Chapter 3
User Needs: Clinicians, Clinical Researchers and Hospital Management

There are different user groups utilising information from patient records. For example, clinicians, such as physicians and nurses, needing information for their daily work; clinical researchers that need to extract patients groups or cohorts, or patient cases with specific diseases to perform research and finally the hospital management that need to gather statistics on various groups of patients, but also to predict the future needs of the hospital. Generally when asking users what type of systems they want, they do not know. One way is to show them a prototype and they can try it out and give feedback on whether they like it or not, and what improvements should be made.

3.1 Reading and Retrieving Efficiency of Patient Records

The physician writes in the patient record the symptoms, the assessment and the treatment of the patient. The physician also reads older notes of the previous treatment of the patient. Garrett et al. (1986) describe an experiment where 134 patient visits were handled manually with paper based records and 111 visits were handled in an electronic patient record system. The two approaches were compared and the conclusion was that an electronic system led to *a significant reduction in the time required for the physicians to obtain data from and enter data into the record*.

In two consecutive articles Nygren and Henriksson (1992) and Nygren et al. (1992) elaborate on the paper based patient record and how it can be improved in the digital form, by giving the user access to retrieval tools to quickly get access to information and obtain a better overview. In the first study by Nygren and Henriksson (1992) the authors carried out requirements engineering for such a tool

H. Dalianis, *Clinical Text Mining*, https://doi.org/10.1007/978-3-319-78503-5_3

by interviewing seven experienced physicians about how they read the paper based patient record. The conclusions from this first study were:

(a) Expose lots of information to the user. Even information the user has not asked for.
(b) Orientation and navigation are essential. Give the user positional structure, so the user can find new information but easily navigate back to the original position and still have a link to a reference.
(c) The user should see everything, so the user can access what is there and what is missing. Do not conceal anything.

In the second study by Nygren et al. (1992) an electronic patient record prototype was constructed and finally in Nygren et al. (1998) all previous research is summed up in a conclusion about the optimal organisation of patient records, not necessarily in electronic form. The authors claim that good organisation of the records may *double the speed*, of retrieving and reading the record.

LifeLines is a prototype patient record system where the physician can see important events in a timeline in the patient record (Plaisant et al. 1998). The events are highlighted and are for example: *problems, allergies, symptoms, diagnosis* and *drug prescriptions (medications)*, the user can click on these and obtain more information, see Fig. 3.2.

In Lifelines2 the follower, the concept is taken a step further, so several patients can be followed simultaneous. This is obviously for clinical research reasons, but can also be used by hospital management (Wang et al. 2011).

3.2 Natural Language Processing on Clinical Text

One very early article on clinical text mining is by Pratt and Pacak (1969), where the authors outline a system for extracting textual information from the digital medical record.

One other article is by Spyns (1996) where he elaborates on Natural Language Processing (NLP) and the concept of Medical Language Processing in form of a number of systems developed for parsing medical language for the purpose of assisting the healthcare personnel.

One note on these systems, they are all rule-based (grammar based) parsing systems in contrast to state of the art systems that are mostly machine learning or statistical systems.

Friedman and Hripcsak (1999) present the current (in 1999) NLP systems for medical texts such as *Linguistic String System (LSP)* used in discharge letters, progress notes and radiology reports, the *Medical Language Extraction and Encoding System (MedLEE)* used to extract, structure and encode clinical information, *an access system for medical records using natural language (MENELAS)* to extract information from discharge summaries in French, English and Dutch and one NLP system developed at Geneva Hospital that can process French, English and German.

Friedman and Hripcsak (1999) continue to elaborate on future systems and future directions where NLP will be used to assist physicians. Examples that are given include the automatic assignment of ICD-9 codes to patient records. Continuous voice recognition will assist the physician in entering text to the patient records, simultaneously the patient record will be encoded in the standard codes using standard terminology.

A important review article by Meystre et al. (2008) makes a nice overview of many systems available (in 2008), and possible directions that these systems will be developed in.

In a study by Velupillai and Kvist (2012), the authors present three scenarios consisting of *adverse event surveillance, decision support alerts* and *automatic summaries* where clinical text mining is used.

Finally, in an article by Jensen et al. (2012) the authors elaborate on disease trajectories and predictions based on big data mining of electronic patient records.

3.3 Electronic Patient Record System

The official bibliographical term is *electronic patient record (EPR)*, other names are electronic health record (EHR), electronic medical record (EMR), computerised patient record, digitised patient record or just health record. Another name is case sheet. The electronic patient record does not live by itself but in a computerised system, which is called electronic patient record system (Åhlfeldt et al. 2006).

The first electronic patient record systems in Sweden were constructed in the mid 1960s and 1970s as a series of pilot tests at Karolinska University Hospital, specifically at the Thorax clinic (chest clinic). These early electronic patient record systems had no real impact on the healthcare.

The first system used was called Costar and came from the high-tech, advanced, academic environment of Harvard University, Massachussets, USA: the system was developed and was later called Swedestar in Sweden and Finnstar in Finland.

Later in the 1980s a lot of systems were developed both inhouse at the primary care level and later at hospitals, and also involving local companies. In parallel with this was the development of first automation of the chemistry laboratories, which also was a driving force to use an electronic patient record system. These systems were also well received by the clinicians since they were involved in giving feedback, while later when the large centralised system arrived the clinicians did not feel that they really were involved in the requirements engineering process (Kajbjer et al. 2010). Kajbjer et al. (2010) have a nice overview of the different systems and the growth of the electronic patient record systems in Sweden from 1988 to 1995, and how the large variety of suppliers finally was refined down to four major suppliers.

One early study describes the requirements engineering process for the Karolinska Hospital Information System, it shows the basic information that should be included in such a medical record system and how the data should be stored in a database so it can be updated and retrieved easily (Mellner et al. 1974).

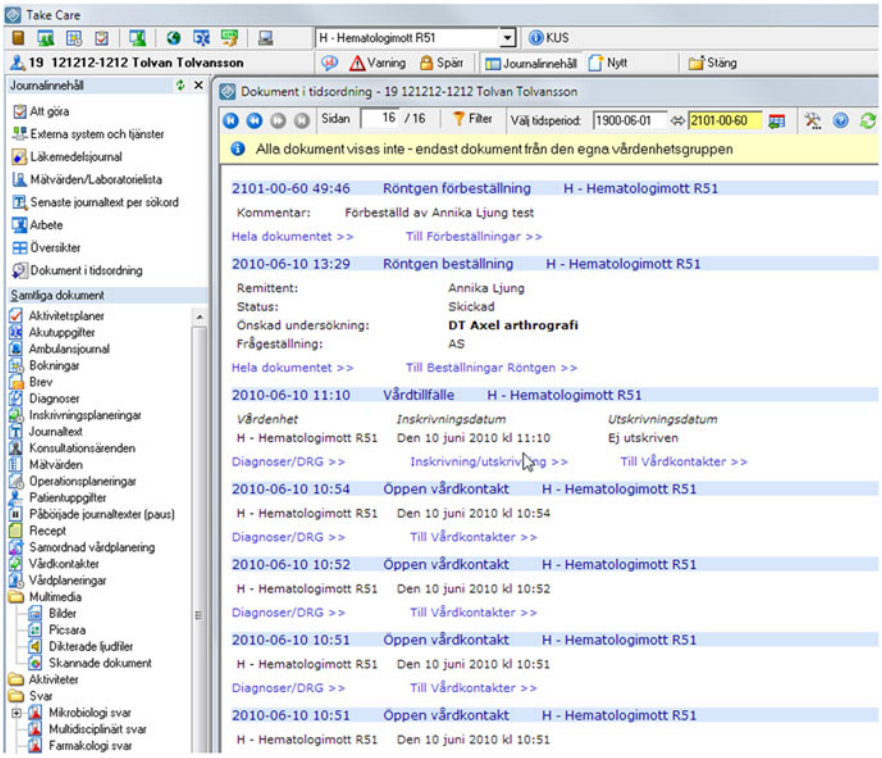

Fig. 3.1 Screenshot from the TakeCare CGM electronic patient record system used at Stockholm County Council (Stockholms läns landsting, SLL)

The paper based patient record has become digitised, in electronic health records systems, without in some cases, really improving the ways the physician can browse in it, see Fig. 3.1.

The improvements are mainly that the record is available faster when digitised than obtaining it in paper form from the archive, where the paper record file had to be fetched by the assistant and sometimes the file was missing in the archive. In the electronic patient record the laboratory results, X-ray images etc. are also directly available and other physicians located at other places involved in the healthcare process of the patient can easily access the patient record. A radiology report is written by the radiologist and is an interpretation in text of the X-ray image.

In Metzger et al. (2012) there is an interesting overview of the number of electronic patient record systems in use in contrast to paper based system, where the USA and Canada are at the bottom in the western world with only 46 and 37% respectively, together with France (where 68% of French general practitioners use EHRs) while Norway and New Zealand with 97% use of electronic patient records systems; of course now in 2017 these numbers must have changed.

Many of the previous ways of observing the paper file have disappeared in the electronic patient record system. However, there has been research in how to improve the ways to browse the patient record. Early work included LifeLines (Plaisant et al. 1998), where the patient record is presented in a timeline where the physician can browse back in time and can easily observe what findings (problems), diagnosis and drugs (medications) have been documented; the physician can also click (or zoomin) on the medications and obtain more details on the type of medications, see Fig. 3.2.

In an interesting article by Roque et al. (2010), the authors compare six different prototype electronic patient record systems that propose different viewing systems for temporal data. The systems studied are LifeLines, Lifelines2 (the extension of LifeLine), Timeline, CLEF KNAVE-II and finally AsbruView. Lifelines2 and CLEF can also be used by clinical researchers. CLEF has built-in automatic generation of summaries. The conclusion is the systems need to improve the way the granularity of the data is presented. Since much of the data stored in patient record systems is in textual form, different text mining tools would be appreciated for presenting the semantic content of the patient records. We can consider Lifelines2 and CLEF as the new type of electronic patient record that can search the whole patient record repository to perform *cohort studies*. Cohorts are groups of individuals with similar characteristics, such as disease, drug use, age, gender etc.

3.4 Different User Groups

The current and possible user groups of advanced electronic patient record systems are firstly, of course, clinicians such as physicians, nurses, physiotherapists, dieticians and psychologists treating individual patients. Secondly clinical researchers, medical researchers, pharmacologists and epidemiologists studying cohorts of patients (that is groups of patients with similar characteristics, social parameters, geographical information or location), but also data scientists for development of new tools. Thirdly hospital management and administration, along with national health board officials. lastly the business world, such as pharmaceutical companies and electronic patient records system suppliers for development of systems.

3.5 Summary

This chapter summarised the user needs and presented the different user groups in medical healthcare such as clinicians, clinical researchers, hospital management and administration, the business world and data scientists. The needs of clinicians accessing, reading and writing the patient record, previously in paper form but now in electronic form were described along with the first attempts to use natural language processing of the patient record. The chapter also described the difference

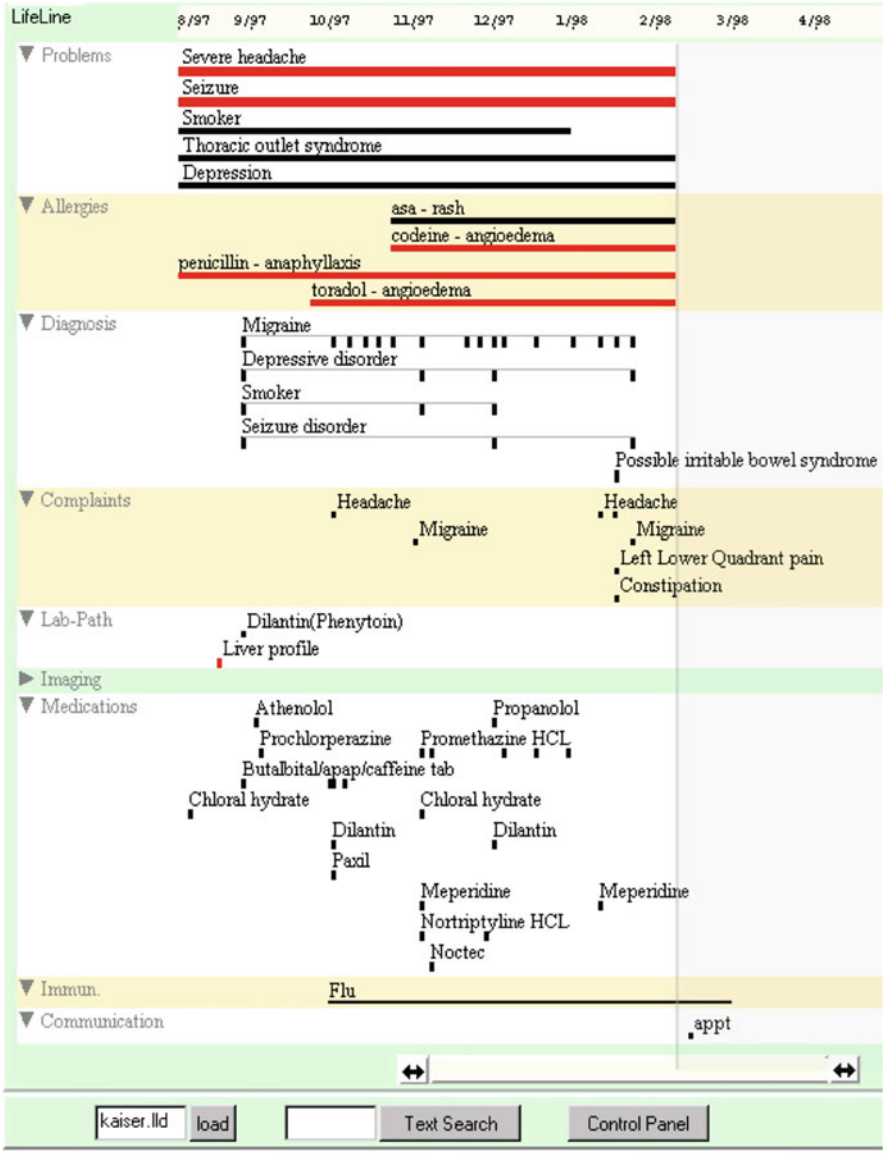

Fig. 3.2 Screenshot of the Lifelines (Lifelines, http://www.cs.umd.edu/hcil/lifelines/kaiserlifelines.jpg. Accessed 2018-01-11.) prototype electronic patient record system

between individual patient record access (LifeLines prototype) and accessing all patient records (Lifelines2 prototype) in the repository, and the reason for studying several patient records simultaneously to predict the future and collect statistics. The need to present various prototypes for clinicians to show them the possibilities of medical healthcare information systems was also discussed.