# Task 1 of the CLEF eHealth Evaluation Lab 2014 Visual-Interactive Search and Exploration of eHealth Data

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**Abstract.** Discharge summaries serve a variety of aims, ranging from clinical care to legal purposes. They are also important tools in patient empowerment, but a patient's comprehension of the information is often suboptimal. Continuing in the tradition of focusing on automated approaches to increasing patient comprehension, The CLEFeHealth2014 lab tasked participants to visualize the information in discharge summaries while also providing connections to additional online information. Participants were provided with six cases containing a discharge summary, patient profile and information needs. Of fifty registrations, only the *FLPolytech team* completed all requirements related to the task. They augmented the discharge summary by linking to external resources, inserting structure related to timing of the information need (past, present future), enriching the content, i.e., with definitions, and providing meta-information, e.g., how to make future appointments. Four panellists evaluated the submission. Overall, they were positive about the enhancements, but all agreed that additional visualization could further improve the provided solution.

**Keywords:** Comprehension, Information Retrieval, Information Visualization, Evaluation, Medical Informatics, Patient Education, Records as Topic, Software Design, Test-set Generation, Text Classification, User-Computer Interface

**Contributor Statement:** HS, TS, GL, HSH, DK, LG, and LK designed the task and its evaluation methodology. Together with JN and GF, they developed the task description. LG and LK chose the six patient cases and extracted the respective subset from the CLEFeHealth2013 data. HS and DLM automatically de-identified discharge summaries of this subset by hand. HS, HH, TS, JN, and GL prepared initial example designs as a starting and inspiration point for participants. HS, TS, and GL led the task as a part of the CLEFeHealth2014 evaluation lab, chaired by LG and LK. HS drafted this paper and after this all authors expanded and revised it. All authors have read and approved the final version.

## 1 Introduction

*Discharge summaries* transfer information in health care services between working shifts and geographical locations. They are written or dictated by nurses, physicians, radiologists, specialists, therapists, or other clinicians responsible for patient care to describe the course of treatment, the status at release, and care plans. Their primary purpose is to support the care continuum as a handoff note between clinicians, but they also serve legal, financial, and administrative purposes.

However, patients, their next-of-kin, and other laypersons are likely to perceive the *readability* of discharge summaries as poor, in other words, have difficulties in understanding their content (Fig. 1) [1]. Improving the readability of these summaries can *empower* patients, providing partial control and mastery over health and care, leading to patients making better health/care decisions, being more independent from health care services, and decreasing the associated costs [2]). Specifically, supportive, patient-friendly, personalized language can help patients have an active role in their health care and make informed decisions. Making the right decisions depends on patients' access to the right information at the right time; therefore, it is crucial to provide patients with personalized and readable information about their health conditions for their empowerment.



Fig. 1. Summary of the CLEFeHealth2013 tasks and outcomes

The overall problem of the CLEFeHealth2013 Task 1: Visual-Interactive Search and Exploration of eHealth Data was to help patients (or their next-of-kin) with these

readability issues.<sup>1</sup> The CLEFeHealth2013 Tasks 1–3 developed and evaluated automated approaches for discharge summaries (see Section 2, and Fig. 1):

- 1. terminology standardization for medical diseases/disorders (e.g., *heartburn* as opposed to *gastroesophageal reflux disease*),
- 2. shorthand expansion (e.g., *heartburn* as opposed to GERD), and
- 3. text linkage with further information available on the Internet (e.g., care guidelines for heartburn).

With the 2014 Task 1, we challenged participants to design interactive visualizations that help patients better understand their discharge summaries and explore additional relevant documents in light of a large document corpus and their various facets in context.

As a *scenario*, assume that an English-speaking, discharged patient (or her next of kin) is in her home in the USA and wants to learn about her clinical treatment history and implications for future behavior, possible symptoms or developments, and situational awareness related to their own health and healthcare in general. That is, *target-ed users* were layperson patients (as opposed to clinical experts).

We asked participants to design an interactive visual representation of the discharge summary and potentially relevant documents available on the Internet. The goal of this tool was to provide an effective, usable, and trustworthy environment for navigating, exploring, and interpreting both the discharge summary and the Internet documents, as needed to promote understanding and informed decision-making. More precisely, the participants were challenged to provide a prototype that demonstrates the effectiveness of the proposed solutions. Although functioning prototypes were preferred, we also accepted paper, mock screenshots or other low-fidelity prototypes.

We assumed a standard application environment as given, including a networked desktop system and mobile device (e.g., smartphone or tablet). The challenge was structured into two different but connected tasks:

- *la: Discharge Resolution Challenge* and

### - 1b: Visual Exploration Challenge.

The participants could choose to work on these tasks separately, or address both together in an integrated task (i.e., *Grand Challenge*).

The rest of the paper is organized as follows: In Section 2, we justify the novelty of our task by reviewing related work and *evaluation labs* (a.k.a. shared tasks, challenges, or hackathons where participants' goal is to solve the same problem, typically using the same data set) for clinical text processing and information visualization. In Section 3, we introduce our data set and its access policy, detail our challenge, and specify our evaluation process for participant submissions. In Sections 4 and 5 respectively we present and discuss our results.

<sup>&</sup>lt;sup>1</sup> http://clefehealth2014.dcu.ie/task-1 (accessed 16 April 2014)

## 2 Related Work

In this section, we first describe previous evaluation labs for clinical text processing. Then, we continue to justify the novelty of this task by relating the first subsection with related evaluation labs and visual analysis of health-oriented data.

### 2.1 Evaluation Labs for Clinical Text Processing

*Language/text technologies* to generate, search, and analyze spoken or written natural, human language were already being recognized as ways to automate text analysis in health care in the 1970s [3, 4, 5, 6, 7]. However, their development and flow to health care services was – and still is – substantially hindered by the barriers of lack of access to shared data; insufficient common conventions and standards for data, techniques, and evaluations; inabilities to reproduce the results; limited collaboration; and lack of user-centricity [8]. Evaluation labs began addressing these barriers in the early 2000s [9].

The first evaluation labs related to clinical language were in the *Text REtrieval Conference* (TREC).<sup>2</sup> This on-going series of annual evaluation labs, conferences, and workshops was established in 1992 with its focus on information search. In 2000, the *TREC filtering track* considered user profiling to filter in only the relevant documents [10].<sup>3</sup> Its data set contained approximately 350,000 abstracts related to biomedical sciences over five years, manually created topics, and a topic set based on the standardized Medical Subject Headings (MeSH). In 2003–2007, the *TREC genomics track* organized annual shared tasks with problems ranging from ad-hoc search to classification, passage retrieval, and entity-based question answering [11].<sup>4</sup> Its data sets originated from biomedical papers and clinical reports. In 2011–2012, the *TREC medical records track* challenged the participants to develop search engines for identifying patient cohorts from clinical reports for recruitment as populations in comparative effectiveness studies [12].<sup>5</sup> Its data set consisted of de-identified clinical reports, searches that resemble eligibility criteria of clinical studies, and associated relevance assessments.

In 1997, a Japanese counterpart of TREC, called *NII Test Collection for Information Retrieval Systems* (NTCIR), was launched.<sup>6</sup> In 2013 and 2014, its *MedNLP track* considered clinical documents (i.e., simulated medical reports in Japanese) [13].<sup>7</sup> Tasks of this track included text de-identification in 2013; complaint/diagnosis extraction in 2013 and 2014; complaint/diagnosis normalization in 2014; and an open challenge, where participants were given the freedom to try to solve any other natural

<sup>&</sup>lt;sup>2</sup> http://trec.nist.gov/ (accessed 16 April 2014)

<sup>&</sup>lt;sup>3</sup> http://trec.nist.gov/data/filtering.html (accessed 16 April 2014)

<sup>&</sup>lt;sup>4</sup> http://ir.ohsu.edu/genomics/ (accessed 16 April 2014)

<sup>&</sup>lt;sup>5</sup> http://trec.nist.gov/data/medical.html (accessed 16 April 2014)

<sup>&</sup>lt;sup>6</sup> http://research.nii.ac.jp/ntcir/index-en.html (accessed 16 April 2014)

<sup>&</sup>lt;sup>7</sup> http://mednlp.jp/medistj-en (accessed 16 April 2014)

language processing (NLP) task on the clinical data set of the task in 2013 and 2014. In 2014, participant submissions are due by August 1.8

In 2000, the Conference and Labs of the Evaluation Forum (CLEF) began as a European counterpart of TREC.9 In 2005, ImageCLEFmed introduced annual tasks on accessing biomedical images in papers and on the Internet [14].<sup>10</sup> In 2005–2014, it targeted language-independent techniques for annotating images with concepts; multilingual and multimodal (i.e., images and text) information search; and automated form filling related to analyzing computed tomography scans. In 2013, the Question Answering for Machine Reading Evaluation (OA4MRE) track introduced a pilot task on machine reading on biomedical text about Alzheimer's disease and in 2014, QA4MRE organized a task on biomedical semantic indexing and question answering [15].<sup>11</sup> In 2012, CLEFeHealth was created as a new CLEF track dedicated to electronic clinical documents [16].<sup>12</sup> In 2012, it organized a workshop to prepare an evaluation lab and in 2013 and 2014 (called ShARe/CLEF eHealth), it ran both evaluation labs and workshops. The 2013 tasks aimed to improve patients' understanding of their clinical documents and consisted of three tasks: 1) disease/disorder extraction and normalization; 2) abbreviation/acronym normalization; and 3) information search on the Internet to address questions patients may have when reading their clinical records. The tasks used a subset of 300 de-identified clinical reports (i.e., discharge summaries together with electrocardiogram, echocardiogram, and radiology reports) in English from about 30,000 US intensive care patients and also used approximately one million web documents (predominantly health and medicine sites). In 2014, the data set was similar and the tasks included visual-interactive search and exploration – as described in this paper - together with revisions of the 2013 tasks 1 and 3 [17].

In 2006–2014, the *Informatics for Integrating Biology and the Bedside* (i2B2) considered clinical documents through its following seven evaluation labs [18]:<sup>13</sup> text deidentification and identification of smoking status in 2006; recognition of obesity and comorbidities in 2008; medication information extraction in 2009; concept, assertion, and relation recognition in 2010; co-reference analysis in 2011; temporal-relation analysis in 2012; and text de-identification and identification of risk factors for heart disease over time in 2014. Data sets for these labs originated from the USA, were in English, and included approximately 1,500 de-identified, expert-annotated discharge summaries.

In 2007 and 2011, the *Medical NLP Challenges* addressed automated diagnosis coding of radiology reports and classifying the emotions found in suicide notes [19]. <sup>14</sup> In 2007, its data set included nearly two thousand de-identified radiology reports in English from a US radiology department for children and in 2011, over a thousand suicide notes in English were used.

<sup>&</sup>lt;sup>8</sup> http://mednlp.jp/ntcir11/ (accessed 16 April 2014)

<sup>&</sup>lt;sup>9</sup> http://www.clef-initiative.eu/ (accessed 16 April 2014)

<sup>&</sup>lt;sup>10</sup> http://ir.ohsu.edu/image/ (accessed 16 April 2014)

<sup>&</sup>lt;sup>11</sup> http://nlp.uned.es/clef-qa/ (accessed 16 April 2014)

<sup>&</sup>lt;sup>12</sup> http://clefehealth2014.dcu.ie (accessed 16 April 2014)

<sup>&</sup>lt;sup>13</sup> https://www.i2b2.org/ (accessed 16 April 2014)

<sup>&</sup>lt;sup>14</sup> http://computationalmedicine.org/challenge/ (accessed 16 April 2014)

In 1998 through 2004, *Senseval Workshops* promoted system development for word sense disambiguation for thirteen different languages including English, Italian, Basque, Estonian, and Swedish. In 2007, Senseval transitioned to become *SemEval* shifting the focus on other semantic tasks such as semantic role labeling, information extraction, frame extraction, temporal annotation, etc. while continuing to address multilingual texts. In 2014, SemEval addressed unsupervised learning of disease/disorder annotations from the ShARe/CLEF eHealth 2013 clinical texts including 440 de-identified reports of four types – discharge summaries, electrocardiograms, echocardiograms, and radiology reports [20].<sup>15</sup> These reports were in English from the US.

### 2.2 Related Evaluation Labs and Visual Analysis of Health-Oriented Data

As described above, CLEFeHealth2013 is, to the best of our knowledge, the first evaluation lab dedicated to improving patients' understanding of their clinical documents using text processing and visual-interactive techniques. The novelty of the 2014 Task 1 described in this paper lies in combining this timely topic with promising techniques from the field of Information Visualization.

A number of related research challenges have considered visualization and analysis of health-oriented data before. In 2013, the *Health Design Challenge* had an evaluation lab aiming to make clinical documents more usable by and meaningful to patients, their families, and others who take care of them.<sup>16</sup> This design/visualization task attracted over 230 teams to participate. However, this challenge did not specifically address text documents or their processing. Furthermore, the challenge mainly aimed at static designs, where in context of our challenge, we aim at interactive approaches which allow users to query, navigate and explore the data using visual representations.

The international *VAST Challenge series* asks researchers to design and practically apply visual analysis systems that allow analyzing and understanding of large and complex data sets which are provided as part of the challenge definition. Typically, the challenge data contains unrevealed relationships and facts which need to be discovered by the participants, as part of the evaluation approach. The VAST Challenge has previously defined challenge data sets which relate to health-oriented problems.<sup>17</sup> Specifically, in the 2011 and 2010 challenges, analysis of epidemic spread scenarios has been proposed. Based on synthetic social media data and hospitalization records, the task was to characterize and identify possible root causes of hypothetical epidemic spreads.

Research in Information Visualization has previously addressed design of visualinteractive systems to help understand and relate clinical and health record data. One example work is the *LifeLines2* system, which allows comparison of categorical events (exemplified on electronic health record data) for ranking, summarizing, and

<sup>&</sup>lt;sup>15</sup> http://alt.qcri.org/semeval2014/task7/ (accessed 30 May 2014)

<sup>&</sup>lt;sup>16</sup> http://healthdesignchallenge.com (accessed 16 April 2014)

<sup>17</sup> http://www.cs.umd.edu/hcil/vastchallenge/ (accessed 30 May 2014)

comparing event series [21]. More works, which support analysis and exploration of electronic clinical documents have recently been surveyed in [22]. Many of these works are oriented towards expert use by physicians and clinical researchers, and less for layperson patient use. The latter is the focus of our lab definition.

A strong recent interest in the research of visualization and visual analysis of health-oriented data is also evident from a number of scientific workshops organized previously in conjunction with the *IEEE VIS conference*. These include the *Workshop on Visual Analytics in Healthcare*, which has started in 2011,<sup>18</sup> and the *Public Health's Wicked Problems: Can InfoVis Save Lives*? <sup>19</sup> Workshop.

## 3 Materials and Methods

In this section, we introduce our data set and its access policy, detail our challenge, and specify our evaluation process for participant submissions. In summary, we used both discharge summaries and relevant Internet documents; participants' task was to design an interactive visual representation of these data; and the evaluation process followed the standard peer-review practice and consisted of optional draft submission in March 2014, followed by final submission two months later.

### 3.1 Dataset

The input data provided to participants consists of *six carefully chosen cases* from the CLEFeHealth2013 data set [16]. Using the first case was mandatory for all participants and the other five cases were optional.

Each case consisted of a discharge summary, including the *disease/disorder spans* marked and mapped to *Systematized Nomenclature of Medicine Clinical Terms, Concept Unique Identifiers* (SNOMED-CT), and the *shorthand spans* marked and mapped to the *Unified Medical Language System* (UMLS). Each discharge summary was also associated with a profile (e.g., *A forty year old woman, who seeks information about her condition* for the mandatory case) to describe the patient, a narrative to describe her information need (e.g., *description of what type of disease hypothyroidism is*), a query to address this information need by searching the Internet documents, and the list of the documents that were judged as relevant to the query. Each query consisted of a description (e.g., *What is hypothyreoidism*) and title (e.g., *Hypothyreoidism*).

To access the data set on the *PhysioNetWorks* workspaces, the participants had to first register to CLEF2014 and agree to our data use agreement.<sup>20</sup> The dataset was accessible to authorized users from December, 2013. Participant access to these documents was facilitated by HS. The data set is to be opened for all registered PhysioNetWorks users in October 2014.

<sup>18</sup> http://www.visualanalyticshealthcare.org/ (accessed 30 May 2014)

<sup>&</sup>lt;sup>19</sup> http://www.cc.gatech.edu/gvu/ii/PublicHealthVis/ (accessed 30 May 2014)

<sup>&</sup>lt;sup>20</sup> https://physionet.org/works/CLEFeHealth2014Task1/ (accessed 16 April 2014)

### Case 1 (mandatory).

- 1. Patient profile: *This 55-year old woman with a chronic pancreatitis is worried that her condition is getting worse. She wants to know more about jaundice and her condition*
- 2. De-identified discharge summary, including the disease/disorder spans marked and mapped to SNOMED-CT, and the shorthand spans marked and mapped to UMLS (Fig. 2)
- 3. Information need: *chronic alcoholic induced pancreatitis and jaundice in connection with it*
- 4. Query (Fig. 3): is jaundice an indication that the pancreatitis has advanced
  - (a) Title: *chronic alcoholic induced pancreatitis and jaundice*
  - (b) 113 returned documents of which 26 are relevant

| 3873      19791      12345      DISCHARGE_SUMMARY      2019-01-31<br> 00:00:00.0  |  |  |  |
|---|--|--|--|
| Admission Date: [**2019-01-19**] Discharge Date: [**2019-01-31**]   |  |  |  |
| Date of Birth: [**1963-08-10**] Sex: F  |  |  |  |
| Service: SURGERY  |  |  |  |
| Allergies:<br>Sulfa (Sulfonamides)  |  |  |  |
| Attending:[**Attending Info 2145**]<br>Chief Complaint:<br>Abdominal Pain<br>Jaundice<br>Nausea/Vomiting  |  |  |  |
| Major Surgical or Invasive Procedure:<br>Small Bowel Resection; IOUS<br>Roux-en-Y Cholecysto-jejunostomy<br>Pseudocyst-Jejunosotmy<br>J-tube Placement  |  |  |  |
| History of Present Illness:<br>This 55-year-old lady has a history of chronic alcoholic-induced pancreatitis. She has had a pseudocyst problem in the<br>past that resolved over time and has previously had an open J tube placement in the last year for malnutrition during<br>this period.  |  |  |  |
| She recently presented with overt jaundice from bile duct obstruction and a history of many weeks of decline. She has<br>only lost 4 pounds over this period of time, but has been malnourished and unable to eat regular foods and has sustained<br>herself only on liquids because of gastric outlet obstruction. She was transferred to our care for assessment of her<br>biliary obstruction and thoughts of therapeutic approaches to this and the large pseudocyst that was identified that was<br>on the order of 10 x 10 cm in her mid- abdomen. When we assessed her CAT scan, it was clear that she had three problems.                                 |  |  |  |
| <ol> <li>Biliary obstruction from an obstructed bile duct.</li> <li>Gastric outlet obstruction from the duodenum being splayed across this large pseudocyst in the head of the pancreas.</li> <li>Sinistral hypertension from her pseudocyst as well.</li> </ol>  |  |  |  |
| It was clear that the whole upper abdomen was full of massive venous collaterals in that in fact the superior mesenteric vein drained into the splenic vein in order to drain her bowels. The interface between the lower aspect of the portal vein and the superior mesenteric vein was completely splayed out and attenuated and probably thrombosed by the pseudocyst mass effect. With Dr. [**First Name (STitle) **] [**Nome (STitle) 1453**], we decided that there was no value in any endoscopic approaches to either the pseudocyst or the biliary obstruction and it was clear that an operative approach was the safest and only way to approach this. |  |  |  |
| Past Medical History:<br>Alcoholic pancreatitis, hyperlipidemia, EtOH abuse (last drink 10 days ago), h/o regional thrombosis, cirrhosis,<br>glaucoma PSH: J-tube (removed [**06-07**]), C-section x2, tonsillectomy  |  |  |  |

Fig. 2. Partial screenshot of the case 1 discharge summary

```
<query>
    <id>query>
    <id>qtest40</id>
    </discharge_summary>19791-003873-
        DISCHARGE_SUMMARY.txt</discharge_summary>
    <title>chronic alcoholic induced pancreatitis and jaundice</title>
    <desc>is jaundice an indication that the pancreatitis has
        advanced</desc>
    <narr>chronic alcoholic induced pancreatitis and jaundice in
        connection with it</narr>
    <profile>This 55-year old woman with a chronic pancreatitis is
        worried that her condition is getting worse. She wants to
        know more about jaundice and her condition.</profile>
    </query>
```

Fig. 3. Case 1 query

### Case 2 (optional).

- 1. Patient profile: A forty year old woman, who seeks information about her condition
- 2. De-identified discharge summary, including the disease/disorder spans marked and mapped to SNOMED-CT, and the shorthand spans marked and mapped to UMLS
- 3. Information need: description of what type of disease hypothyroidism is
- 4. Query: *What is hypothyroidism* 
  - (a) Title: *Hypothyroidism*
  - (b) 96 returned documents of which 15 are relevant

### Case 3 (optional).

- 1. Patient profile: *This 50-year old female is worried about what is MI, that her father has and is this condition hereditary. She does not want additional trouble on top of her current illness*
- 2. De-identified discharge summary, including the disease/disorder spans marked and mapped to SNOMED-CT, and the shorthand spans marked and mapped to UMLS
- 3. Information need: *description of what type of disease hypothyroidism is*
- 4. Query: MI
  - (a) Title: *MI and hereditary*
  - (b) 132 returned documents of which 14 are relevant

### Case 4 (optional).

- 1. Patient profile: *This 87-year old female has had several incidences of abdominal pain with no clear reason. The family now wants to seek information about her bruises and raccoon eyes. Could they be a cause of some blood disease*
- 2. De-identified discharge summary

- 3. Information need: can bruises and raccoon eyes be symptoms of blood disease
- 4. Query: bruises and raccoon eyes and blood disease
  - (a) Title: bruises and raccoon eyes and blood disease
  - (b) 110 returned documents of which 5 are relevant

### Case 5 (optional).

- 1. Patient profile: A 60-year-old male who knows that helicobacter pylori is causing cancer and now wants to know if his current abdominal pain could be a symptom of cancer
- De-identified discharge summary, including the disease/disorder spans marked and mapped to SNOMED-CT, and the shorthand spans marked and mapped to UMLS
- 3. Information need: *is abdominal pain due to helicobacter pylori a symptom of cancer*
- 4. Query: *cancer, helicobacter pylori and abdominal pain*(a) Title: *abnominal pain and helicobacter pylori and cancer*(b) 674 returned documents of which 610 are relevant

### Case 6 (optional).

- 1. Patient profile: A 43-year old male with down Syndrome lives in an extended care facility. The personnel wants to know if they can avoid frothy sputum in connection with the patient's chronic aspiration and status post laryngectomy
- De-identified discharge summary, including the disease/disorder spans marked and mapped to SNOMED-CT, and the shorthand spans marked and mapped to UMLS
- 3. Information need: how to avoid frothy sputum
- 4. Query: frothy sputum and how to avoid and care for this condition(a) Title: frothy sputum and care
  - (b) 169 returned documents of which 7 are relevant

**Discharge Summaries.** Six discharge summaries were selected from a larger annotated data set, the *Shared Annotated Resources* (ShARe) corpus. The ShARe corpus was selected from an extensive database, *Multiparameter Intelligent Monitoring in Intensive Care* (MIMIC-II)<sup>21</sup> that contains intensive care unit data including demographics, billing codes, orders, tests, monitoring device reads, and clinical free-text notes. The data was originally automatically de-identified using de-identification software, all dates were shifted, and realistic surrogates were added for names, geographic locations, medical record numbers, dates, and other identifying information. For this task, two authors (HS and DM) independently reviewed the six discharge summaries and manually removed other types of information that could potentially reidentify a patient e.g., the name of a facility the patient was transferred from. We replaced the exact character span of this information with "\*"s to ensure the original

<sup>&</sup>lt;sup>21</sup> https://mimic.physionet.org/database.html (accessed 30 May 2014)

CLEFeHealth2013 annotation offsets were preserved. We provided our consensus annotations to a MIMIC-II representative for review.

**Query Set.** Six real patient queries (i.e. the six cases) generated from the six discharge summaries, a set of in the order of 1 million health-related documents (predominantly health and medicine sites) that the queries can be searched on, and a list of the documents which were judged to be relevant to each of the queries (named result set) were used (Fig. 3). This document set originated from the *Khresmoi project*.<sup>22</sup> The queries were manually generated – as a part of the CLEFeHealth2013 Task 3 - by healthcare professionals from a manually extracted set of highlighted disorders from the discharge summaries. A mapping between each query and the associated matching discharge summary (from which the disorder was taken) was provided. We used the TREC format to capture the document title, description, and narrative and supplemented it with the following two fields:

- 1. discharge summary: matching discharge summary, and
- 2. *profile*: details about the patient extracted, or inferred, from the discharge summary (which is required for determining the information which is being sought by the patient).

**Document Set.** Documents consisted of pages on a broad range of health topics and targeted at both the general public and healthcare professionals. They were made available as DAT files, including the original Internet address (i.e., *Uniform Resource Locator* called #URL) and the document text called (#CONTENT). For example, for the mandatory query, the folder included 113 files with their size varying from two to eighty kilobytes (1.28 megabytes in total) (Fig. 4).

<sup>&</sup>lt;sup>22</sup> http://www.khresmoi.eu (accessed 30 May 2014)

#### Document ID: virtu4909\_12\_000034.dat

#URL:http://www.virtua.org/ADAM/Health%20IIlustrated%20Encyclopedia/2/19512.htm #CONTENT: $i_{b_i}$  Jaundice Jaundice Jaundice is a condition produced when excess amounts of bilirubin circulating in the blood stream dissolve in the subcutaneous fat (the layer of fat just beneath the skin), causing a yellowish appearance of the skin and the whites of the eyes. With the exception of normal newborn jaundice in the first week of life, all other jaundice indicates overload or damage to the liver, or inability to move bilirubin from the liver through the biliary tract to the gut. Review Date: 4/17/2011 Reviewed By: David C. Dugdale, III, MD, Professor of Medicine, Division of General Medicine, Department of Medicine, University of Washington School of Medicine; George F. Longstreth, MD, Department of Gastroenterology, Kaiser Permanente Medical Care Program, San Diego, California. Also reviewed by David Zieve, MD, MHA, Medical Director, A.D.A.M., Inc. The information provided herein should not be used during any medical emergency or for the diagnosis or treatment of any medical condition. A licensed medical professional should be consulted for diagnosis and treatment of any and all medical conditions. Call 911 for all medical emergencies. Links to other sites are provided for information only -- they do not constitute endorsements of those other sites. © 1997- A.D.A.M., Inc. Any duplication or distribution of the information contained herein is strictly prohibited.

Fig. 4. Example document for Case 1

**Result Set.** The document contents were judged for relevance, using the DAT file names, called *document IDs*, as a reference. The relevance judgments were performed by medical professionals – as a part of the CLEFeHealth2013 Task 3 – and mapped to a 2-point scale of *Irrelevant* (0) and *Relevant* (1). The relevance assessments were provided in a file in the standard TREC format with four columns: the first column refers to the query number, the third column refers to the document ID, and the fourth column indicates if the document is relevant (1) or not relevant (0) to the query. We did not need the second column in this task, so it was always given the value of 0. For example, for the mandatory document, 113 documents were judged, resulting in 26 relevant and 87 irrelevant documents.

### 3.2 Challenge

Challenges were deliberatively defined in a creative way and involved visual interactive design and ideally, a combination of automatic, visual and interactive techniques.

**Task 1a: Discharge Resolution Challenge.** The goal was to visualize a given discharge summary together with the disorder standardization and shorthand expansion data in an effective and understandable way for laypeople. An interactive visualization was to be designed based on the input discharge summary, including the disorder spans marked and mapped to SNOMED-CT, and the shorthand spans marked and mapped to the UMLS. The design should allow the patient (or his/her next of kin) to perceive the original document together with the appropriate processing (i.e., disorder standardization and shorthand expansion), thereby conveying an informative display of the discharge summary information. Solutions were to include visualizations of the

space of processed terms, including their location in the SNOMED-CT/UMLS terminologies. Appropriate interaction methods, including linked navigation and detail on demand, should support navigating the original discharge summary processed terms, and foster the understanding of the record and the trust of the users in the presented information. Although side-by-side linked views of the original discharge summary and the space of processed terms could make up for an effective visualization, participants were encouraged to explore additional views and presentations, including presentation of similarity between terms, identification of multiple abbreviations for a given term, and semantic relationships between abbreviated and nonabbreviated terms.

Task 1b: Visual Exploration Challenge. Given that discharge summaries had been understood by the patients, the goal then was to explore a space of relevant documents from a large corpus of documents. As a scenario, we assumed a forty year old woman, who seeks information about her condition of hypothyroidism. She wanted to find a document that describes what type of disease hypothyroidism is by using the query: "What is hypothyroidism?" We assumed that a search engine is given and this engine can retrieve and rank the large collection of documents from the Internet. Each document consisted of text and possibly also images and links to other documents. Given this scenario, the goal was to design a visual exploration approach that will provide an effective overview over a larger set of possibly relevant documents to meet the patient's information need. The successful design should include appropriate aggregation of result documents according to categories relevant to the documents, and/or by applying automatic clustering techniques that help to understand the distribution of relevant aspects in the answer set. Basic solutions should support the visual interactive exploration of the top three to twenty relevant documents. However, participants were encouraged to also consider larger result sets in their solutions, supported, for example, by means of visual document navigation or aggregation by appropriate visualization approaches. To that end, the system should include interactive facilities to efficiently change the level of detail by which results are shown and to navigate in the potentially very large space of search results, possibly using concept and/or document hierarchies.

**Grand Challenge: Integrating 1a and 1b.** We encouraged interested participants to work on an integrated solution, which addresses both Task 1a and 1b in an integrated approach. A key aspect of an effective integrated solution was the possibility to navigate seamlessly between individual concepts from the discharge summary and explore relevant Internet documents from the perspective of the concepts identified in the reports, by ad-hoc querying for concepts found both in the discharge summary and the currently viewed Internet documents. To that end, participants could (but did not have to) implement their own term expansion and document retrieval algorithms, or reuse results from the 2013 challenge. Ideally, solutions would provide full interactive support for term expansion and document retrieval, possibly also considering uncertainties of the automatic expansion algorithm (if applicable) or user-adaptive functions

that assess the relevance of documents. Integrated solutions should also consider the inclusion of external information sources into the exploration process by appropriate navigation and search functionality. Possible sources could include but are not limited to Wikipedia, Flickr, and Youtube.

### 3.3 Evaluation

Participants were given an option to submit to two evaluations via the official Easy-Chair system of the task on the Internet:

- 1. By 1 February 2014 (optional, extended to March 1, 2014): *drafts* for comments. Based on this submission, we provided participants comments that may help them to prepare their final submission. We encouraged all participants to submit this draft, but this submission was not mandatory.
- 2. By 1 May 2014: *final submissions* to be used to determine the final evaluation results. Final submissions needed to encompass the following mandatory items:
  - (a) a *concise report* of the design, implementation (if applicable), and application results discussion in form of an extended abstract that highlights the obtained findings, possibly supported by an informal user study or other means of validation and
  - (b) two *demonstration videos* illustrating the relevant functionality of the functional design or paper prototype in application to the provided task data.
    - (i) In the first video, the user should be from the development team (i.e., a person who knows the functionality).
    - (ii) In the second video, the user should be a novice, that is, a person with no previous experience from using the functionality and the video should also explain how the novice was trained to use the functionality.

Solutions were supposed to address the task problems by appropriate visualinteractive design and need to demonstrate its effectiveness. Participants were encouraged to implement prototypical solutions, but also pure designs without implementation were allowed.

Submissions were *judged* towards their rationale for the design, including selection of appropriate visual interactive data representations and reference to state-of-the-art techniques in information visualization, natural language processing, information retrieval, machine learning, and document visualization. They had to:

- 1. Demonstrate that the posed problems are addressed, in the sense that the layperson patient is helped in their complex information need,
- 2. Provide a compelling use-case driven discussion of the workflow supported and exemplary results obtained, and
- 3. Highlight the evaluation approach and obtained findings.

Each final submission was assessed by a *team of four evaluation panelists*, supported by *an organizer*. *Primary evaluation criteria* included the *effectiveness* and

*originality* of the presented submissions. By following [23], submissions were judged on *usability*, *visualization*, *interaction*, and *aesthetics*. Our usability heuristics were:

- 1. *Minimal Actions:* whether the number of steps needed to get to the solution is acceptable,
- 2. *Flexibility:* whether there is an easy/obvious way to proceed to the next/other task, and
- 3. Orientation and Help: ease of undoing actions, going back to main screen and finding help.

Our visualization heuristics were

- 1. Information Encoding: whether the necessary/required information is shown,
- 2. Dataset Reduction: whether the required information is easy to perceive,
- 3. *Recognition rather than Recall:* Users should not remember or memorize information to carry out tasks or understand information presented,
- 4. Spatial Organization: layout, efficient use of space, and
- 5. Remove the Extraneous: uncluttered display.

Depending on the field of all submissions, we promised to give *recognition* to the best submissions along a number of categories. *Prospective categories* included but were not limited to effective use of visualization, effective use of interaction, effective combination of interactive visualization with computational analysis, solution adapting to different environments (e.g., desktop, mobile/tablet or print for presentation), best use of external information resources (e.g., Wikipedia, Social Media, Flickr, or Youtube), best solutions for Task 1a, 1b, and Grand Challenge, and best integration of external information resources.

## 4 Results

In this section, we first introduce our organizers' initialization to the problem in order to help the participants to get started. Then, we briefly describe our participant submission – we received one final submission to the task – together with its evaluation. We received 50 registrations in total, but only two teams (and three organizers) were granted data access – other registrants did not return the data use agreement. Finally, to enable comparisons, we provide our organizers' approach. The initialization and organizers' comparative approach are not model solutions but rather intended to inspire critical thinking and new ideas.

#### 4.1 Organizers' Initialization

As starting points, we gave reading [24, 25, 26, 27], related labs (i.e., the aforementioned Health Design Challenge and IEEE VIS Workshop on Public Health's Wicked Problems 2013), and software recommendations [28] to the participants. In addition, we provided example designs to inspire all participants (Fig. 5–7).

## WEB VERSION



PRINT VERSION



**Fig. 5** (continued from previous page). Task 1a inspiration: Designs for presenting discharge record data using layout to indicate record structure and color to indicate status. We asked participants to consider adapted designs for various output devices (e.g., desktop, tablet or print output). See http://clefehealth2014.dcu.ie/ for original images.





Fig.6 (continued from previous page). Task 1b inspiration: Example design of an information landscape for overviewing a set of answer documents. In this case, documents are mapped according to relevance and document complexity, with document metadata mapped to color and shape of document marks. See http://clefehealth2014.dcu.ie/ for original images.



**Fig.7.** Grand Challenge inspiration: Indicative sketch of a workflow supporting integrated analysis of discharge report and querying for related documents.

### 4.2 Participant Submission

We received one final submission to the task. This submission has also been assessed during the draft round. See [29] for the final submission description.

The submission was from the *FLPolytech team*. It is a partnership between Florida Polytechnic University's Department of Advanced Technology and the commercial information science firm Retrivika. Florida Polytechnic is a public university located in Lakeland, Florida. The Advanced Technology department is committed to excellence in education and research in the areas of data analytics, cloud computing and health informatics. Retrivika is a commercial software development company operating in the domain of information science applications, specifically electronic discovery (eDiscovery) and electronic health records (eHealth). The team members are Dr. Harvey Hyman and Warren Fridy.

Dr. Harvey Hyman is an assistant professor of advanced technology at Florida Polytechnic University in Lakeland, Florida, USA. He is a commercial software developer and an inventor of three U.S. patents in the domain of electronic document search and information retrieval. He holds the following advanced degrees: PhD in Information Systems from University of South Florida (2012), MBA from Charleston Southern University (2006), and JD from University of Miami, Florida (1993). He has a diverse background that includes over 20 years of experience in complex litigation, technology development and business process modeling. His current research projects include: Information Retrieval Models and Processes, Exploration Behaviors in Electronic Search, Project Management Success Predictors, and Health Informatics Support Systems. His book Systems Acquisition, Integration and Implementation for Engineers and IT Professionals is a best practice guide for software design and development life cycle. It is available through Sentia Publishing. He may be contacted by email: hhyman@floridapolytechnic.org

Warren Fridy is co-founder, Chief Technology Officer, and Director of Product Design and Development at Retrivika, a cloud based eDiscovery software service innovator. His love of computers and technology began at a very early age. When he was just a junior in high school, he opened his first computer consulting company. That passion for technology has continued through his Bachelor and Master degrees in Computer Science and into his professional career. His knowledge and experience reaches a wide variety of fields including insurance, financial, and education. In addition to his professional work, he collaborates with Dr. Harvey Hyman on a variety of computational and data related topics, and recently trained several interns through an internship program at a local college. He can be contacted at warren@retrivika.com and twitter @wfridy

The submission addressed both Tasks 1a and 1b together with their integration as the Grand Challenge solution. It related to the task evaluation category of Effective use of interaction. Although the submission did not describe tests with real expert and/or novice users, the described system seems to be rather good at these two. The final submission was evaluated by four evaluation panelists and one review by the organizers. The draft submission was reviewed by five organizers.

### 4.3 Organizers' Comparative Approach

For comparison purposes, we described organizers' viewpoints of the system design in Figures 8-13. Namely, we developed a *digital design* (Fig. 8) and *printable design* (Fig. 9-12). The workflow of producing these contents is described in Figure 12. Our fundamental principle was to prioritize simplicity. We used WebBook and Web Forager,23 QWiki,24 primary school books, and health pamphlets as our sources of inspiration.

Both designs divided a given patient's discharge summary with respect to time to sections for *Past*, *Present*, and *Future* information. The present section consisted of a summary image together with subsections for admission and discharge dates; participating healthcare services and care team members; patient identifiers; history of present illness, and hospital course. The future section had subsections related to the patient discharge together with recommended Internet sites, search phrases, and

<sup>&</sup>lt;sup>23</sup> http://www.sigchi.org/chi96/proceedings/papers/Card/skc1txt.html (accessed 1 May 2014)

<sup>&</sup>lt;sup>24</sup> http://www.qwiki.com/ (accessed 1 May 2014)

glossary terms for further information. The past section included all other content of the discharge summary.

The enriched or altered content was indicated as follows: All expanded shorthand was faded underlined in the digital and printable version (Fig 8 and 10). Relevant diseases and disorders were marked as definition hyperlinks in the digital version (Fig. 8) and glossary terms in the printable version (Fig. 11). The recommended internet sites and search phrases originated from the query and result sets (Fig. 8 and 11). We assumed that the healthcare provided gave their patients an access to this electronic and interactive glossary and digital version on the Internet.

The content was supplemented with a *privacy statement*, *return address* for lost pamphlets, and contact details for *healthcare services*, *description of this imaginary hospital's project for making health documents easier to understand for their patients* (Fig. 9).

| 80 year old male with 2 years history of shortness of  | Disorder codes (SNOMED-CT)  |                                 |
|--|---|---------------------------------|
| breath (definition, treatment guidelines) and heartburn  | Aortic valve stenosis   | C0003507                        |
| (also known as gastroesophageal reflux disease;  | Echocardiogram abnormal   | C0476369                        |
| definition, treatment guidelines).   | Gastroesophageal reflux disease   | C0017168                        |
| Had an echocardiogram ultrasound test that revealed  | Shortness of breath   | C0013404                        |
| aortic valve stenosis ( <u>definition</u> ; <u>treatment guidelines</u> ;<br><u>guidelines on separating the symptoms of heart</u><br><u>conditions from heartburn</u> ). Has had serial<br>echocardiograms since, with the last done on [] which<br>showed worsening aortic valve stenosis. | Shorthand expansions (UMLS)<br>aortic valve stenosis<br>echocardiogram ultrasound test<br>gastroesophageal reflux disease<br>history of | AS<br>echo, Echo<br>GERD<br>h/o |
| Hyperlinking uses  | shortness of breath   | SOB                             |
| Patient or next-of-kin's information need  | year old  | y/o                             |
| Online health resources  | years   | year                            |
| Laypeople's preferences  | Preferred terms (UMLS)  |                                 |
| Laypeople's assessment on the content reliability  | GERD heartburn  | C0018834                        |

Fig. 8. Digital version: Closer look of Fig. 1

#### Understanding Your Health

#### Electronic health records made easy

Existing discharge summaries are fraught with medical terminology that is often difficult for the typical patient to understand. In the Hospital of CLEFeHealth, we aim to combat this problem by designing an interactive visual representation of the discharge summary and potentially relevant documents available on the Internet. Our goal is to provide an effective, usable and trustworthy environment for navigating, exploring and interpreting both the discharge summary and Internet documents, as needed to promote understanding and informed decision making.

More information: http://clefehealth2014.dcu.ie/

#### Support and Health Centres

Post questions to your peers

https://groups.google.com/forum/?hl=en-GB#!forum/clef-ehealth-task-1

Visit or call the health centre Open from Monday to Friday, 9 AM - 5 PM

PAST

EXAMINATION: At the time

ment, the patient h rate 139 decreasing to decreasing to 145/61 s 39; 99% was the p

e some ith rare rales. The patient S1 and S2 (heart sounds) wi The abdomen was softly pigastrically and in the left a was negative with no stool.

tended, but s int. There was

be between 1 and 3 cm lower than the right IONS AT THE TIME OF ADMISS PH. Lisinopril 20 mg p.o. q. day. Protonin mg. Lipiter. Atenolol. Paxil, 10 mg q. day. Cole y. Atenolol 25 mg p.o. q. day. JRY DATA: CBC was as follows at admission. 7.

PPD (purified protein deri ency. Diabetes mellitus. Tra vascular disease. Chro me O2 (oxygen). Coron pass graft in 2003, st ry embolism in 2009; re

aise of the right sl

van an follows at admission, hills, 25% lymphocytes, 5% a sodiam of 1.8. PTT was 26 a sodiam of 141, potan .1, glucose 368 at first mer the 20 to 25 mage. Tropon T 18, AST 18, alkaline ph e 2.8. magnesium 1.7. TS

2

Hospital of CLEFeHealth Tower A, 7 London Circuit Canberra City ACT 2600 Australia Phone: 02 6267 6351

#### PRIVACY STATEMENT

This booklet may include personal information. The Australian Privacy Act 1988 defines personal information as information or an opinion, whether true or not, about an identified individual. Common examples are an individual's name, address, telephone number, date of birth, and health records. Information in this booklet is targeted to the patien him/herself. In case of an emergency, it may also erve as a summary for healthcare providers

If you find a lost booklet, please respect patient confidentiality, do not read the content, and return the booklet to Locked Bag 8001, Canberra ACT 2601 Australia.

Hospital of CLEFeHealth CLEF Tower A. 7 London Circuit Canberra City ACT 2600 Australia Phone: 02 6267 6351 info@hospitalofCLEE ospitalofCLEFeHealth.cor

6

FUTURE ONDITION AT DISCHARGE: S MEDICATIONS AT DISCHARGE By mouth three times a day: Bactri presumed Proteus mirabilis urinary t By mouth twice a day: Diltiazem 12 By mouth once a day: Atenolol 25 r 10 mg, Protonix r: Atenolol, Cola :40 mg min 0.5 mg. Linitor THER DISCHARGE INSTRUCTIONS THER DISCHARGE INSTRUCTIONS Tease note that the patient will also be discharged on Meteree nhalers for presumed chronic obstructive pulmonary disease eactive component and will follow-up with her primary care phy o determine whether this treatment is necessary. FURTHER INFORMATION RECOMMENDED INTERNET SITES OSPITAL COURSE: p.o. q. day MENDED GLOSSARY TERM

Hospital of **CLEF** eHealth

1

Patient's

**Discharge Summary** 

PRESENT 0-Admission Date: 2011-04-15 Discharge Date: 2011-04-16 Service: Emergency Room Care Team Leaders: Dr Hill, Dr River, Dr Willow Name: Maria Carvarino Date of Birth: 1924-02-02 Sex: F (female) IISTORY OF PRESENT ILLNES fiss Carvarino is an 87 year old Pr

Fig. 9. Printable pamphlet design for the optional case 4. This is intended for double-sided A4 printing. When the bottom figure is visible, the right hand side is to be folded first, followed by the left hand side. This results in the page 1 (6) to be on top (bottom). The design is also available at http://goo.gl/4y8PXT (accessed 11 June 2014).

# PRESENT

0.2

Admission Date: 2011-04-15 Discharge Date: 2011-04-16 Service: Emergency Room Care Team Leaders: Dr Hill, Dr River, Dr Willow Name: Maria Carvarino Date of Birth: 1924-02-02



Date of Birth: 1924-02-02 Sex: F <u>(female)</u>

HISTORY OF PRESENTILLNESS

Miss Carvarino is an 87 year old Portugese-Creole speaking only woman who presented to the Hospital of CLEFeHealth Emergency Room on 11-04-15, complaining of left lower quadrant abdominal pain, sharp or knife-like in quality, which had begun the night prior to admission and increased with bowel movements. There was no blood in the stool per the patient. She denied vaginal bleeding, urinary symptoms, dyauria, recent travel or fevers. In the Emergency Room, there was some question of whether the patient was having chest pain and in fact the patient was found to have a left bundle branch block with a tachycardia superimposed to the 140 range. In the EmergencyRoom, the patient was placed on a Diltiazem drip as well as heparin and her systolic blood pressure at one point was noted to be above 200, lowered to an acceptable range. She received chest CT (computerized tomography) scan for a question of a pulmonary embolian and was sent initially to the Medical Intensive Care Unit for question of hypertensive crisis.

HOSPITAL COURSE: The patient was admitted to the Medical Intensive Care Unit with the above-stated complaints on a heparin drip as well as a Diltiazem drip. The patient's cardiac issues rapidly settled with the patient once again developing a regular rate. The patient's EKG (electrocardiogram) was felt to represent tachycardia with left bundle branch block but without other pathology. The patient ruled out by cardiac enzymes. Once the patient was stabilized, the patient was rapidly transferred to the Dept. for further management. Secondary to concerns surrounding the additional history that the patient gave of a fall approximately three days prior to admission with racoon's eyes on examination, the patient was sent for a CT scan of the head to rule out intra-cranial bleeding or base of the skull fracture. This study was negative. In the absence of evidence to suggest acute cardiac process, heparin was discontinued. Stool studies were sent which are pending at the time of this discharge. The patient's urine did grow out between 10 and 100,000 organisms of Proteus mirabilis as stated above. On 04-16, the patient was thought to be much improved with no significant abdominal tenderness and no Telemetry events overnight with a pulse in the 80s and systolic blood pressure in the 160s. As the patient had formerly multiple times been evaluated for abdominal pain including mesenteric angiography and CT scan of the abdomen without a diagnosis appropriate outpatient follow-up with her outpatient provider, Dr. Willow. being reached, the decision was made to discharge the patient home or 5

Fig. 10. Present section

## FUTURE

#### DISCHARGE DIAGNOSES

Ruled out for myocardial infarction. No evidence for pulmonary embolism. No evidence of acute intracranial process. Recurrence of chronic intermittent abdominal pain of unexplained etiology. Diabetes mellitus. Asthma.

CONDITION AT DISCHARGE: Stable.

MEDICATIONS AT DISCHARGE

By mouth three times a day: Bactrim DS one tablet times ten days for presumed Proteus mirabilis urinary tract infection.

By mouth twice a day: Diltiazem 120 mg

By mouth once a day. Atenolol 25 mg, Imdur 60 mg, Lisinopril 20 mg, Paxil 10 mg, Protonix 40 mg

Other: Atenolol, Colace, Klonopin0.5 mg, Lipitor,

OTHER DISCHARGE INSTRUCTIONS

Please note that the patient will also be discharged on Metered-Dose Inhalers for presumed chronic obstructive pulmonary disease with reactive component and will follow-up with her primary care physician to determine whether this treatment is necessary.

# FURTHER INFORMATION

RECOMMENDED INTERNET SITES

- http://www.everydayhealth.com/health-centenbruises-and-blood-spotsunder-the-skin.aspx
- http://www.everydayhealth.com/health-center/bruises-and-blood-spotsunder-the-skin-oreparing-for-your-appointment aspx
- under the skin preparing for your appointment aspx 3. http://www.mayoclinic.com/healthfirst-aid-bruise/FA00039
- 4. http://www.pathologyoutlines.com/topic/coagulationamyloidosis.html
- 5. http://www.virtualpediatrichospital.org/patients/coga/bruise.shtml

RECOMMENDED SEARCH PHRASES

- 1. bruises and raccoon eyes and blood disease
- 2. can bruises and raccoon eyes be symptoms of blood disease
- RECOMMENDED GLOSSARY TERMS

| abdominal pain           | crackles                 | ovstagmus                 |
|--------------------------|--------------------------|---------------------------|
| abdominal tenderness     | crisis hypertensive      | obesity                   |
| asthma                   | decreased blood pressure | pleural calcification     |
| bilateral cataracts      | diabetes mellitus        | pleural condition         |
| blood in stool           | distressed breathing     | skin cyanosis             |
| bruise                   | edema                    | traction bronchiectasis   |
| chest pain               | fractured shull          | transient ischemic attack |
| chronic abdominal pain   | harsh breath sounds      | urinary symptoms          |
| chronic kidney failure   | heart attack             | urinary tract infection   |
| chronic obstructive lung | hematotympanum           | urination pain            |
| disease                  | inflammation             | vagina bleeding           |
| clubbing                 | intracranial hemorrhage  |                           |
| conjunctival             | left bundle branch block |                           |
| haemorrhage              | left lower quadrant pain |                           |
| coronary artery disease  | lung embolism            | 4                         |

Fig. 11. Future section

## PAST

MEDICAL HISTORY: PPD (purified protein derivative) positive. Chronic renal insufficiency. Diabetes mellitus. Transient ischemic attacks. Peripheral vascular disease. Chronic obstructive pulmonary disease (asthma), home O2 (oxygen). Coronary artery disease status post coronary artery bypass graft in 2003, status post cholecystectomy. History of pulmonary embolism in 2009; recently on Coumadin for anticoagulation. History of what were evidently had been multiple myocardial infarctions.

PHYSICAL EXAMINATION: At the time of admission in the Emergency Department, the patient had vital signs noted 97.2 F., temperature; heart rate 139 decreasing to 110 on a Diltiazem drip; blood pressure 180/120 decreasing to 145/61, again on the Diltiazem drip; respiratory rate was 39; 99% was the pulse oxygenation. In general, a moderately obese woman in respiratory distress. She was noted to be normocephalic with raccoon eyes. Oropharynx was clear. There were no bruits appreciated. No jugular venous distention was noted. There was thought to be some accessory muscle use. Breath sounds were coarse at the bases with rare rales. The patient was, on cardiac examination, tachycardic. S1 and S2 (heart sounds) were normal. No murmurs, rubs or galloos. The abdomen was softly distended with tendemess to palpation epigastrically and in the left lower quadrant. The rectal examination was negative with no stool. There is no cyanosis, clubbing or edema. Racoon's eyes were noted again bilaterally without battle signs. Tympanic membranes were poorly visualized, but there was no clear evidence for hemotympanum. The neck was supple. There was no jugular venous distention. Cardiac examination was unremarkable. The chest was clear with a left sided pleural rub heard throughout the left side of the chest. The abdomen was soft with positive bowel sounds, not significantly distended, but some minor tenderness to palpation in the left lower quadrant. There was a bruise of the right shin and the left heel appeared to be between 1 and 3 cm lower than the right.

MEDICATIONS AT THE TIME OF ADMISSION: Imdur 60 mg p.o. q. day. NPH. Lisinopril 20 mg p.o. q. day. Protonix 40 mg p.o. q. day. Klonopin 0.5 mg. Lipitor. Atenolol. Paxil, 10 mg q. day. Colace. Dithia.rem 120 mg p.o. twice a day. Atenolol 25 mg p.o. q. day.

LABORATORY DATA: CBC was as follows at admission, 7.7 was the white blood cell count, hematecrit 41.7, with 67% neutrophile, 25% hymphocytes, 5% monopytes. Platelet count of 214. PT on admission was 16.1, with an DX of 18. PTT was 26.9. Unindysis was negative. Chem-7 at time of admission showed a sodium of 141, petassium of 3.7, chloride 101, bieschonate 29, BUN 22, creatining of 1.1, glucose 368 at first measure. Cardiac ensymes were repeatedly cycled with values all within the 20 to 25 range. Teoponin were less than or equal to 0.4. Amylane was 100; lipace of 20, ALT 18, AST 18, alkaline pherphatase 117, total to bilabilin 0.4, abumin 32, calcium 9.0, pherphate 28, magnesium 1.7. TSH is preding at the time of discharge. Steol studies are pending at the time of discharge. Unine culture showed 10 to 100,000 organisms of Proteus minibilis. Chest x-exy on 04-15, was as follows: No south cardinglementary process. A chest CT scent performed on the same day showed no pulmonary embelous, left planal and parenchymal calcifications and left lower lobe volume low, i.e. fibrothema, from pine inflammatory process as well as traction bronchizetasis. The head CT scent was performed on [04-16, with the following impression: No interannial hemembage, no evidence of skull facture. Hip x-exys are pending at the time of this dictation.

2

Fig. 12. Past section



Fig. 13. Workflow of producing electronic and paper-based documents. The design is also available at http://goo.gl/4y8PXT (accessed 11 June 2014).

### 5 Discussion

Continuing a tradition of evaluation labs that started in the 90s with TREC and since 2000 with CLEF, the CLEF tasks aim to provide a forum where different solutions for the same problem can be compared and contrasted. While the CLEFeHealth2013 task focused on readability, the 2014 Task also delved into the next step: interactive visualization for increasing comprehension of a discharge summary and connecting to additional online information. In this 2014 visualization challenge, 50 teams registered, two teams were granted data access and one team completed the tasks. This team augmented the given discharge information with textual visualization, e.g., adding structure, definitions and links. The panelists who reviewed the submission agreed that more advanced visualization would be beneficial. However, a user study would need to be conducted to verify that such augmentations do not make the material more complex, especially for patients with low health literacy or limited computer skills. A natural first step would be the evaluation of the effectiveness of the proposed interface changes, e.g. the imposed time structure. For example, such a change could potentially reduce cognitive load in patients upon discharge from the hospital by structuring and managing the acquisition of additional information.

More generally, we argue that visual-interactive displays can be very effective tools to help users navigate, explore and relate complex information spaces. Information Visualization to date has researched a variety of techniques, many of which are potentially applicable to tasks in understanding discharge records and related information resources. Respective Information Visualization techniques include, for example, document visualization for over-viewing and navigating document collections, network visualization for communicating relationships between facts and concepts, and timeoriented visualization for understanding developments happening over time. While to date, a number of systems exist for visualization of health records data [22], these often are geared toward expert usage, and we expect further work is needed to enable lay persons to take advantage of the analytic capabilities of such expert systems. We recognize that the defined task was indeed a challenge in that it implied substantial interdisciplinary work: Medical domain data understanding had to be paired with techniques from Information Retrieval, text analysis and interactive data visualization. Our task definition also implied work on implementation, application and user evaluation, which in turn require expertise in software engineering and usability studies. Given this indeed challenging task, we are glad to have received one contribution which tackled the posed problems from the perspective of Information Retrieval. We hope that our task definition, the presented data, instantiation and results will foster more interest in the community to work on the problem of visual-interactive access to personal health information by lay persons. We consider this task an important and challenging problem with potentially high benefit for individuals and society alike.

### Acknowledgements

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We gratefully acknowledge the participating team's hard work. We thank them for their submission and interest in the task.

We greatly appreciate the hard work and feedback of our evaluation panelists Hilary Cinis, Senior User Experience Designer, NICTA, Sydney, NSW, Australia; Chih-Hao (Justin) Ku, Assistant Professor in Text mining and information visualization, Lawrence Technological University, Southfield, MI, USA; Lin Shao, PhD student, in Computer and Information Science, University of Konstanz, Konstanz, Germany; and Mitchell Whitelaw, Associate Professor in Media Arts & Production, University of Canberra, Canberra ACT, Australia. We also acknowledge the contribution of George Moody, Harvard-MIT, Cambridge, MA,USA in proofing and supporting the release of our six double de-identified (manually and automatically) discharge summaries.

We thank Dr. Wendy W Chapman, University of Utah, Salt Lake City, UT, USA and Dr. Preben Hansen, SICS and Stockholm University, Stockholm, Sweden for their contribution to the initial Task conceptualization.

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