event Types** can occur: symptoms, diagnoses, provider visits, tests, procedures, medications, treatments, or lifestyle changes
- Event Groups:** people use different groupings of events to structure their narratives
 - Conditions** are specific medical issues (e.g. diabetes, tuberculosis, arthritis)
 - Condition Groups** are a group of related Conditions (e.g. back problems, digestive issues)
 - Time Groups** are high-level temporal periods (e.g., childhood, 8th grade, pre-surgery)

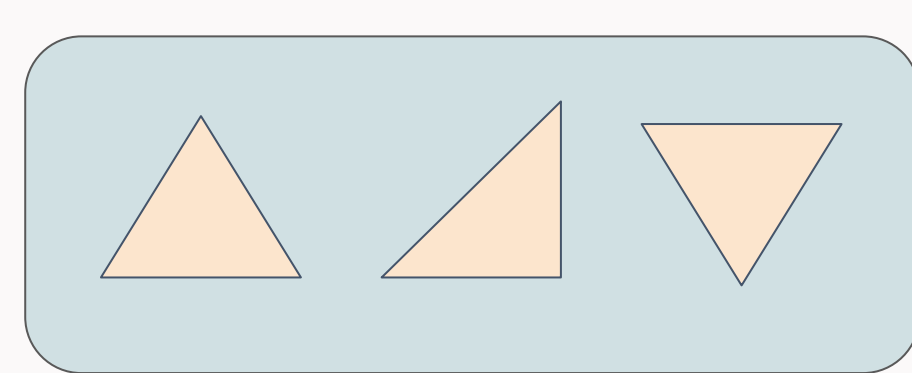
Strategies for telling a health story

Stage 1: Partitioning Strategies

Temporal partitioning
Event Time or Time Groups



Categorical partitioning
Event Type, Conditions, or Condition Groups

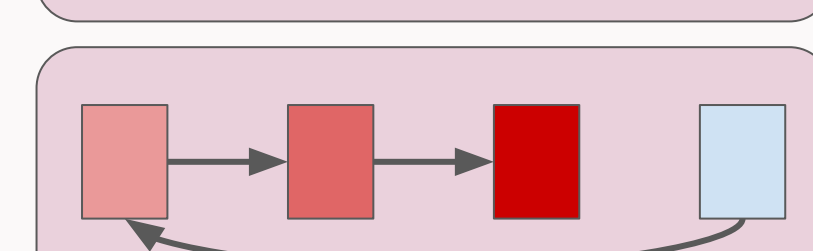
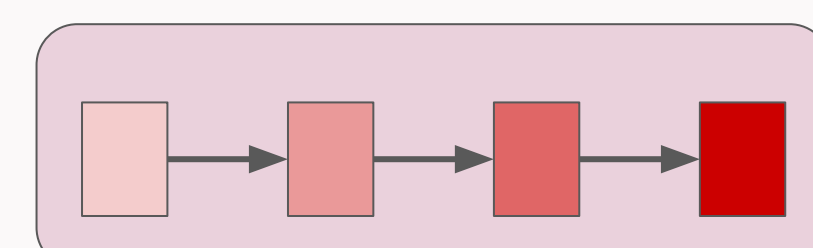


Other partitioning
Different partitioning strategy

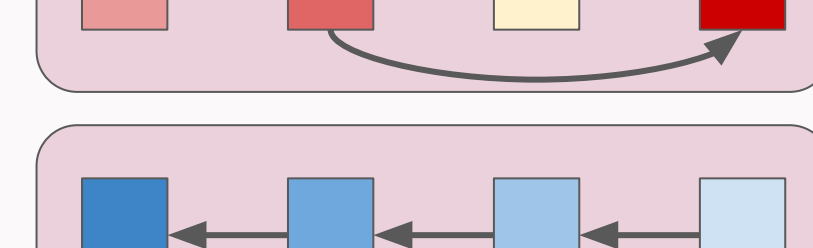
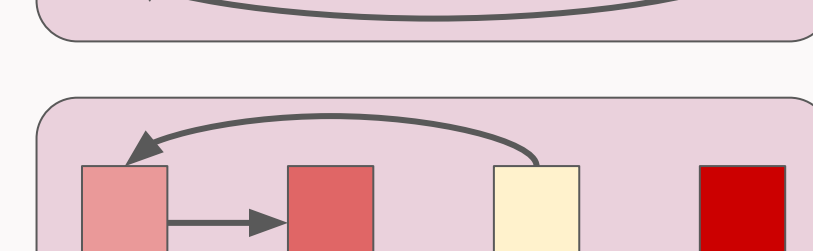


Stage 2: Sequencing Strategies

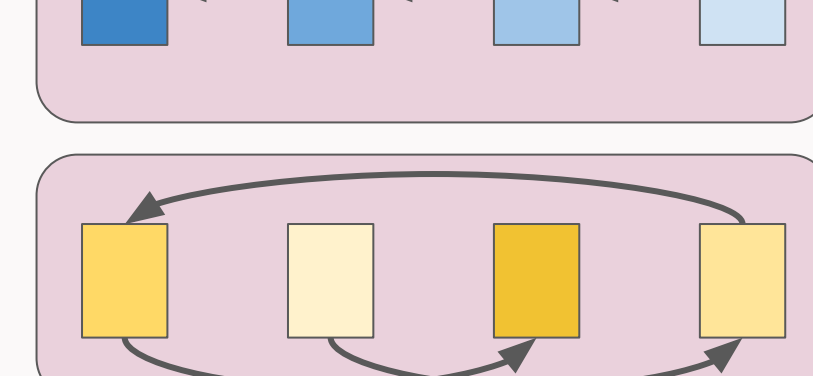
Chronological
Start: First
Proceed: Chronologically
Anchor-Recent -> **Chronological**
Start: Most recent
Then: First chronological
Proceed: Chronologically



Anchor-Important -> **Chronological**
Start: Most important
Then: First chronological
Proceed: Chronologically
Reverse Chronological
Start: Most recent
Proceed: Reverse chronologically



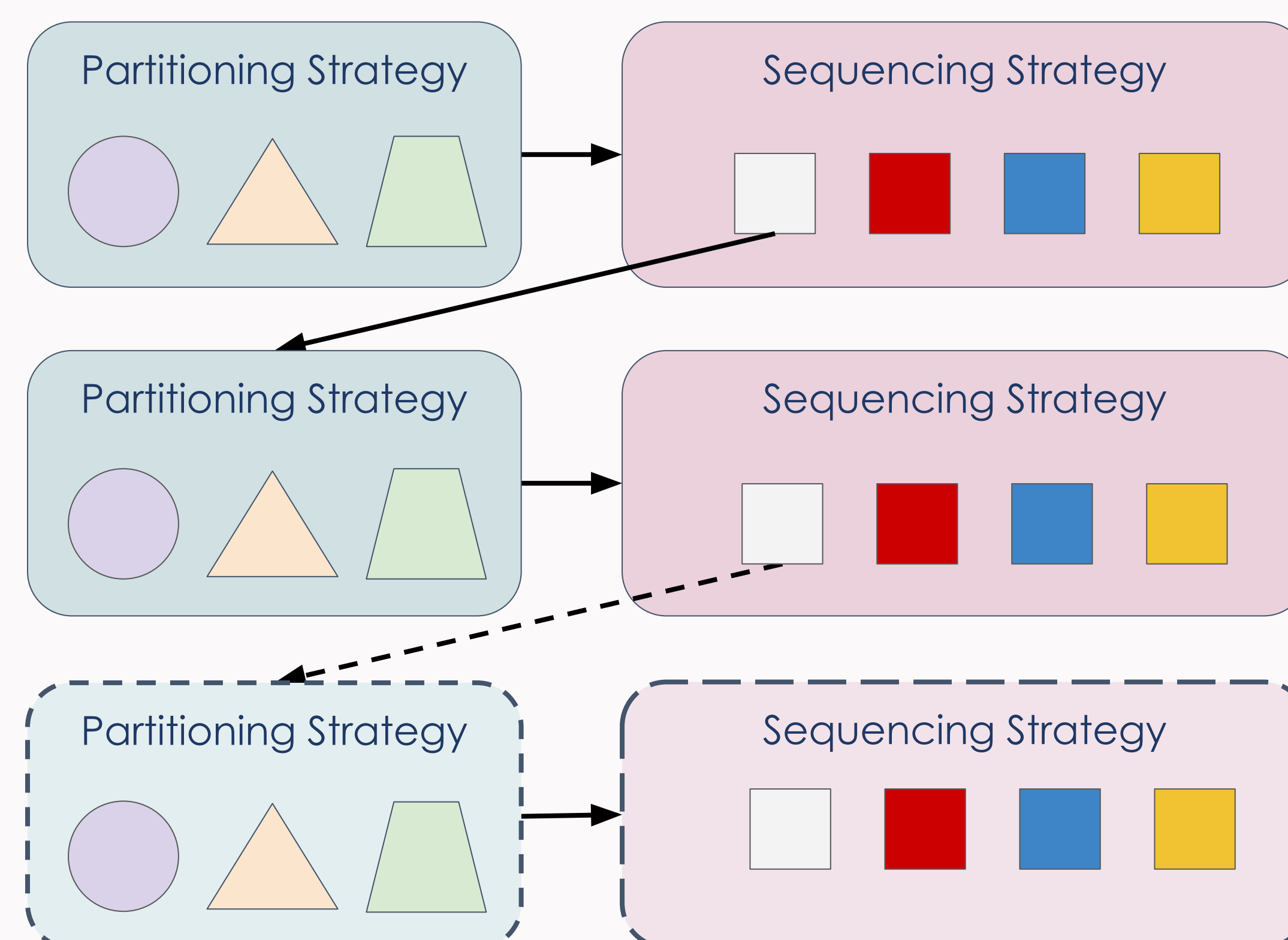
Importance
Start: Most important element
Proceed: Based on importance



Structure of a health story

- Narrative hierarchy of a health story: patients first **partition**, then **sequence** elements
- Partitioning and sequencing can continue recursively
- Most stories have two levels, but can have more

Health Story Hierarchical Structure

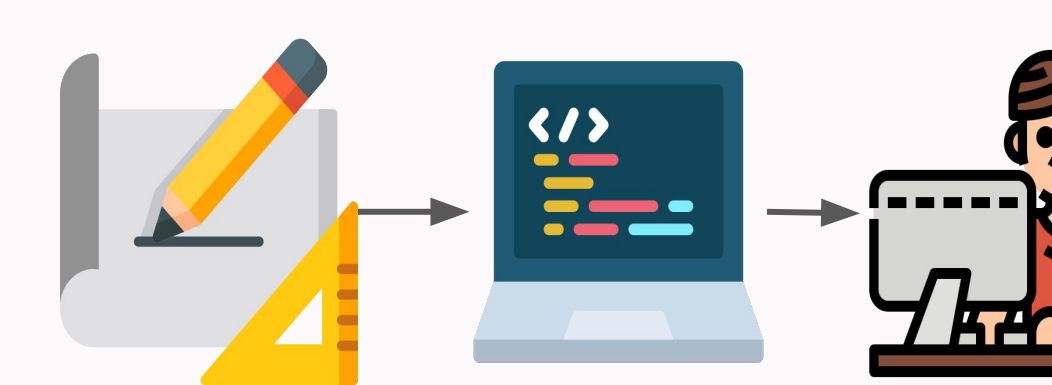


Next steps: Building a health story authoring tool

- Motivation: Active patient participation improves outcomes, enhances patient-provider communication, lowers costs
- Few tools exist that support patients
- Build and test tool with patients and providers

Formative User Testing

Does the tool balance flexibility, expressiveness, and guidance?



Summative Clinical Team Evaluation

Does this tool actually help providers understand health stories?

