HealthTale: A Patient-Centric Health Story Visualization Tool

Ryan Smith, Kyle D. Chin, Tamara Munzner

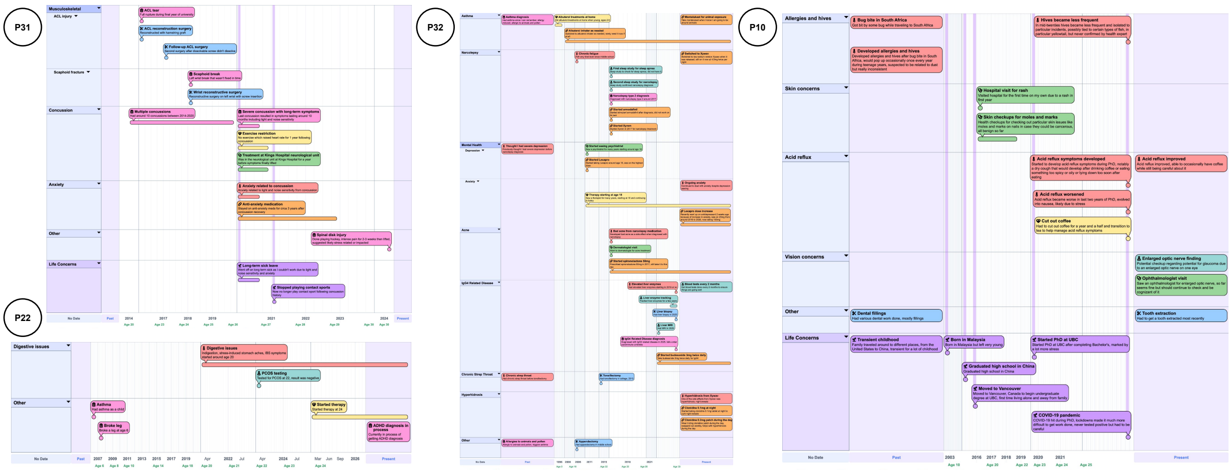

Fig. 1: Example health stories created during the evaluation of the patient-centric HealthTale system. These visualizations illustrate the diversity of patient-generated narratives, ranging from relatively simple stories focused on a small number of Events to more complex stories spanning multiple Conditions and Timescales. HealthTale preserves individual differences in what patients choose to include and emphasize, and supports the integration of non-medical Life Concerns relevant to health outcomes, while providing an interpretable common overall structure to support rapid communication during time-constrained clinical encounters.

Abstract—Patients often struggle to communicate coherent accounts of their health histories during time-constrained clinical encounters. These accounts, which we refer to as health stories, include both clinical events and lived experiences. Existing systems prioritize structured, clinician-centered data and provide limited support for eliciting and communicating patient-generated narratives. We present HealthTale, a patient-centric visualization system designed to elicit health stories from patients and structure them to facilitate communication during initial clinical conversations. Its design arises from a multi-stage qualitative investigation across domain expert discussions, online narratives ($n = 20$), patient ($n = 11$) and clinician ($n = 6$) interviews, and elicited health stories ($n = 22$), identifying recurring patterns in how individuals construct and communicate their health stories. HealthTale transforms freeform narratives into structured timeline representations, grounded in a data abstraction that models health stories as events that are grouped by health concern and time, capturing both clinical and contextual information, with the flexibility to handle temporally imprecise data and non-linear distributions of events across time. Through evaluation with patients ($n = 34$) and clinicians ($n = 3$), we find that HealthTale supports recall, organization, and self-advocacy, while enabling clinicians to rapidly interpret patient-generated narratives and establish a shared understanding.

Index Terms—Healthcare Visualization, Narrative Visualization, Patient-Generated Data, Patient–Clinician Communication, Temporal Visualization, Data Abstraction.

1 Introduction

Patients must often convey complex, personal accounts of their health to clinicians in order to receive effective care, particularly during initial clinical encounters where little prior context is available. In these settings, clinicians rely heavily on patient-provided narratives to form an initial understanding of the patient's condition, history, and priorities [7]. These accounts extend beyond clinical facts to include contextual factors and personal interpretations that shape how individuals understand their health. We refer to these accounts as **health stories**: patient-generated narratives that integrate medical events with lived experience over time. While these narratives are central to clinical understanding, existing electronic medical record systems primarily capture structured, clinician-centered data, creating a gap between how patients understand their health and how it is represented in clinical contexts [13, 17, 19, 39].

We address this problem through a visualization system to elicit health stories from patients and help them communicate those stories with clinicians, with a particular focus on supporting initial clinical visits where patients must efficiently convey their history to new providers. The system was designed in collaboration with a project partner, a digital health solutions company and its clinical team.

We began by conducting a multi-stage qualitative investigation into patient-generated narratives via discussions with the clinical team domain experts ($n = 3$), collecting and analyzing online health stories ($n = 20$), interviews with patients ($n = 11$) and clinicians ($n = 6$), and directly eliciting written health stories ($n = 22$). Through this process, we identified recurring patterns in how patients think about and communicate their health stories, especially in the context of preparing for and navigating first-time clinical interactions.

From these observations, we derive a data abstraction that models health stories as a series of events with associated attributes and organizes them across two cross-cutting grouping structures: the type of health concern, and the timing of when they occurred. This abstraction

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captures both clinical information and contextual experience, while supporting events specified with a broad range of temporal precision and that are unevenly distributed across time.

We present **HealthTale**, a patient-centric health story visualization system designed to support this data abstraction by transforming freeform narratives into structured timeline representations. The system supports patients in preparing for initial clinical encounters and communicating with clinicians to help them rapidly form a coherent understanding of a patient's history. We evaluate HealthTale through studies with patients ($n = 34$) and clinicians ($n = 3$), showing that it supports patient recall, organization, and self-advocacy, while providing preliminary evidence that these representations enable clinicians to quickly interpret patient-generated health stories during early-stage interactions.

The primary contributions of this work are:

- A flexible data abstraction for health stories, grounded in a multi-stage qualitative investigation of patient-generated narratives across diverse sources.
- HealthTale, a patient-centric Health Story visualization system that transforms elicited free-form text into this structured data abstraction and visually encodes it to support patient-clinician communication, particularly for initial clinical encounters. We provide preliminary evidence of utility through evaluation with patients and clinicians, demonstrating support for both health story elicitation and communication.

The secondary contributions of this work are:

- A corpus of health stories ($n = 85$) collected across multiple sources.
- A grouping and layout algorithm for visualizing health stories that accommodates events specified at different levels of temporal precision, and with non-linear temporal distribution.

2 Background and Motivation

Patient-centered care emphasizes understanding a patient's experiences, context, and priorities when making clinical decisions [19]. When patients feel heard and understood, health outcomes improve. Increased participation has been linked to greater engagement with treatment, improved understanding of health status, and increased empowerment in managing conditions [3, 20, 55]. At a system level, effective patient–clinician communication is also associated with improved healthcare efficiency and reduced costs [19, 49, 50, 54, 56].

In practice, however, communicating these narratives remains challenging, particularly during initial clinical visits where clinicians have little prior context and patients must establish their health story from scratch [28, 43]. Unlike follow-up encounters, where shared understanding can be incrementally refined, first-time interactions require patients to summarize complex and sometimes long-term histories to a new clinician within a constrained time window. During these encounters, patients typically complete structured intake forms in advance and then verbally summarize their histories within the limited first few minutes of an appointment [35]. Intake forms prioritize standardized, clinician-centered data and provide little space for contextual detail, while verbal accounts are often incomplete, non-linear, and difficult to organize. As a result, clinicians must reconstruct patient histories from fragmented information, meaning important contextual details may be overlooked [19, 40, 44, 46].

Existing tools do not adequately support this process. Electronic medical records (EMRs) provide structured representations of patient data but are fundamentally clinician-centered, focusing on coded medical events such as diagnoses, treatments, and tests [11, 23]. While effective for documentation and clinical review, they omit the contextual and experiential elements that patients use to make sense of their health [13, 39]. Similarly, patient-facing tools often rely on predefined inputs or continuous tracking, capturing discrete data points rather than supporting patients in constructing and organizing their own health stories, and can introduce cognitive and emotional barriers to effective communication [28]. A disconnect remains between patient-generated health stories and their representation within clinical systems.

This gap motivates two core design goals:

- **DG-E, Elicitation:** Support patients in constructing relevant and context-rich health stories, enabling recall and self-advocacy.
- **DG-C, Communication:** Support efficient communication through a static, shareable visualization artifact brought by the patient to an initial encounter with a clinician, enabling the rapid formation of a shared mental model.

These goals aim to improve both the efficiency and quality of early-stage clinical interactions by aligning patient-generated narratives with clinically interpretable representations.

3 Related Work

We situate our work within prior research on eliciting patient information, electronic medical record visualization, and narrative visualization.

3.1 Eliciting Patient Information

Healthcare systems commonly rely on structured methods such as intake forms, symptom checklists, Patient-Reported Outcome Measures (PROMs), and Patient-Reported Experience Measures (PREMs) to collect patient information [11, 23, 31, 34, 52]. These approaches improve consistency and efficiency but constrain how patients express their experiences, often limiting responses to predefined categories.

Digital tools, including electronic forms, health applications, and wearables, extend these approaches but continue to prioritize structured data collection over patient-generated narratives [5, 30, 48]. As a result, they often fail to capture contextual and experiential information that patients consider important [4, 10, 16]. Additionally, these systems frequently require consistent data entry, which can be burdensome and difficult to maintain over time [8, 18, 24, 41, 47].

Narrative approaches allow patients to describe their experiences in their own terms and highlight meaningful relationships between events [9, 39]. Such narrative accounts have also been shown to support reflection and personal understanding of one's health over time [32]. However, such narratives are difficult to structure, compare, and integrate into clinical workflows. This tension between flexibility and structure motivates the need for approaches that can transform patient-generated narratives into interpretable representations.

Our work addresses this gap by enabling freeform narrative input while automatically deriving structured representations for visualization, preserving expressiveness while improving interpretability and communication in clinical contexts.

3.2 Electronic Medical Record Visualization

Visualization systems for electronic medical records (EMRs) commonly represent patient histories as timelines of diagnoses, treatments, and clinical Events [21, 38, 42, 53]. These systems support clinicians in navigating large volumes of structured data and identifying temporal patterns [2].

However, EMR visualizations are inherently constrained by the structure and scope of the underlying data [38]. They focus on clinically coded events and omit contextual and narrative elements present in patient-generated health stories. As a result, they reflect a clinician-centered view of patient history and do not support how patients construct or communicate their experiences. The intersection between EMR visualization and narrative-driven representations remains limited, highlighting an opportunity for approaches that incorporate patient-generated data [39, 51].

This gap motivates our work, which bridges clinician-centered EMR visualizations and patient-authored narratives by transforming health stories into structured, interpretable visual representations.

3.3 Visualization for Storytelling

Narrative visualization explores how visual representations can structure and communicate stories by guiding interpretation and emphasizing relationships between events [14, 45]. Such representations can support comprehension and memorability, reduce cognitive load, and improve understanding of temporal relationships [27], while enabling subjective organization of narratives [6].

Some visualization systems extend this work by enabling users to construct visualizations through graphical interfaces, supporting non-expert users in creating and externalizing their own representations [25, 26]. Systems such as timeline-based storytelling tools allow users to flexibly structure temporal narratives [15, 36], while others support reflection over personal data [22, 32, 33].

However, none of this prior work addresses the specific needs of patient-driven communication of a health story during a clinical encounter.

Moreover, prior work on storytelling assumes that the underlying data is already structured or requires users to manually organize it, so these systems do not address how unstructured, freeform narratives can be transformed into consistent representations that support both elicitation and communicating. In particular, they do not account for the variability, ambiguity, and temporal imprecision inherent in patient-generated health stories, limiting their effectiveness in clinical contexts.

All of these past approaches demonstrate the potential of narrative visualization, but it remains largely unexplored in the context of patient-generated health stories. Our work addresses this gap by applying narrative visualization techniques to patient-authored health stories, transforming freeform narratives into structured, interpretable representations for clinical communication.

4 Data Abstraction

We both derive a data abstraction for health stories and motivate our two design goals through a multi-stage data collection and analysis process involving healthcare domain experts, patients, and clinicians. Across these stages, we examine how individuals construct, group, and temporally describe their health experiences in narrative form. From this analysis, we identify recurring structural patterns and use them to inform a formal representation of health stories and the design goals that guide system development. We first present the formalization of this representation, followed by an explanation of the process and the empirical observations resulting from it that motivated and justified our choices.

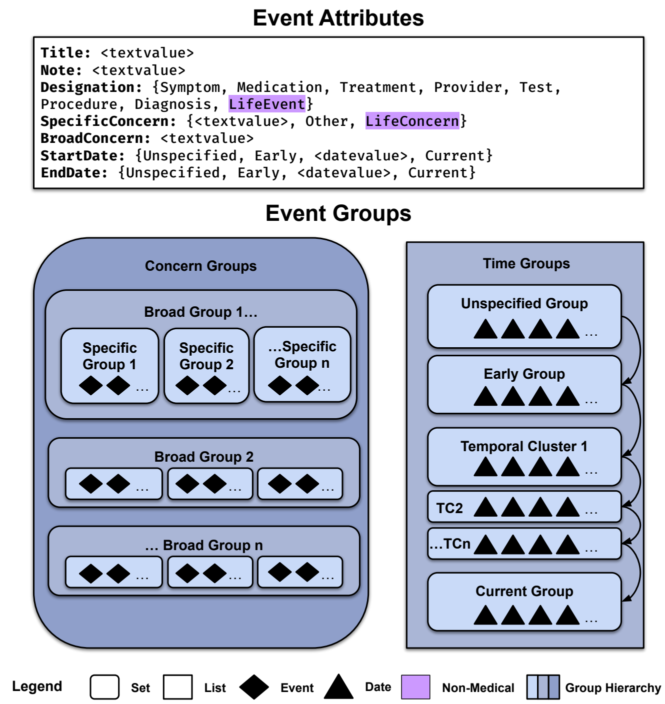

Fig. 2: Health story data abstraction. Events are atomic items with multiple attributes. Some attributes, such as *Title*, have freeform text as values, while others, like *Designation*, use predefined values; some, such as *Concern*, support both. *Life Event* and *Life Concern* are highlighted in purple to emphasize that these non-medical elements are typically absent from standard medical abstractions. Events are organized into two cross-cutting structures: *Concern Groups* and *Time Groups*.

4.1 Data Abstraction Formalization

Fig. 2 presents our data abstraction, which centers an **Event** as the atomic unit of a health story. Events in a health story represent changes, processes, or interactions within an individual's health experience, such as the onset of a symptom, the initiation of taking a medication, a specific clinical visit, or a non-medical incident or experience that pertains to health outcomes.

4.1.1 Event Attributes

Each Event contains a set of attributes that describe what occurred, what it relates to, and when it happened. The attributes associated with each Event were derived from recurring patterns observed in how participants described and structured these experiences, so as to capture the variability and ambiguity inherent in patient-generated narratives.

The **Title** and **Notes** attributes have values that are free-form text; Title captures the primary descriptor of the Event, like the name of a medication or a very brief summary of what occurred, while Notes provide additional contextual detail. This separation between title and supporting information supports expressive input while preserving structured interpretation.

Designation is a categorical attribute describing the type of Event, with eight possible values: *Symptom*, *Medication*, *Treatment*, *Provider*, *Test*, *Procedure*, *Diagnosis*, and *Life Event*. The first seven correspond to standard clinical categories, while *Life Event* captures non-medical experiences like job changes or moves or anything that is central to how patients understand and communicate their health. This category is not typically captured in structured medical records.

The **SpecificConcern** and **BroadConcern** attributes describe what kind of problem the Event is associated with. SpecificConcern identifies a particular problem, like *arthritis*, with a free-form text value. It may also be set to the pre-specified values *Other*, indicating that there is no specific associated problem. For all Events of type Life Event, this attribute is set to the pre-specified value of *Life Concern*, the category for all non-medical problems. BroadConcern represents a higher-level grouping, such as *musculoskeletal* or *mental health*, with a free-form text value, and is optional. These attributes are used to create groups, as described below.

StartDate and **EndDate** describe when an Event occurs. Each attribute takes one of four values: *Unspecified*, *Early*, *Date*, or *Current*. *Unspecified* indicates that no temporal information is available for that aspect of the Event. *Early* indicates that no explicit date is given, but the surrounding health story provides enough information to infer that the Event occurred before the first Event with explicitly specified timing. *Date* represents an explicitly provided temporal reference by the patient, which may be specified either as an absolute calendar date, or as a relative age. Relative age values are ultimately mapped into calendar dates, using the date of birth. *Current* indicates that no explicit date is given, but there is implicit meaning that the Event is ongoing at the present time. This formulation explicitly supports the imprecision and variability observed in patient narratives. Events may be loosely situated in time or entirely without timestamps, enabling patients to construct meaningful representations without conforming to the rigid temporal requirements typical of EMRs.

4.1.2 Event Groups

Events are organized across two cross-cutting grouping structures: Concern Groups and Time Groups. These structures are derived from attributes across the full set of Events and provide complementary organizational views of that set.

Concern Groups are structured as a two-level hierarchy of sets: a SpecificGroup is a set of Events, and a BroadGroup is a set of SpecificGroups. Both a **SpecificGroup** and a **BroadGroup** simply contain all Events with the same values for attributes of SpecificConcern and BroadConcern respectively, and their name is set to that value.

Time Groups operate on the individual StartDate and EndDate attributes rather than on whole Events. Each date associated with an

Event is assigned independently to a Time Group based on its value, meaning a single Event may be associated with multiple Time Groups if its StartDate and EndDate fall into different partitions.

Time Groups are structured as a list containing sets of dates, partitioned according to the **StartDate** and **EndDate** attribute values. The **Unspecified**, **Early**, and **Current** Groups are sets that contain all dates with those respective values. Events with explicit date values are organized into one or more **Temporal Clusters**, each of which is a set of dates derived from global patterns in the data, allowing the non-uniform temporal distribution of health stories to be explicitly represented.

The combination of Concern Groups and Time Groups provides a cross-cutting structure to capture the salient aspects of patient narratives in a very flexible way. Unlike traditional EMR data abstractions, which prioritize precise, standardized, and clinician-centered representations, this model accommodates temporal ambiguity and integrates non-medical contextual information.

4.2 Data Abstraction Process and Evolution

Our data abstraction and the articulation of our design goals emerged from a multi-stage data collection and analysis process centered on gathering and analyzing health story artifacts across different contexts. This analysis examined how health stories are constructed, communicated, and interpreted, allowing us to iteratively refine both the abstraction and the design goals for supporting health story elicitation and communicating.

All studies with human participants described in this paper were approved by our university's Behavioural Research Ethics Board (BREB), and we obtained informed consent from all participants.

4.2.1 Initial Domain Characterization (Expert Discussion)

We began with an initial domain characterization phase to ground our understanding of health stories within clinical practice. We conducted dozens of interactions with our industry partner's internal clinical team ($n = 3$), all of whom are practicing healthcare professionals. These interactions varied in length and modality, ranging from brief Slack discussions to formal 30–60 minute meetings.

Through these discussions, we developed a foundational understanding of the clinical context surrounding patient intake and how patient histories are interpreted in practice. The clinicians emphasized the importance of key diagnoses and treatments, and their temporal progression, when forming an understanding of a patient's health, particularly in the early moments of an encounter. These insights informed which types of health information should be represented in our system and directly influenced the development of the Designation attribute in our abstraction, supporting both the capture of relevant patient information for DG-E (Elicitation) and its efficient interpretation in clinical settings for DG-C (Communication).

Following this initial domain characterization, we refined the scope of the problem and shifted our focus toward understanding how people initially tell their health stories in practice. To do this, we collected health story artifacts across multiple contexts to examine how these narratives are constructed, communicated, and externalized by real patients. We designed a multi-stage data collection process spanning natural, clinical, and controlled settings, allowing us to identify recurring structures and inform both the data abstraction and design goals.

4.2.2 Stage 1: Unsolicited Health Stories (Online Narratives)

Motivation. We first sought to understand what constitutes a health story by examining naturally occurring, unsolicited patient narratives, using online posts as a proxy for how individuals externalize and communicate their experiences outside of clinical settings.

Methods. We analyzed online health stories, using a netnographic approach [29] that adapts ethnographic methods to digital contexts. We selected posts ($n = 20$) from the `/r/chronicillness` subreddit that represented apparent individual health stories. These unsolicited narratives provide insight into how patients describe their experiences without external prompting.

The first author performed thematic analysis and iteratively open coded the stories, decomposing each into individual Events and developing a coding schema of Designations through repeated passes over the data. Coding proceeded until termination, defined as the point at which no new codes were identified and the existing schema sufficiently covered new stories.

Data Abstraction Results. We observed that Events may include temporal information as either singular instances or ranges, and that patients employ diverse temporal strategies. Narratives often reflect a dominant temporal framing, but may interleave multiple strategies or omit temporal information entirely. These observations motivated a flexible StartDate and EndDate representation, including support for unspecified cases. We also observed variation in the granularity and density of Events over time, motivating support for having multiple Time Clusters.

Design Goal Results. These findings support DG-E by highlighting the need to capture diverse, patient-driven narrative structures, including incomplete and non-standard temporal information. They also support DG-C by motivating representations that preserve temporal variation and density, enabling clinicians to interpret patterns of activity and inactivity over time.

4.2.3 Stage 2: Patient and Clinician Interviews

Motivation. We next examined how health stories are constructed and communicated in clinical contexts, focusing on how patient narratives align with clinical needs.

Methods. We conducted semi-structured interviews with patients ($n = 11$; age range = 24–69; $M = 49.1$, $Mdn = 54.5$) and clinicians ($n = 6$; age range = 31–43; $M = 38.8$, $Mdn = 39.5$; years in field range = 3–19; $M = 10.0$), including a registered nurses in internal medicine and critical care, a speech pathologist, a registered physiotherapist, and an associate professor of clinical medicine. Interviews combined roleplaying scenarios with process-oriented discussion of how health stories are shared and interpreted.

We recruited patients with complex or chronic conditions from our project partner's network (CAD$25 honorarium) and clinicians from the same network (CAD$40 honorarium).

The first author performed thematic analysis and iteratively open coded interview transcripts, analyzing patient and clinician responses as separate but related corpora to capture differences in how health stories are produced and interpreted. We reached termination when additional interviews no longer produced new codes and instead revealed limitations of spoken recall, motivating a shift toward eliciting health stories in a more structured, written form.

Data Abstraction Results. We identified systematic differences between clinical expectations and patient-generated narratives, reinforcing the need for a representation that bridges these perspectives. Patients described Events using varied and often imprecise temporal strategies, including missing, relative, and ongoing time references. These observations further supported the StartDate and EndDate Unspecified, Early, and Current values.

Design Goal Results. These findings support DG-E by highlighting challenges in recall, ordering, and completeness when patients describe their histories verbally, motivating support for structured yet flexible narrative construction. They support DG-C by emphasizing the time-constrained nature of clinical encounters and the need for concise, structured, and easily scannable representations. Participants described bringing prepared materials into visits and noted the difficulty of communicating with clinicians through long, unstructured narratives, motivating representations that align patient expression with clinical interpretability while preserving patient perspective. Although patients commonly relied on printed materials, the clinicians emphasized the need for electronically shareable artifacts. This finding elaborated our understanding of DG-C with the idea that the end result of using the system should be an artifact that remains interpretable without interaction, supporting effective communication within static, artifact-based clinical workflows.

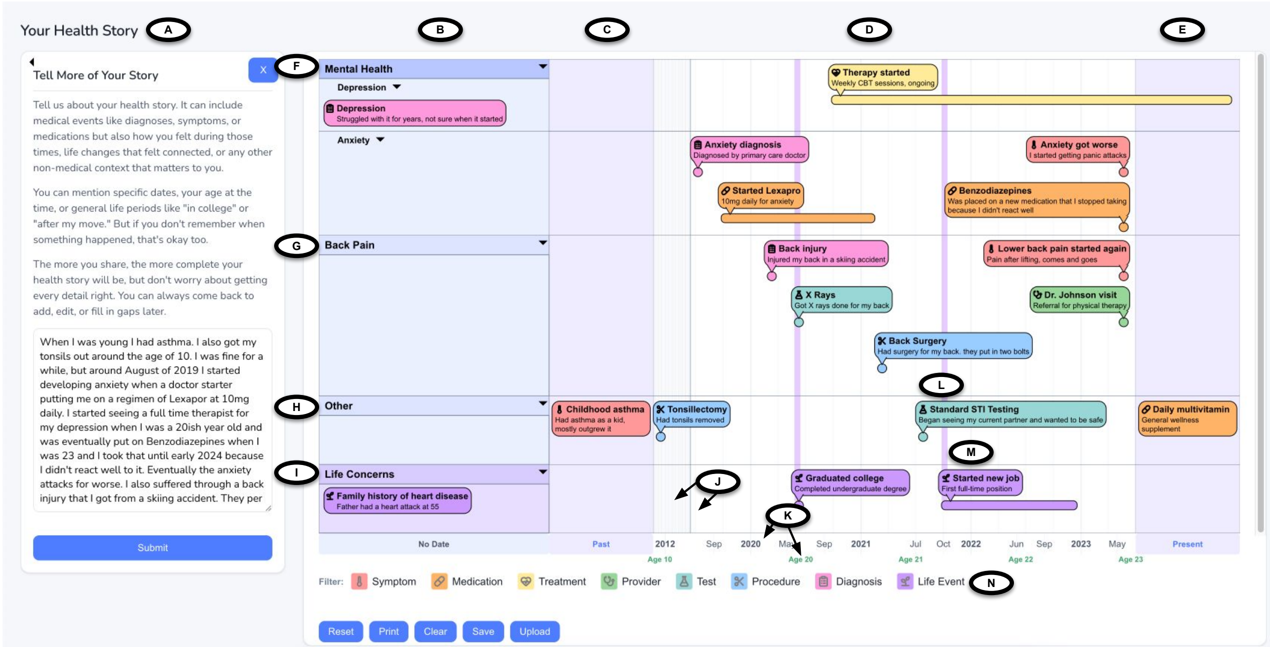

Fig. 3: In HealthTale, after the patient writes free-form text in the Elicitation Panel on the left (A), it is automatically transformed into structured data visually encoded in the canvas on the right. The vertical segments show temporally ordered groups, starting with No Time (B), then Past (C), with multiple Timescale segments (D), followed by Present (E). Events are contained within horizontal tracks based on Concerns, with two-level groups of Broad and Specific Conditions (F), followed by individual Condition tracks (G), with Other (H) and Life Concerns (I) at the bottom. The density of the multiple Timescales are shown with grid lines (J), with absolute date labels and relative age labels on the horizontal axis (K). Individual Events are represented as InfoBoxes (L), and the Life Events also have vertical lines spanning tracks to support cross-track comparison (M). Event color encodes Designation (N).

4.2.4 Stage 3: Elicited Health Stories (In-Person Sessions)

Motivation. Finally, we sought to understand how patients construct health stories when explicitly asked to externalize them in written form.

Methods. We conducted an in-person elicitation study with patients ($n = 22$; age range = 19–71; $M = 32.4$, $Mdn = 28.5$), where each session lasted approximately 60 minutes. Participants were recruited as individuals with complex health conditions through our project partner's network and via flyers distributed across the city, and received a CAD$30 honorarium.

Participants were asked to create written health story artifacts in their own words, followed by a reflection on their thought process. The first author, again, performed thematic analysis and iteratively open coded these artifacts, building on and refining the code structures developed in Stages 1 and 2. Coding continued until additional artifacts did not yield new codes, indicating that the existing schema sufficiently captured the observed structures.

Data Abstraction Results. We observed that patients frequently include contextual and non-medical experiences, leading us to formalize Life Events as a distinct Designation. Patients often described distant Events using vague temporal references and explicitly identified ongoing Events, reinforcing the need for Early and Current values. We also observed that Events cluster within specific periods, with bursts of activity and gaps, motivating support for multiple Temporal Clusters.

Design Goal Results. These findings support DG-E by showing that patients naturally construct narratives that combine freeform expression with implicit structure, motivating systems that support flexible input while capturing underlying organization. They also support DG-C by highlighting that patients prioritize certain Events while omitting others they consider routine, suggesting the need for representations that preserve patient priorities while enabling clinicians to quickly identify relevant gaps and patterns.

5 HEALTHTALE DESIGN

HealthTale is a patient-centric health story visualization system with a unified interface that couples elicitation through free-form text (DG-E), automated structuring of that text according to our data abstraction, and its visual encoding designed for efficient communication with a clinician (DG-C).

Fig. 3 shows the HealthTale interface, which has a collapsible information pane on the left and a visualization canvas on the right. The information pane displays one of three panels at a time: the Health Profile Panel, the Elicitation Panel, or the Event Editing Panel.

The user flow of HealthTale begins with the Health Profile Panel, where users provide their name and date of birth, which enables relative time expressions to be resolved into absolute time. The Elicitation Panel then appears, with lightweight prompts asking them to provide their health story as freeform text (Fig. 3(A)). This input is automatically transformed into a structured visualization in the canvas. Users can refine this representation if desired, by adding new events and editing existing Event attributes in the Event Editing Panel. The resulting visualization can be saved and printed as a static artifact for use during clinical encounters.

5.1 Visual Encoding

The visual encoding of the structured health story positions InfoBoxes representing Events into horizontal Tracks according to Concerns and vertical Segments ordered by Time.

5.1.1 Event InfoBoxes

Each Event item is encoded with an **InfoBox** glyph (Fig. 3(L)), which serves as the primary visual unit of the health story. Each InfoBox includes the Title and Note text, placed within a surrounding box with rounded corners that is sized to encompass both fields. The horizontal position of InfoBoxes is determined by the Event's StartDate and EndDate attributes and their vertical position by the Concern.

Temporal extent is encoded using a marker placed directly below the main box, where a circle encodes a single point in time and a horizontal line encodes a duration. The box is styled to look like a dialogue bubble, with the downward triangle pointing to the marker. The box and marker are color coded according to the Designation attribute (Fig. 3(N)), which is also encoded with an icon in the upper left.

5.1.2 Concern Group Horizontal Tracks

Concern Groups are shown as horizontal **Tracks** that contain Events, vertically ordered with the larger two-layer BroadCondition sets (Fig. 3(F)) at the top and the singleton SpecificCondition sets below (Fig. 3(G)). Within these categories the positioning follows the narrative order in the health story, except that the *Other* track (Fig. 3(H)) is always just above the *LifeConcern* track at the very bottom, if these groups exist (Fig. 3(I)). The InfoBoxes for Life Events are augmented with a vertical purple line spanning tracks (Fig. 3(M)), to make temporal correspondences between these and all other Events easy to notice.

5.1.3 Time Group Vertical Segments

The ordered list of Time Groups are shown as vertical **Segments**. On the left is the Unspecified Group labelled as *No Time* (Fig. 3(B)), followed by the Early Group labelled as *Past* (Fig. 3(C)), and the rightmost segment contains the Current Group labelled as *Present* (Fig. 3(E)). These segments do not display explicit axes.

Each Temporal Cluster is represented within the absolute timeline as a **Timescale** (Fig. 3(D)), with boundaries indicated by darker separators. Within each Timescale, the density of the grid lines (Fig. 3(J)) conveys the temporal density of each segment.

Although absolute calendar time and relative age date values are unified within the data abstraction, they are represented distinctly in the visual encoding to preserve the nuance in how patients express time in their health stories. The horizontal axis uses dual labels to show complementary temporal context, with absolute encoded above in black and relative below in green (Fig. 3(K)).

5.2 Algorithm and Architecture

HealthTale translates freeform health stories into structured visualizations through a pipeline consisting of three stages. First, the text is parsed to create a structured representation based on Events. Then, a grouping and layout algorithm creates Event Groups, determines the size of Tracks and Segments, and arranges the Event InfoBoxes within them. Finally, a visual styling pass fine tunes the appearance of all the on-screen elements.

5.2.1 Parsing

Given a freeform narrative, the parser identifies Events and assigns their attributes, extracting as much temporal information as is available to record in the Time attributes.

We use a large language model (LLM), Claude Sonnet 4.6 [1], to parse freeform health stories into structured data that incorporates all of the previously described attributes, along with a unique per-item identifier. The model is used strictly for transformation, not generation, and extracts Events and their associated attributes without introducing new information. The system is accessed via an API key tied to a version of the model approved by our project partner for handling medical data, ensuring that all processing aligns with appropriate data governance requirements.

5.2.2 Grouping and Layout Algorithm

The grouping and layout algorithm is designed to support health story representations for initial clinical encounters, where clinicians must rapidly interpret patient histories under time constraints. The design target thus is a moderate number of Events, typically on the order of dozens. We prioritize readability, compactness, and interpretability over scalability to arbitrarily large inputs. These assumptions inform key design decisions in the algorithm, including the use of adaptive temporal clustering, density-based width allocation, and layout optimizations that reduce canvas vertical height for artifact-based use. Fig. 4 summarizes the algorithm as pseudocode.

```
TIMELINE_LAYOUT(events, W) {
    // Cluster dated Events (DBSCAN)
    d = min(d_base, (2.5 yrs / span) * 100)
    C = CLUSTER_DATES(dated(events), d, minPts=1)

    // Optimize non-temporal / temporal split
    bestHeight = infinite
    rFinal = 10%
    for each r in [10%, 15%, ..., 50%]:
      h = DRAFT_LAYOUT(events, W, C, r)
      if h < bestHeight:
        bestHeight = h
        rFinal = r
    DRAFT_LAYOUT(events, W, C, rFinal)
}

DRAFT_LAYOUT(events, W, C, r) {
    // Width by event count
    for each s in [C: Past, C1..Ck, Present]:
    s.width = |s| / |all temporal events|
          s.width = s.width * (W * (1 - r))

    // Segment bounds
    x = W * r
    for each s in [C: Past, C1..Ck, Present]:
      s.left = x
      s.right = s.left + s.width
      c.scale = MAP(dateRange(c), c.left, c.right)
      x = s.right

    // Track layout (first-fit event stacking)
    for each track in GROUP(events):
      for each e in track:
        lane = 0
        if FITS(lane, e) PLACE_IN_LANE(lane, e)
        else PLACE_IN_LANE(lane++, e)
        compute e.left, e.right
        compute e.top, e.bottom
      track.height = sum(lane heights)
      track.top = previous(track).bottom
      track.bottom = track.top - track.height
}
```

Fig. 4: Pseudocode for the grouping and layout algorithm.

The grouping and layout algorithm `TIMELINE_LAYOUT` takes an unordered set of Events as input and outputs Timescale, Track, and InfoBox coordinates that determine their spatial arrangement. The algorithm proceeds in three stages: *clustering*, *segment construction*, and *track layout*, explicitly computing horizontal and vertical bounds.

Concern Groups and simple Time Groups (*Unspecified*, *Early*, *Current*) are derived directly from Event attributes, while Temporal Clusters require a global computation. In `CLUSTER_DATES`, we group dated Events using DBSCAN [12], reflecting the punctuated nature of health stories without assuming a fixed number of clusters.

Events are mapped onto a normalized time axis from earliest date to most recent and clustered with a minimum of one event per cluster. The DBSCAN adjusts the clustering radius based on the overall timespan, using a baseline of 30 and a reference gap of approximately 2.5 years, becoming more selective for longer histories and more permissive for shorter ones. Parameters were empirically tuned to produce coherent groupings.

Segments are constructed with widths proportional to the number of dates they contain, emphasizing periods of higher temporal density. Segments are positioned sequentially from left to right with *s.left* and *s.right* bounds, including *Past* and *Present* segments on either side of Temporal Clusters. Within each segment, a linear mapping from date values to pixel positions defines the local timescale. An Event's horizontal placement is derived from its StartDate and EndDate, which may span multiple segments.

Events are arranged within Tracks using a first-fit packing strategy. Each Track is divided into horizontal lanes of non-overlapping InfoBoxes, placed in the first available lane or in a new lane if needed. Track height is the sum of lane heights, and Tracks are stacked vertically by setting the *track.top* of each track to the previous track's *track.bottom* position.

Finally, in `DRAFT_LAYOUT` we determine the horizontal partition between non-temporal and temporal segments by evaluating candidate split ratios from 10% to 50% in 5% increments, recomputing the layout for each candidate, and selecting the split that minimizes total height. This approach produces compact visualizations suitable for printing and rapid interpretation.

Figure 5 compares this multi-timescale approach to a single-timescale baseline, which produces taller layouts with inefficient whitespace. Our approach compacts the structure, preserves temporal context, and improves visibility of short-duration ranges.

Fig. 5: Layout comparison for participant E22 from the elicitation sessions, contrasting a uniform single-timescale layout (left) with our multi-timescale approach (right).

5.2.3 Visual Styling Pass

The elements in the visual encoding are then styled to create the final visual representation, using the alignment and positioning information from the layout computation. Additional marks, including the subtle grid line density variations that convey Timescales, the vertical boundaries of Timescale segments, and the horizontal lines delineating Tracks, are also added in this phase, with their placement determined by calculations from the grouping and layout algorithm section of the pipeline. This level of visual polish ensures that the visualization remains legible as both an interactive interface and a static artifact, supporting quick interpretation without introducing visual clutter.

5.2.4 Development

HealthTale was implemented using TypeScript, Lit, and D3. The system was developed through an iterative prototyping process involving multiple feedback cycles with the research team and our project partner. This process ensured that the prototype aligned with both the research goals and the practical constraints of integration within the partner's ecosystem and clinical workflows.

We used Claude Code [1] to assist with the visual styling pass, enabling rapid iteration on visual polish as well as general code cleanup.

6 Evaluation

We conducted a multi-stage evaluation of HealthTale combining formative refinement and summative assessment, structured around both our system components and design goals. The evaluation assesses the level of system support for elicitation (DG-E) and communication (DG-C) by targeting four aspects: *data parsing*, *data abstraction*, *grouping and layout algorithm*, and *visual encoding*.

6.1 Stage 1: Formative System Validation

We first conducted formative testing using previously collected health story artifacts, namely the unsolicited online narratives from Reddit ($n = 20$) and written narratives from our final pre-design study ($n = 22$). The research team provided these artifacts verbatim to HealthTale and reviewed the resulting visualizations.

This stage focused on evaluating parser prompting strategies and stress-testing the grouping and layout algorithm across variations in event density, temporal spread, and narrative complexity. We examined whether Events were correctly extracted, whether temporal groupings aligned with expectations, and whether the visualization remained legible under different conditions.

Based on these observations, we refined parser prompts, debugged layout behaviors, and adjusted visual styling details prior to human testing. We saved the visual artifacts and JSON data for use in Stage 4: Clinician Formative Review.

6.2 Stage 2: Patient Formative Evaluation

We conducted a user study with patients ($n = 34$; age range = 24–65; $M = 35.9$, $Mdn = 31.0$), consisting of 30-minute Zoom or in-person sessions. Participants received a CAD$20 honorarium and were recruited through snowball sampling and social media posts to capture a range of health complexities.

During each session, participants typed their health story into the Elicitation Panel, then considered the output visualization generated by the system and had the opportunity to interact with it via the interface. Participants engaged in a think-aloud process while researchers asked targeted and open-ended questions. We saved their freeform health story, visual artifact and JSON containing the structured data. Fig. 1 shows a subset of artifacts generated during both formative and summative phases using the final iteration of our visual styling.

The first 19 sessions were used for formative refinement. We conducted sessions in an iterative cycle, where participant feedback from interviews informed targeted adjustments to the system, which were then evaluated in subsequent sessions. Iterations were introduced when consistent patterns of feedback emerged across participants, specifically when the same concern was raised repeatedly. These iterations were limited to the visual styling of the system and were intended to improve usability. The underlying functionality and utility of the artifact remained unchanged.

Iteration 1 ($n = 7$): We redesigned the InfoBox styling to resemble dialogue bubbles rather than rectangles.

Rationale: Multiple participants misinterpreted box width as event duration.

Iteration 2 ($n = 7$): We introduced example health stories prior to elicitation and simplified the editing interface.

Rationale: Multiple participants expressed uncertainty about how much detail to include and found the editing interface overwhelming.

Iteration 3 ($n = 5$): We adjusted the InfoBox styling to a pill shape and color-matched temporal markers to their boxes. We also refined the elicitation prompt to encourage inclusion of temporal information.

Rationale: Multiple participants were misinterpreting the time encoding and confused by the lack of temporal detail.

6.3 Stage 3: Patient Summative Evaluation

We report findings from the final 15 summative evaluations.

6.3.1 Data Parsing

Participants found freeform text input natural and easy to use, supporting DG-E by lowering the barrier to constructing health stories. Parsing was generally effective at extracting Events and associated attributes.

> *(PT33) "I like the free-form approach, because I appreciated I could just type, and then letting the AI go through and filter out the text itself and make decisions. . . I liked that a lot more than having to go through [the event panel]. . . "*

However, some confusion remained around distinctions between earlier Events and the Past Segment, partly due to occasional parsing errors.

6.3.2 Data Abstraction

Participants reported that the visualization supported recall and organization of past experiences, aligning with DG-E. The inclusion of Life Events was particularly valuable for contextualizing medical histories.

> *(PT16) "Especially if I wanted them to know more extensive about my medical history and things I'd gone through and life events, I think that'd be helpful."*

6.3.3 Grouping and Layout

The layout accommodated variation in event density and temporal distribution, supporting both DG-E and DG-C by structuring patient narratives while preserving their inherent variability. Participants interpreted temporal groupings without requiring precise timestamps, suggesting alignment with how they conceptualize their histories.

6.3.4 Visual Encoding

Participants described the visualization as supporting self-advocacy and improving communication with clinicians, directly supporting DG-C.

> *(PT32) "I think sometimes it can be hard when you're seeing a new doctor, because you're like, 'Here's where I currently am, but here's all the history and how we got here,' and that can get kind of brushed over sometimes. So to see it all visualized in the same place, I think would help get them up to speed a little bit faster without feeling like a big burden on myself as the patient."*

They also valued the ability to view their experiences holistically.

> *(PT15) "I think this is nice to see as a patient, how you view what's happening with your body and other health aspects."*

6.4 Stage 4: Clinician Formative Review

We conducted three 60-minute semi-structured interviews with clinicians ($n = 3$) from our project partner's network.

Clinicians reviewed the patient-generated visualizations, regenerated using the most recent styling iteration, with minimal context to simulate real clinical encounters, followed by think-aloud interpretation and guided discussion.

6.4.1 Data Abstraction

Clinicians found the abstraction aligned with their needs and emphasized the importance of Life Events, supporting DG-C by enabling a more complete understanding of patient context.

> *(CT2, on if the inclusion of Life Events is important) "Oh, absolutely. I see those as being the precursors that a lot of clinicians aren't looking for."*
>
> *(CT2) "One of the things that often gets missed by clinicians is when they're not seeing the whole history."*

6.4.2 Grouping and Layout

Clinicians reported that visualizations were easy to scan and supported rapid identification of *information scents* [37], aligning with DG-C.

> *(CT1) "In a typical summary, it's very hard to piece together what happened when. Timeline is always a really hard thing to piece together, so having a visual depiction like this is really helpful. I feel like that's always been a limitation on a lot of EMRs, where everything is documented in just, like, blocks of text with timestamps. "*

6.4.3 Visual Encoding

Clinicians noted that the visualization supported a broader understanding of the patient beyond clinical records, directly supporting DG-C.

> *(CT1) "It gives you a view not only of their medical history, but also of them as a person."*

They also described its usefulness for assessing the level of patient engagement with care.

> *(CT1) "This kind of just means that they're on top of their own health."*

Based on clinician feedback, we made very minor styling adjustments to improve the clarity of hierarchical grouping by strengthening visual boundaries between levels of Concern Groups.

7 Discussion

Our findings highlight the importance of supporting both elicitation (DG-E) and communication (DG-C) in patient-generated health stories. Across evaluations, narrative-first input enabled patients to construct representations that reflect their own understanding of their health, while structured visualizations made these representations interpretable in clinical contexts.

These promising outcomes have motivated our project partner to explore integrating the system into their environment, which would enable more extensive evaluation within real clinical workflows.

7.1 Elicitation, Autonomy, and Holistic Understanding

HealthTale's ability to support elicitation (DG-E) is a crucial first step: patients must first construct a coherent account of their health before it can be effectively communicated. Our findings highlight that enabling patients to externalize their experiences in a structured yet flexible way helps support both reflection and communication.

Participants consistently described HealthTale as a tool for self-advocacy. Many noted that it is difficult to convey the full extent of their experiences during clinical encounters, particularly when histories are long, complex, or fragmented across multiple providers. By constructing a visual representation of their health story, patients externalized patterns, duration, and severity in ways that are difficult to communicate verbally. This externalization shifts the burden of recall and explanation from real-time conversation to pre-constructed representation, enabling patients to arrive at encounters better prepared to communicate their experiences.

Participants also emphasized the importance of maintaining ownership over their health narrative. Unlike EMRs, where patients are often uncertain what information clinicians can see or how they interpret it, HealthTale allows patients to curate and present a complete account of their experiences. It supports a shift from passive reporting to active authorship, where patients can ensure that they include and communicate relevant context. Importantly, this authorship is not only about completeness, but about framing. Patients are able to decide what is important to tell and how it is told.

Surprisingly, while HealthTale supports editing and refinement, participants engaged in less curation than we anticipated. Past work from ten years ago on curating freeform text into visual timelines emphasized the need of iterative user correction of imperfect natural language processing (NLP) results [15]. However, in our current studies, we found that users rarely made substantial changes to the automatically generated visualization, suggesting that the initial structuring was generally sufficient for their needs. Across datasets, we observed relatively few parsing errors, 17/320 events from Reddit, 6/345 from the elicitation sessions, and 18/425 from the patient testing, with a total of 41/1090 misparced events, indicating generally robust performance. Although these results are generally a positive sign that NLP has passed a crucial usability threshold, this limited engagement with curation introduces a challenge: when errors occur, they often go uncorrected. For example, we observed cases where Events were incorrectly placed into the Past segment despite containing temporal signals that should place them in a Temporal Cluster on the timeline, yet participants did not notice or adjust these misplacements.

An outcome that we found especially compelling is that from these visualizations, clinicians were able to infer clinically relevant aspects of the patient's personality that were richer than straightforward medical information such as diagnoses and timelines. Examples mentioned by the clinicians were assessing whether a patient was likely to adhere to a stringent treatment regimen, whether patients were symptom- or treatment-focused, and how well patients understood their own medical condition. These inferences were not only driven by the presence of contextual information, but by what patients chose to include and how they structured it. Patterns such as frequent provider visits, detailed tracking, or emphasis on certain types of Events signaled how engaged, attentive, or systematic patients were in managing their health. Participants' selections and organization of Events revealed personal priorities, implicit reasoning, and approaches to care that are not well captured in EMRs. This information is not extraneous; it provides critical insight into how patients engage with and manage their health, highlighting the need for tools that preserve and make these signals interpretable in clinical contexts.

Our findings also surface a tension between patient-authored narratives and structured clinical data, suggesting a potential role for integration with existing systems. While HealthTale prioritizes patient-authored narratives, selectively incorporating structured information, such as known diagnoses or timestamps from EMRs, could help anchor Events temporally and reduce misclassification. However, we must integrate such data carefully. Over-integration risks shifting the system away from a patient-centered narrative toward a clinician-centered record. Instead, EMR data may be most valuable as a scaffolding mechanism during elicitation, supporting accuracy while preserving patient control over interpretation and inclusion.

7.2 Communicating, Shared Understanding, and Efficiency

HealthTale's ability to support communication (DG-C) allows clinicians to more rapidly interpret and act on patient information during time-constrained encounters.

From a clinical perspective, the visualization supports rapid orientation and shared understanding. Clinicians described using the timeline to get a high-level understanding at the beginning of an encounter, enabling them to quickly identify relevant Events and areas for further inquiry. This ability to establish a "lay of the land" is particularly valuable in time-constrained settings, where clinicians must quickly form a mental model of a patient's history.

The timeline structure also provides a shared reference point for communication. Clinicians noted that they could point to specific Events or time periods and ask patients to elaborate, supporting more targeted and efficient conversations. Rather than reconstructing a patient's history through questioning alone, the visualization enables a more collaborative interaction, where both patient and clinician can reference the same external representation. This approach reduces ambiguity and helps align mental models between the two parties.

Although HealthTale provides filtering and collapsible track functionality that could be used to reduce visual complexity, patients consistently preferred to keep all information visible in the static artifact they would use during clinical encounters. Participants stated that even details they perceived as less relevant might be important to the clinician, and thus favored presenting a complete view and selectively discussing key points rather than pre-filtering the representation. These decisions suggests that completeness, rather than minimalism, is critical in supporting effective communication.

Importantly, the visualization supports a more holistic understanding of the patient. By including Life Events alongside clinical information, clinicians were able to interpret health trajectories in context, such as identifying stressors or environmental factors that may influence outcomes.

Again, the potential of tighter integration between HealthTale and existing clinical systems presents both an opportunity and a challenge. EMR data could provide temporal anchors or validation signals that improve the reliability of the visualization, helping clinicians trust the representation as a summary of the patient's history. At the same time, clinicians expressed that the value of HealthTale lies in its ability to surface information not typically captured in EMRs. As such, the goal is not to merge these systems into a single representation, but to allow them to complement one another, where EMRs provide structured, clinically validated data, and HealthTale provides contextualized, patient-authored narratives.

Together, these findings suggest that structuring patient-generated narratives can help bridge the gap between patient and clinician mental models. By supporting both expressive input and interpretable output, HealthTale enables patients to communicate their experiences more effectively while allowing clinicians to engage with those experiences in a structured and efficient manner.

7.3 Implications of LLM-Supported Data Abstractions

Another notable insight that arose from our work is in how LLMs enable a shift in how visualization systems acquire and structure data. Rather than requiring users to conform to predefined schemas, systems can now accept freeform input and extract structured representations from how people naturally describe their experiences. This fluidity can lower the barrier to data entry and makes it possible to capture forms of data that were previously difficult to formalize, particularly those that are narrative, contextual, or loosely specified.

This shift places new emphasis on the design of data abstractions. As users provide input in their own words, the resulting data is inherently ambiguous, incomplete, and unevenly specified. Our data abstraction reflects this reality by explicitly accommodating imprecision and incorporating non-seemingly relevant context such as Life Events. Rather than enforcing strict standardization, the abstraction preserves how individuals express and structure their experiences, while still enabling organization and interpretation.

More broadly, this shift suggests a potential transition away from rigid, precision-oriented data abstractions toward more flexible representations that can accommodate the variability of human expression. In this paradigm, the role of user-generated narrative visualization systems is not only to display structured data, but to mediate between ambiguous, user-generated input and interpretable representations. While this paradigm introduces challenges, such as less transparency between the input and output, it also creates opportunities to design systems that surface uncertainty, support refinement, and better align with how people naturally think and communicate.

Although the explorations we report here occur solely in the context of health stories, these implications do extend to other domains where user-generated, narrative data is used. As LLM-supported pipelines become more common, the need for abstractions that balance flexibility with interpretability will become increasingly important.

7.4 Limitations and Future Work

This work has several limitations. First, although we conducted many rounds of evaluation, the system has not yet been evaluated in a full clinical setting. Participants created their health stories within a study context, and several noted that they would likely include more detailed information when preparing for an actual appointment. As a result, our findings may underestimate the richness and density of health stories in practice.

Also, while HealthTale is designed to support both the elicitation and communication of health stories, our validation to date primarily focuses on the elicitation process. Our findings show that patients can effectively construct structured representations and benefit from recall, organization, and self-advocacy, with initial evidence that these representations support communication. Future work should more directly evaluate how these representations are used in real clinician–patient interactions and how they influence communication, decision-making, and shared understanding.

Moreover, clinicians were recruited from our project partner's clinical team. While this approach allowed us easy access to domain-relevant feedback, these clinicians may be more technologically inclined and familiar with the broader project context than the general population of healthcare providers.

Additionally, future work should explore how patient-generated narratives can be integrated with clinical systems in a way that supports both accuracy and expressiveness. While our work focuses on initial clinical encounters, EMRs play a critical role in long-term record maintenance. An important direction is determining how structured clinical data can be selectively incorporated to support temporal grounding and continuity while preserving patient authorship and contextual richness, alongside developing grouping and layout strategies that scale to larger, continuously curated health stories.

8 Conclusion

We present HealthTale, a patient-centric health story visualization system that supports elicitation and communication of patient-generated narratives. We introduce a data abstraction that models health stories as

Events organized across multiple dimensions, capturing both clinical information and ambiguous lived experience, grounded in a multi-stage qualitative investigation.

Through evaluation with patients and clinicians, we demonstrate that structuring health stories into visual representations can support patient recall, organization, and self-advocacy, while enabling clinicians to more quickly interpret patient histories and develop a shared understanding. These findings highlight the value of patient-generated narrative data as a complementary source of information within clinical contexts.

Overall, this work suggests that tools that support patients in creating and communicating their health stories offer a promising approach to bridging the gaps between patient and clinician perspectives, enabling more efficient, contextualized, and patient-centered care.

9 Supplementary Materials

Supplementary materials can be found at https://osf.io/t75qn/overview?view_only=e3476fba26094f90918d9569a22751c3. We provide the scripts and protocols for all human-subjects studies and the demographics of the participants. We also provide the transcripts of the early patient roleplay interviews. We provide the health story artifacts of the written elicitation sessions and the collected Reddit posts, the results of visualizing these written stories in the final version of HealthTale, and all visualization results from the evaluation sessions where patients directly used HealthTale. We also provide the JSON datasets with parsed Events corresponding to all visualization results.

We also provide the intermediate analysis artifacts of structured decompositions of the Reddit posts and elicitation session results, and our thematic analysis of the patient and clinician interviews. We provide the LLM parser prompts used in HealthTale, a more detailed version of the grouping and layout algorithm pseudocode, and a complete list of all cases where the parser incorrectly categorized events in the summative evaluation sessions. Finally, we have a PDF and video walkthrough to show the look and feel of a HealthTale usage session.

References

[1] Anthropic. Claude sonnet 4.6. https://www.anthropic.com/claude, 2025. Large language model. 6, 7

[2] R. Bade, S. Schlechtweg, and S. Miksch. Connecting time-oriented data and information to a coherent interactive visualization. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems (CHI)*, pp. 105–112. ACM, 2004. doi: 10.1145/985692.985706 2

[3] O. Bhattacharyya, K. Mossman, L. Gustafsson, and E. C. Schneider. Using human-centered design to build a digital health advisor for patients with complex needs: Persona and prototype development. *Journal of Medical Internet Research*, 21(5):e10318, 2019. doi: 10.2196/10318 2

[4] R. Campbell, A. Ju, M. T. King, and C. Rutherford. Perceived benefits and limitations of using patient-reported outcome measures in clinical practice with individual patients: a systematic review of qualitative studies. *Quality of Life Research*, 31(6):1597–1620, 2022. doi: 10.1007/s11136-021-03003-z 2

[5] S. Canali, V. Schiaffonati, and A. Aliverti. Challenges and recommendations for wearable devices in digital health: Data quality, interoperability, health equity, fairness. *PLOS digital health*, 1(10):e0000104, 2022. doi: 10.1371/journal.pdig.0000104 2

[6] S. Carpendale, A. Thudt, C. Perin, and W. Willett. Subjectivity in personal storytelling with visualization. *Information Design Journal*, 23(1):48–64, Jan 2017. doi: 10.1075/idj.23.1.07thu 2

[7] R. Charon. Narrative medicine: A model for empathy, reflection, profession, and trust. *Annals of Internal Medicine*, 135(10):930–934, 2001. doi: 10.7326/0003-4819-135-10-200111200-00022 1

[8] E. K. Choe, N. B. Lee, B. Lee, W. Pratt, and J. A. Kientz. Understanding quantified-selfers' practices in collecting and exploring personal data. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems (CHI)*, pp. 1143–1152. Association for Computing Machinery, New York, NY, 2014. doi: 10.1145/2556288.2557372 2

[9] S. Detmar, N. K. Aaronson, L. Wever, M. Muller, and J. Schornagel. How are you feeling? who wants to know? patients' and oncologists' preferences for discussing health-related quality-of-life issues. *Journal of Clinical Oncology*, 18(18):3295–3301, 2000. doi: 10.1200/JCO.2000.18.18.3295 2

[10] P. Dodson, A. M. Haase, M. Jeffreys, and C. Hales. Capturing patient experiences of care with digital technology to improve service delivery and quality of care: A scoping review. *Digital Health*, 10:20552076241282900, 2024. doi: 10.1001/jamanetworkopen.2023.21746 2

[11] K. Esmail, K. Nanji, and S. Ziai. Evaluation of the effectiveness of ophthalmology emergency clinic intake forms. *University of Ottawa Journal of Medicine*, 10(2):42–46, 2021. doi: 10.18192/uojm.v10i2.4851 2

[12] M. Ester, H.-P. Kriegel, J. Sander, and X. Xu. A density-based algorithm for discovering clusters in large spatial databases with noise. In *Proceedings of the 2nd International Conference on Knowledge Discovery and Data Mining (KDD)*, pp. 226–231, 1996. 6

[13] S. Faisal, A. Blandford, and H. W. Potts. Making sense of personal health information: challenges for information visualization. *Health Informatics Journal*, 19(3):198–217, 2013. doi: 10.1177/1460458212465213 1, 2

[14] A. Figueiras. Narrative visualization: A case study of how to incorporate narrative elements in existing visualizations. In *2014 18th International Conference on Information Visualisation*, pp. 46–52. IEEE, Paris, France, 2014. doi: 10.1109/IV.2014.79 2

[15] J. Fulda, M. Brehmer, and T. Munzner. TimeLineCurator: Interactive authoring of visual timelines from unstructured text. *IEEE Transactions on Visualization and Computer Graphics*, 22(1):300–309, 2016. doi: 10.1109/TVCG.2015.2467531 3, 8

[16] K. J. Gilmore, I. Corazza, L. Coletta, and S. Allin. The uses of patient reported experience measures in health systems: A systematic narrative review. *Health Policy*, 128:1–10, 2023. doi: 10.1016/j.healthpol.2022.07.008 2

[17] J. M. Hall and J. Powell. Understanding the person through narrative. *Nursing research and practice*, 2011(1):293837, 2011. doi: 10.1155/2011/293837 1

[18] D. Herrmann. Reporting current, past, and changed health status: what we know about distortion. *Medical Care*, 33(4):AS89–AS94, 1995. 2

[19] E. Hickmann, P. Richter, and H. Schlieter. All together now–patient engagement, patient empowerment, and associated terms in personal healthcare. *BMC Health Services Research*, 22(1):1116, 2022. doi: 10.1186/s12913-022-08501-5 1, 2

[20] T. Higgins, E. Larson, and R. Schnall. Unraveling the meaning of patient engagement: a concept analysis. *Patient Education and Counseling*, 100(1):30–36, 2017. doi: 10.1016/j.pec.2016.09.002 2

[21] J. S. Hirsch, J. S. Tanenbaum, S. L. Gorman, C. Liu, E. Schmitz, D. Hashorva et al. Harvest: A longitudinal patient record summarizer. *Journal of the American Medical Informatics Association*, 22(2):263–274, 2015. doi: 10.1136/amiajnl-2014-002945 2

[22] D. Huang, M. Tory, B. A. Aseniero, L. Bartram, S. Bateman, S. Carpendale et al. Personal visualization and personal visual analytics. *IEEE Transactions on Visualization and Computer Graphics*, 21(3):420–433, 2015. doi: 10.1109/TVCG.2014.2359887 3

[23] J. S. Hudson et al. Outcomes of using an electronic anesthesia-focused electronic intake form. *Journal of PeriAnesthesia Nursing*, 40(4):e62–e63, 2025. doi: 10.1016/j.jopan.2025.05.078 2

[24] J. A. Kientz, R. I. Arriaga, and G. D. Abowd. Baby steps: evaluation of a system to support record-keeping for parents of young children. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems (CHI)*, pp. 1713–1722, 2009. doi: 10.1145/1518701.1518965 2

[25] N. W. Kim, B. Bach, N. Kerracher, S. Drucker, D. Wigdor, and S. Carpendale. Datatoon: Drawing dynamic network comics with pen + touch interaction. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems (CHI)*, pp. 1–12, 2019. doi: 10.1145/3290605.3300657 3

[26] Y.-S. Kim, B. Lee, S. Drucker, and N. Elmqvist. Inking your insights: Investigating digital externalization behaviors during data analysis. In *Proceedings of the ACM International Conference on Interactive Surfaces and Spaces (ISS)*, pp. 255–267, 2019. doi: 10.1145/3343055.3359706 3

[27] Y.-S. Kim, K. Reinecke, and J. Hullman. Explaining the gap: Visualizing one's predictions improves recall and comprehension of data. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems (CHI)*, pp. 1375–1386. Association for Computing Machinery, 2017. doi: 10.1145/3025453.3025592 2

[28] H.-K. Kong and K. Karahalios. Addressing cognitive and emotional barriers in parent-clinician communication through behavioral visualization webtools. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems (CHI)*, pp. 1–12. ACM, 2020. doi: 10.1145/3313831.3376687 2

[29] R. Kozinets. *Netnography: The essential guide to qualitative social media research*. SAGE, 3rd ed., 2020. 4

[30] S. Lagan, A. Ramakrishnan, E. Lamont, et al. Digital health developments and drawbacks: a review and analysis of top-returned apps for bipolar disorder. *International Journal of Bipolar Disorders*, 8(39), 2020. doi: 10.1186/s40345-020-00202-4 2

[31] K. O. Leslie and J. Rosai. Standardization of the surgical pathology report: formats, templates, and synoptic reports. *Seminars in Diagnostic Pathology*, 11(4):253–257, 1994. 2

[32] I. Li, A. K. Dey, and J. Forlizzi. Understanding my data, myself: Supporting self-reflection with ubicomp technologies. In *Proceedings of the 13th International Conference on Ubiquitous Computing*, pp. 405–414. Association for Computing Machinery, 2011. doi: 10.1145/2030112.2030166 2, 3

[33] Z. Liang, B. Ploderer, W. Liu, and T. Nagel. Sleepexplorer: A visualization tool to make sense of correlations between personal sleep data and contextual factors. *Personal and Ubiquitous Computing*, 20(6):985–1000, 2016. doi: 10.1007/s00779-016-0966-9 3

[34] K. Manalili, M. J. Santana, and I. P. in Clinical Practice Implementation Science Work Group. Using implementation science to inform the integration of electronic patient-reported experience measures (eprems) into healthcare quality improvement: description of a theory-based application in primary care. *Quality of Life Research*, 30(11):3073–3084, 2021. doi: 10.1007/s11136-020-02588-1 2

[35] R. Norouzinia, M. Aghabarari, M. Shiri, M. Karimi, and E. Samami. Communication barriers perceived by nurses and patients. *Global Journal of Health Science*, 8(6):65, 2015. doi: 10.5539/gjhs.v8n6p65 2

[36] A. Offenwanger, M. Brehmer, F. Chevalier, and T. Tsandilas. Timesplines: Sketch-based authoring of flexible and idiosyncratic timelines. *IEEE Transactions on Visualization and Computer Graphics*, 30(1):34–44, 2024. doi: 10.1109/TVCG.2023.3326933 3

[37] P. Pirolli, S. K. Card, and M. M. Van Der Wege. The effect of information scent on searching information: visualizations of large tree structures. In *Proceedings of the Working Conference on Advanced Visual Interfaces*, pp. 161–172. Association for Computing Machinery, New York, NY, USA, 2000. doi: 10.1145/345513.345304 8

[38] C. Plaisant, B. Milash, A. Rose, S. Widoff, and B. Shneiderman. LifeLines: visualizing personal histories. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems (CHI)*, pp. 221–227. Association for Computing Machinery, New York, NY, 1996. 2

[39] F. Rajabiyazdi, C. Perin, L. Oehlberg, and S. Carpendale. Communicating patient health data: A wicked problem. *IEEE Computer Graphics and Applications*, 41(6):179–186, 2021. doi: 10.1109/MCG.2021.3112845 1, 2

[40] F. Rajabiyazdi, C. Perin, J. Vermeulen, H. MacLeod, D. Gromala, and S. Carpendale. Differences that matter: In-clinic communication challenges. In *Proceedings of the 11th EAI International Conference on Pervasive Computing Technologies for Healthcare*, pp. 251–260. Association for Computing Machinery, New York, NY, 2017. doi: 10.1145/3154862.3154885 2

[41] A. Rapp and F. Cena. Personal informatics for everyday life: How users without prior self-tracking experience engage with personal data. *International Journal of Human-Computer Studies*, 94:1–17, 2016. doi: 10.1016/j.ijhcs.2016.05.006 2

[42] N. Rostamzadeh, S. S. Abdullah, and K. Sedig. Data-driven activities involving electronic health records: an activity and task analysis framework for interactive visualization tools. *Multimodal Technologies and Interaction*, 4(1):7, 2020. doi: 10.3390/mti4010007 2

[43] H. Ryu et al. "you can see the connections": Facilitating visualization of care priorities in people living with multiple chronic health conditions. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems (CHI)*, pp. 1–17. ACM, 2023. doi: 10.1145/3544548.3580916 2

[44] B. Schaad, C. Bourquin, F. Bornet, T. Currat, M. Saraga, F. Panese et al. Dissatisfaction of hospital patients, their relatives, and friends: analysis of accounts collected in a complaints center. *Patient education and counseling*, 98(6):771–776, 2015. doi: 10.1016/j.pec.2015.02.019 2

[45] E. Segel and J. Heer. Narrative visualization: Telling stories with data. *IEEE Transactions on Visualization and Computer Graphics*, 16(6):1139–1148, Nov-Dec 2010. doi: 10.1109/TVCG.2010.179 2

[46] K. Sepehri, L. Holsti, S. Niasati, V. Chan, and K. E. Maclean. Beyond the bulging binder: Family-centered design of a digital health information management system for caregivers of children living with health complexity. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems (CHI)*, pp. 1–19. Association for Computing Machinery, New York, NY, 2023. doi: 10.1145/3544548.3581459 2

[47] B. K. Smith, J. Frost, M. Albayrak, and R. Sudhakar. Integrating glucometers and digital photography as experience capture tools to enhance patient understanding and communication of diabetes self-management practices. *Personal and Ubiquitous Computing*, 11(4):273–286, 2007. doi: 10.1007/s00779-006-0087-2 2

[48] M. Smuck, C. A. Odonkor, J. K. Wilt, et al. The emerging clinical role of wearables: factors for successful implementation in healthcare. *npj Digital Medicine*, 4(45), 2021. doi: 10.1038/s41746-021-00418-3 2

[49] M. A. Stewart. Effective physician-patient communication and health outcomes: a review. *CMAJ: Canadian Medical Association Journal*, 152(9):1423, 1995. 2

[50] R. L. Street Jr, G. Makoul, N. K. Arora, and R. M. Epstein. How does communication heal? pathways linking clinician–patient communication to health outcomes. *Patient education and counseling*, 74(3):295–301, 2009. doi: 10.1016/j.pec.2008.11.015 2

[51] N. Sultanum, F. Naeem, M. Brudno, and F. Chevalier. Chartwalk: Navigating large collections of text notes in electronic health records for clinical chart review. *IEEE Transactions on Visualization and Computer Graphics*, 29(1):1244–1254, 2022. doi: 10.1109/TVCG.2022.3209444 2

[52] P. N. Valenstein. Formatting pathology reports: applying four design principles to improve communication and patient safety. *Archives of Pathology & Laboratory Medicine*, 132(1):84–94, 2008. doi: 10.5858/2008-132-84-FPRAFD 2

[53] K. Wongsuphasawat, J. A. Guerra Gómez, C. Plaisant, T. D. Wang, M. Taieb-Maimon, and B. Shneiderman. Lifeflow: Visualizing an overview of event sequences. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems (CHI)*, pp. 1747–1756. ACM, 2011. doi: 10.1145/1978942.1979196 2

[54] R. Zachariae, C. G. Pedersen, A. B. Jensen, E. Ehrnrooth, P. B. Rossen, and H. von der Maase. Association of perceived physician communication style with patient satisfaction, distress, cancer-related self-efficacy, and perceived control over the disease. *British Journal of Cancer*, 88(5):658–665, 2003. doi: 10.1038/sj.bjc.6600798 2

[55] H. Zhu, J. Colgan, M. Reddy, and E. K. Choe. Sharing patient-generated data in clinical practices: An interview study. In *AMIA Annual Symposium Proceedings*, vol. 2016, p. 1303, 2017. 2

[56] K. B. H. Zolnierek and M. R. DiMatteo. Physician communication and patient adherence to treatment: a meta-analysis. *Medical care*, 47(8):826–834, 2009. doi: 10.1097/MLR.0b013e31819a5acc 2