Patient trajectory visualization for FHIR healthcare data: A use case on melanoma patients

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Abstract

Fast Healthcare Interoperability Resources (FHIR) is gaining popularity as a standard framework for the exchange of electronic health record (EHR) data. Despite the advantages of FHIR, it is difficult for clinicians to understand the data in EHR. To support clinicians in accessing data about a patient, we created a pipeline that extracts, transforms, and visualizes patient data from FHIR. We employ a web-based timeline visualization that shows all clinical data recorded for the patient over their disease trajectory. This can help clinicians to use the patient data more efficiently and to get a clear picture of the patient's disease progress and physical condition more quickly, which could help them to develop the best treatment plan for their patients. The source code with an example synthetic, but realistic patient is available at https://github.com/rtg-wispermed/Patient_trajectory_public.

Keywords

Clinical data visualization, Electronic Health Records, Patient history visualization, FHIR

1. Introduction

Since the enactment of the Health Information Technology for Economic and Clinical Health (HITECH) Act of 2009 [1], the adoption of electronic health records (EHR) in hospitals has grown rapidly [2]. The EHR contains data for each patient, including diagnoses, lab tests and results, prescriptions, clinical notes and radiology images [1].

FHIR[1] (Fast Healthcare Interoperability Resource) is a standard for health care data exchange. While FHIR allows for comprehensible capture of patient information, the resulting structure is rather complex and difficult to comprehend. Thus, access to patient data essentially requires

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[1]http://www.hl7.org/fhir, last accessed 01.06.2023

tools that i) process FHIR data, ii) select and transform it for the use case at hand, and iii) display the relevant data in a user-friendly manner.

Visualizations allow users to understand information more effectively, thereby improving judgment and decision-making performance [3]. This is also true for healthcare data, where an efficient display of information is critical for clinicians to understand patient histories [4]. There has been a significant amount of research work on healthcare data visualization [5, 6]. Among them, Cousins and Kahn [7] first introduced the concept of graphical clinical timelines; the LifeLines project [8, 9] and the Health Timeline project [4] further developed the idea of visualizing patient data on the basis of timelines. And in a later evaluation study based on the Health Timeline project [10], it was demonstrated that visualizing clinical data chronologically can effectively help physicians improve their understanding of clinical data and help them identify complex patterns from the data. Prior work on visualizations mostly focused on the design of the presentation and graphics of the data visualization and did not support the pipeline to FHIR encoded EHR data.

In this paper, we present a proof-of-concept for a visualization pipeline that obtains patient data from EHR in FHIR and apply it to a use case of melanoma patients. In place of the long-term and complex development of visualization tools, we utilize the publicly available, web-based charting framework AnyChart[2].

2. Approach

Our pipeline consists of four steps (cf. Figure 1): i) patient selection, ii) relevance judgment of attributes by domain experts, iii) extraction of relevant attributes, and iv) visualization.

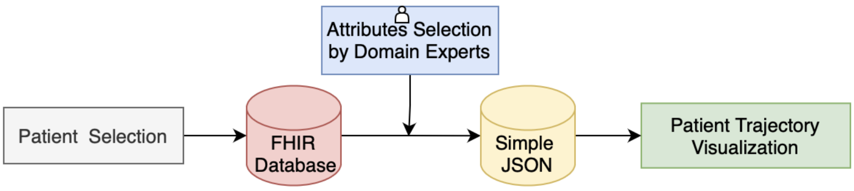

Figure 1: Pipeline. Patients are selected based on exclusion and inclusion criteria and exported to a temporary FHIR database. Based on expert judgments of attribute relevancy, the data is filtered and transformed to a simple JSON file, which is used as input for the patient trajectory visualization.

First, the **patient cohort of interest** is selected and exported from the hospital EHR database based on defined inclusion and exclusion criteria. This export is done using high-level FHIR APIs, such as FHIR-PYrate[3] or fhircrackr[4]. The primary stakeholder of our visualization are clinicians, each with specific information needs about their patients. EHRs contain comprehensive information about patients, including information that is not relevant for a first assessment. To **identify the relevant information** for the visualization, we let clinicians rate the available information. Clinicians rate each available attribute on a 3-point Likert scale (0: not important,

[2]https://github.com/AnyChart, last accessed 12.07.2023
[3]https://github.com/UMEssen/FHIR-PYrate, last accessed 07.06.2023
[4]https://github.com/POLAR-fhiR/fhircrackr, last accessed 07.06.2023

1: moderately important, 2: very important). We then selected the attributes that at least one clinician considered very important. In the whole process, domain experts only need to do the relevance judgment of attributes once for all the patients in one patient cohort.

The selected attributes are then **extracted from FHIR and transformed into a simple JSON file**. First, the resources were flattened, i.e. we changed the nested structure of the original FHIR resource such that each field in the newly transformed JSON only contains atomic values to make it easier readable and usable. Secondly, we removed unnecessary and redundant information based on the patient ID and date. Lastly, in cases where information stems from the same event but is distributed between multiple resources, the information is merged.

For the **visualization of the extracted attributes** as a timeline, we use the AnyChart JavaScript visualization library[2]. The AnyChart library provides interactive functionality designed specifically for temporal data and supports both, time point events (a specific point in time) and time range events. We map the patient information accordingly, e.g., a physical examination is encoded as a time point event, and a medication plan with start and end date to a time range event. AnyChart supports zoom, to adjust the time range showing either a global view or focusing on a particular time period only.

3. Use Case: Melanoma Patients

In this section, we will describe the application of our approach to a specific use case. Due to the confidentiality of patient data, we use a synthetic, but realistic patient to showcase the visualization.

We use the FHIR-based melanoma database from the University Hospital in Essen. As selection criteria, we used the primary tumor diagnosis to only include melanoma patients: `Condition.category = |C0677930 (Primary Neoplasm) AND Condition.code= C43.*`. Each file contains the complete tumor documentation for a patient and other relevant information (e.g. laboratory observations and progress notes). Overall, our cohort includes all possible patients with the start of treatment between 2001 and 2023, with the majority of the cases being from 2014 to 2023 (about 90%). In total, there are 1899 melanoma patients (46.18% female, 53.77% male) in the data set. The vast majority is from the North Rhine-Westphalia.

An example of the relevance judgment of patient attributes is shown in Table 1 (see Appendix A for the full list). Two experienced dermato-oncologists have rated the attributes based on the national guidelines for melanoma treatment[5]. We selected the attributes which at least one clinician rated as very important for inclusion in the patient trajectory visualization. An example of JSON output based on these selected attributes can be seen in Appendix B.

The visualization of the patient trajectory shows general patient information along with the timeline. Figure 2, top, shows the overview including all attributes selected in the relevance judgment step. It presents core diagnostic and treatment information for the patient. To further facilitate clinicians to select the information of interest without being distracted by other information, we also added a filter function, to show only one special attribute or one special combination of different attributes (cf. Figure 2, bottom).

[5]http://www.leitlinienprogrammonkologie.de/leitlinien/melanom, last accessed 31.08.2023

Table 1
Example relevance judgment of attributes (excerpt, translated to English)

Attributes	Clinician 1	Clinician 2	Included
	Careplan		
Time	2	1	✓
Type (very general: e.g., surgery, best supportive care, radiotherapy)	1	1	
Intention (palliative, curative)	2	2	✓
Category (specific, e.g. treatment of relapses)	2	1	✓
...			

Legend:
not important 0 0 moderately important 1 1 very important 2 2 ✓: selected

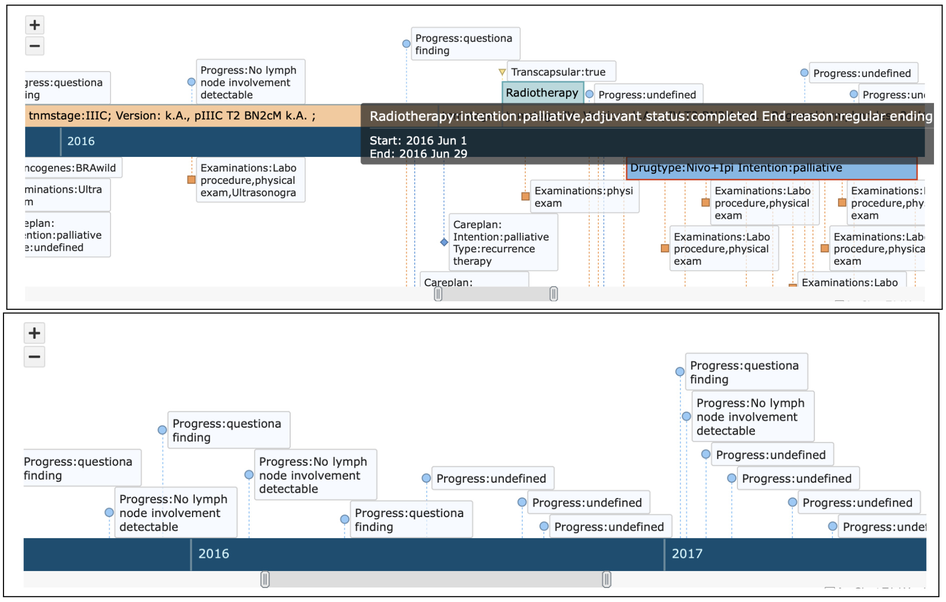

Figure 2: Timeline of an example patient showing the all selected out attributes (cropped due to space constraints). Bottom: Showing only disease progress. Patient meta information (name etc. omitted).

4. Summary

This work presents a method to visualize FHIR healthcare data as patient trajectory which aims to support clinicians in accessing information from EHR (available in FHIR) and in obtaining a comprehensive and concise picture of the patient's disease progress and physical condition. The overall framework is extensible and applicable to other patient cohorts and use cases. However it also has some potential limitations, e.g., relevant attributes might need to be updated due to the changing of guidelines of treatment and ICD versions, and the choice of web technology, some browsers may not support JavaScript. An evaluation of the usability, usefulness and impact of this visualization is planned for future work.

References

[1] G. S. Birkhead, M. Klompas, N. R. Shah, Uses of electronic health records for public health surveillance to advance public health, Annual review of public health 36 (2015) 345–359.

[2] J. Henry, Y. Pylypchuk, T. Searcy, V. Patel, et al., Adoption of electronic health record systems among us non-federal acute care hospitals: 2008–2015, ONC data brief 35 (2016) 2008–2015.

[3] K. Eberhard, The effects of visualization on judgment and decision-making: a systematic literature review, Management Review Quarterly 73 (2023) 167–214.

[4] A. A. Bui, D. R. Aberle, H. Kangarloo, Timeline: visualizing integrated patient records, IEEE Transactions on Information Technology in Biomedicine 11 (2007) 462–473.

[5] V. L. West, D. Borland, W. E. Hammond, Innovative information visualization of electronic health record data: a systematic review, Journal of the American Medical Informatics Association 22 (2015) 330–339.

[6] Q. Wang, R. S. Laramee, Ehr star: the state-of-the-art in interactive ehr visualization, in: Computer Graphics Forum, volume 41, Wiley Online Library, 2022, pp. 69–105.

[7] S. B. Cousins, M. G. Kahn, The visual display of temporal information, Artificial intelligence in medicine 3 (1991) 341–357.

[8] C. Plaisant, R. Mushlin, A. Snyder, J. Li, D. Heller, B. Shneiderman, Lifelines: using visualization to enhance navigation and analysis of patient records, in: The craft of information visualization, Elsevier, 2003, pp. 308–312.

[9] C. Cheng, Y. Shahar, A. Puerta, D. Stites, Navigation and visualization of abstractions of time-oriented clinical data, Section on Medical Informatics Technical Report No. SMI-97 688 (1997).

[10] A. Ledesma, N. Bidargaddi, J. Strobel, G. Schrader, H. Nieminen, I. Korhonen, M. Ermes, Health timeline: an insight-based study of a timeline visualization of clinical data, BMC medical informatics and decision making 19 (2019) 1–14.

A. Full List of Relevance Judgments

Table 2: Relevance judgment of all attributes (translated to English)

Attributes	Clinician 1	Clinician 2	Included
	PATIENT		
Gender	2	2	✓
Birth date	2	2	✓
Deceased time	2	2	✓
	CAREPLAN		
Time	2	1	✓
Type (very general: e.g., surgery, best supportive care, radiotherapy)	1	1	

Intention (palliative, curative)	2	2	✓
Category (specific, e.g., Treatment of relapses)	2	1	✓
Medication			
Name	2	2	✓
Start time	2	2	✓
End time	2	2	✓
Status (e.g., stopped/completed)	2	1	✓
Reason of status (e.g., Abort due to progress)	2	2	✓
Intention of Medication (e.g., Palliative / Curative)	2	2	✓
Quantity (how many times did they get the medication)	2	1	✓
Condition			
ICD Tumor and Location code	2	2	✓
Tumor Location on the body	1	1	
Multiple Locations	1	1	
L2Obs–Progression w.r.t Time	2	2	✓
Comorbidities	1	1	
Tumour stage			
Pathological TNM staging (pTNM)	2	2	✓
Version of pTNM	1	2	✓
T, N, M Stage separately (pTNM)	1	2	✓
Residual-State (pTNM)	0	1	
Sentinel Lymph nodes positive (pTNM)	2	2	✓
Sentinel Lymph nodes examined (pTNM)	1	1	
Regional Lymph nodes positive (pTNM)	2	1	✓
Regional Lymph nodes examined (pTNM)	1	1	
Clinical TNM staging (cTNM)	1	1	
Version of cTNM	1	1	
T, N, M Stage separately (cTNM)	1	1	
Oncogenes			
Results of genetic analysis, if genetic findings frequency and name of the mutation	2	2	✓
Progress			
Result of the regular check up (e.g., No tumor detection, Questionable findings, Progress, Decline, etc.)	2	2	✓
Procedures, Radiotherapy			
Intention (e.g., adjuvant, curative)	2	1	✓
Status (completed or not)	2	1	✓
Reason of status	2	1	✓

Details of on how it was performed(e.g., with Cyberknife)	2	1	✓
Procedures, Surgery			
Ops-Code (e.g., Code for removal of Lymph-Node)	1	1	
Residual state	1	1	
Procedures, Examinations			
Type of examination (e.g., Ultrasound)	2	2	✓
Reason for examinations (e.g., Toxicity Assessment)	1	1	
Primary properties			
Ulceration of primary	1	2	✓
Tumor thickness (in mm)	1	1	
Regression	0	0	
Re-excision	1	1	
Transcapsular (Capsular Breakthrough)	1	2	✓
Mitosis rate	1	1	
%PD1	1	1	
Metastases properties			
Location	2	1	✓
Proof (tumor detection, no tumor detection)	2	1	✓
Type of proof (e.g., Imaging)	2	1	✓

Legend:
0: Not important
1: Moderately important
2: Very important
✓: selected

B. Example JSON File

Example data extract from a synthetic, but realistic patient (excerpt due to space constraints)


```
{
    "patient_info": {
        "resourceType": "patient",
        "id": "01",
        "gender": "female",
        "birthDate": "1961-05-30",
        "deceasedDateTime": "2019-07-21"
    },
    "stages": [
```

```
        {
            "patid": "Patient/01",
            "dt_record": "2013-12",
            "cat_version": null,
            "tnm_stage": "III",
            "tstage": "2 B",
            "nstage": "0",
            "p_or_c": "p",
            "val_print": "Version: k.A., pIII T2 BN0M k.A. ",
            "dt_end": "2013-12-15"
        },
    ...
    ],
    "examinations": [
        {
            "patid": "Patient/01",
            "dt_record": "2014-02-06",
            "cat_examination_type": [
                "Laboratory procedure",
                "physical exam"
            ],
            "cat_reasons": [
                "Initial presentation",
                "Treatment planning"
            ]
        },
        ...
    ],
    "radiotherapy": [
        {
            "patid": "Patient/01",
            "dt_start": "2016-06",
            "dt_end": "2016-06-29",
            "cat_intention": [
                "palliative",
                "adjuvant"
            ],
            "cat_status": "completed",
            "cat_reason_end": "regular ending"
        },
      ...
    ],
    ...
}
```