PERFORM: Building and Mining Electronic Records of Neurological Patients Being Monitored in the Home

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Abstract— **The PERFORM project is building a novel application for the home-based monitoring and assessment of people with neurologically based movement disorders such as Parkinson's disease (PD) and Amyotrophic Lateral Sclerosis (ALS). PERFORM includes a hospital-based EHR data-analysis and mining system compatible with HL7. For EHR to include monitoring data an alert-based system of data reduction is used which supports both patient management and modelling. Pilots will be started in Spain, Greece and Italy in 2009. PERFORM is in the early stages of development and is an FP7 integrated project.**

Keywords—**Digital homecare, EHR, neurology, data mining, home monitoring.**

I. Introduction

There is a clinical deficit of objective data on which neurologists can base the assessment and care of patients with chronic neurologically-based movement disorders. The natural response is to develop digital home monitoring but there is a corresponding lack of experience in storing such data in EHR and in using it to present a coherent view of the patient. The PERFORM project (http://www.perform-project.com/) aims to develop a complete home monitoring system using data gathered by the patient themselves wearing sensors in and outside the home and fusing this into EHR. A home-based wireless unit will pre-process the data before it is transferred to a hospital-based system for fusion, mining and integration with EHR. The strategy for preparing monitoring data for inclusion in EHR is based upon a system of alerts, described below - such systems will always be specific to disease groups. PERFORM is particularly looking at disorders such as Parkinson's disease (PD) and Amyotrophic Lateral Sclerosis (ALS); a type of motor neurone disease. People with PD have symptoms which typically vary throughout the day. It is disempowering not to be able to present the clinician with an objective picture of your disease. Since PERFORM is driven by the patient, they can choose when to be monitored and so can capture the symptoms that most concern them in an objective manner the doctor can exploit. Development of the system is ongoing with pilots in 2009. PERFORM is an integrated project receiving support under Framework Programme 7.

II. Clinical data deficit, acquisition and reduction

Assessment for neurological disorders such as PD and ALS is largely based on intermittent clinical visits and subjective reports by patients and carers. In Europe neurologists and GPs normally care for 50 to 800 patients with PD[1] (fewer with ALS). The range in workload is a result of diversity both in national health systems and in the availability of clinical resources across Europe. Even at 50 patients per clinician this represents a serious challenge to homecare monitoring for specialised conditions. Patients with neurological diseases such as Parkinson's disease and ALS normally visit their specialised clinician or GP every 4-6 months. As a result, any changes in the patient's condition may not be recognised for several months, unless the patient themselves makes contact. Certainly for PD there is the additional complication of symptoms which vary throughout the day (swinging between "on" and "off" phases). It is disempowering for the patient to be asked to present a true picture of their disease in a pre-scheduled one hour appointment. There is therefore a critical need for home monitoring in this class of diseases. The monitoring

O. Dössel and W.C. Schlegel (Eds.): WC 2009, IFMBE Proceedings 25/IX, pp. 533–535, 2009.
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system itself should empower the patient so that they choose when they are monitored. They are effectively in the position of being able to write part of their own EHR.

Home monitoring systems such as PERFORM process patient data on a daily basis and integration with EHR is a challenge. A major objective of home-based monitoring therefore is data reduction by analysing raw data and passing on to the hospital only notifications of events that are of clinical relevance. The correct processing and reduction of data locally is critical to building home-based monitoring EHR of value. The PERFORM strategy is to process the raw data locally and from this develop a system of alerts which are raised when features of clinical relevance are found. This massively reduces the data set and produces data which integrate well with EHR at the expense of making the system specific to a disease family.

In the case of PERFORM data is gathered by wearable sensors; typically five triaxial 50Hz accelerometers, plus gyroscopes, pressure and optionally blood-oxygen and electroculogram (during sleep) sensors. Symptoms of general clinical interest in neurologically-based motion disorders such as Parkinson's disease are tremor, *dyskinesia* (poorly constrained movement) *bradykinesia* (slow movement), *akinesia* (no movement), and falls.[2] Tremor needs to be distinguished between tremor at rest (*rest* tremor) and in activity (*action* tremor). In Parkinson's disease, the fluctuation of the patient between "on" phases of well managed symptoms and "off" phases of poorly managed symptoms is important as is the occurrence of "freezing" (sudden-onset akinesia).[2]

III. Patient management and modelling

PERFORM passes no raw data on to the EHR repository. Instead data is locally processed and notifications (alerts) of clinical events are raised. The event data flowing into the central hospital EHR need to support two distinct objectives: patient management and modelling.

For patient management, events are detected which are known to be of importance to the condition being treated. Patient Management sub-modules are dedicated to supporting the clinician in the management of a specific disease. For example, for a patient with Parkinson's disease it is essential to recognize when an "off" state is appearing earlier than expected, if a fall is connected to a freezing or if recognized tremor is action tremor. Algorithms for the detection of bradykinesia, dyskinesia, tremor and freezing are available in the literature and are not described here.[3-5] Since the PERFORM system is (de)activated by the patient themselves they can guide their own management by using home monitoring to objectively show their doctor the nature of their most difficult symptoms.

Conversely, the patient model is used by the system to capture the patient-specific characteristics of the disease. Commonly in chronic neurological diseases patients do not present the same constellation of symptoms, and even universal symptoms are expressed quite differently across patients. Typical examples would be Parkinson's dyskinesia (the exact pattern of movement is not static and is different for each patient), or tremor (which can appear on different sides of the body and evolve differently during the disease)[1]. For each such symptom, the patient model represents the current expression of the symptom for each specific patient. This provides EHR which can be used to immediately recognize differences in the way a symptom is expressed and trigger corresponding alerts. If the challenge of building an alert-based patient management system and model can be met, EHR based on home-monitoring becomes far more manageable. In PERFORM one metric of the success of the alert-based architecture will be the ability to data mine the EHR.

IV. Pilots

The PERFORM project will be conducting pilots at three sites managed by University of Navarra (Spain) and University of Ioannina (Greece). In each clinical environment different EHR management systems are operative but fundamental clinical information can be exchanged via standard interfaces. The major variables are (where *inbound* denotes flow *into* PERFORM):

- General patient information (demographic data) : *inbound/outbound*
- Patient anamnesis: *inbound*
- Reports on patient pathology: *outbound*
- Medication types and schedule: *outbound*

The exchange of information between the PERFORM Central Hospital Unit and external Clinical Information Systems will be based on the XML-based HL7 version 3. PERFORM will be tested for accessibility since it must be usable by patients whatever their condition.

V. Summary

A fundamental problem in digital homecare is the inclusion of monitoring data in EHRs. The PERFORM project is building an innovative homecare monitoring system for people with neurological diseases such as PD and ALS.

PERFORM puts the patient at the centre of their own disease management. PERFORM solves the EHR problem by processing the monitoring data before EHR storage by reducing the data to a series of events and this can only be done on the basis of clinical knowledge about the diseases. Therefore this is an approach to EHR which is specific to disease groups. The stream of monitoring event data in a digital homecare system must be constructed with the different objectives of patient management and modelling in mind. PERFORM will be running pilots in Spain, Greece and Italy starting in 2009.

Acknowledgment

PERFORM is supported by EU Framework Programme 7, Agreement 215952.

References

1. D3.2 Review of Technologies, System Architecture & Functional Specification, PERFORM Project, January 2009, based on interviews with neurologists.
2. A.Samii, J.Nutt, B.Ransom, Parkinson's disease, *The Lancet* 9423 (2004), 1783-1793
3. .I.Hoff, V. van der Meer, J.J. van Hilten, Accuracy of Objective Ambulatory Accelerometry in Detecting Motor Complications in Patients With Parkinson Disease, *Clin Neuropharmacol* 27 (2004), 53-57
4. G Wu, S Xue, "Portable Pre-impact Fall Detector With Inertial Sensors", *IEEE Transactions on Neural Systems and Rehabilitation Engineering* 16 (2008), 178-183
5. J Gour, R Edwards, S Lemieux, Movement patterns of peak-dose levodopa-induced dyskinesias in patients with Parkinson's disease, *Brain Research Bulletin* 74 (2007), 66-74

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