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Reusing Patient Data to Enhance Patient Empowerment and Electronic Disease Surveillance

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ABSTRACT

Objective: To improve patient empowerment and enhance early detection of infections through reusing physiological data collected by patients with chronic diseases, e.g. diabetes.

Methods: The solution described is based on three different projects at the Norwegian Centre for Telemedicine, University Hospital of North Norway and the University of Tromsø: (1) A self-help tool for people with diabetes, (2) a distributed system (the Snow system) that collects data from Electronic Health Records (EHRs) and laboratories, and after the data has been processed makes it available to end users, e.g. patients and general practitioners (GPs) as statistical data, (3) an electronic disease surveillance system.

Blood glucose levels measured and stored electronically by patients are pulled by the Snow system and after being processed are made available to patients (GPs and other health personnel) so that an individual patient can assess how well their diabetes is being managed in comparison to a similar cohort of patients. Based on elevated blood glucose levels being an early indicator for infection the data is also passed to the electronic disease surveillance system for analysis.

Results: Interaction with patients during the design of the self-help tool for people with diabetes, and in the construction of the disease surveillance system, indicated that for some patients, access to other patients' data (i.e. reusing the data) may be beneficial for a patient's health. The system has not yet been evaluated to see if it can reliably identify patients with an infection in the early stages of the disease.

Conclusion: Through the use of personal health records (electronic diary), a system for transmission of personal health data to general practitioners' electronic health records, a system for extraction of diagnoses codes from EHRs, and a system for transmission of patient data between different EHRs, we have designed a system for electronic disease surveillance that works both on a micro and macro level. The system is expected to provide individual data for the patient to enable comparison between patient groups, and identify early detection of patients with an infection.

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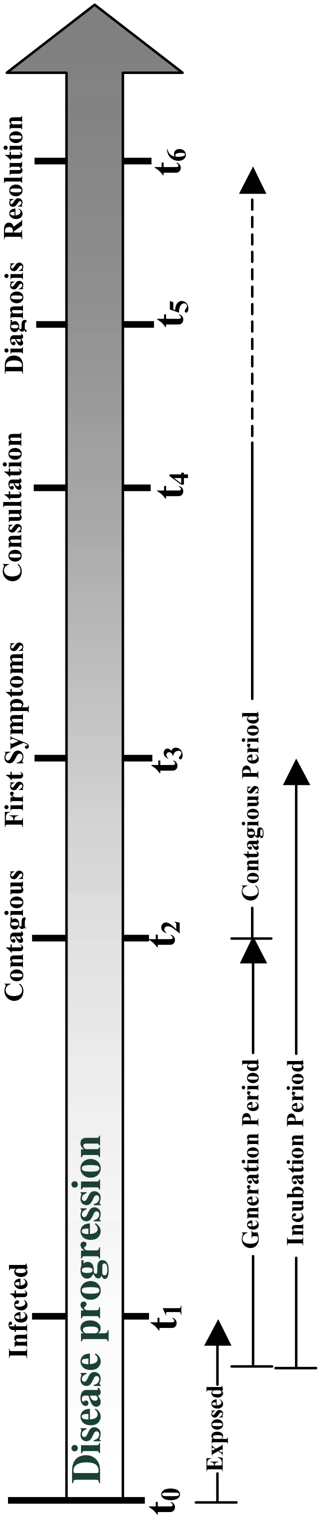

Figure 1. *The subject is exposed to a pathogen and is either infected or not. Various types of data are used for disease surveillance purposes.*

INTRODUCTION

Data for patients with chronic diseases is usually collected and used solely to manage their disease, but the potential for using the data for other purposes exists. Patients usually only compare their data with their own historical data but could compare it with data from other patients to give them a better idea of how well they are managing their disease in comparison to other patients. The potential for reusing the data for other purposes, e.g. infectious disease surveillance, is also possible.

Infectious diseases are an important cause of morbidity and mortality, and early diagnosis of cases is highly desirable as early treatment can both prevent deaths and the spread of disease.

Infectious disease cases characteristically pass through a number of stages as shown in Figure 1. Most disease surveillance systems act at the t4 and t5 stage, i.e. when the patient presents to a doctor and is diagnosed. It would be highly advantageous if infectious cases could be diagnosed before stage 3 and preferably before stage 2. Achieving this goal requires the presence of a measurable marker that appears before the onset of symptoms. Several blood markers rise in the early stages of infection, e.g. the White Blood Cell (WBC) count, but from a practical point of view the marker must be something that is regularly/routinely measured. In diabetic patients a rise in blood glucose levels or difficulty in controlling blood glucose levels is one of the signs of early infection. As blood glucose levels are regularly measured in diabetics it is feasible to develop an infection surveillance model based on detecting rises in blood glucose levels / increased difficulty in controlling blood glucose in diabetic patients.

In this paper we propose an Electronic Disease System (EDS) that uses data collected by diabetic patients to enhance patient empowerment and for early infectious disease surveillance[1,2].

MATERIAL/METHODS

The EDS utilises three other systems that we have developed:

(i) Diabetics Self-help Tool
(ii) The Snow Agent System
(iii) Electronic Disease Surveillance System

Diabetics Self-help Tool

The diabetics self-help tool was developed by the Norwegian Centre for Telemedicine for patients with Type 2 (non insulin dependent) diabetes[1–6]. An overview of the system is shown in Figure 2. It enables input from (A1) Physical exercise (a step counter), (A2) Blood glucose meters and (B) Nutritional data. The collected data is expected to motivate and stimulate users to adopt a healthier lifestyle.

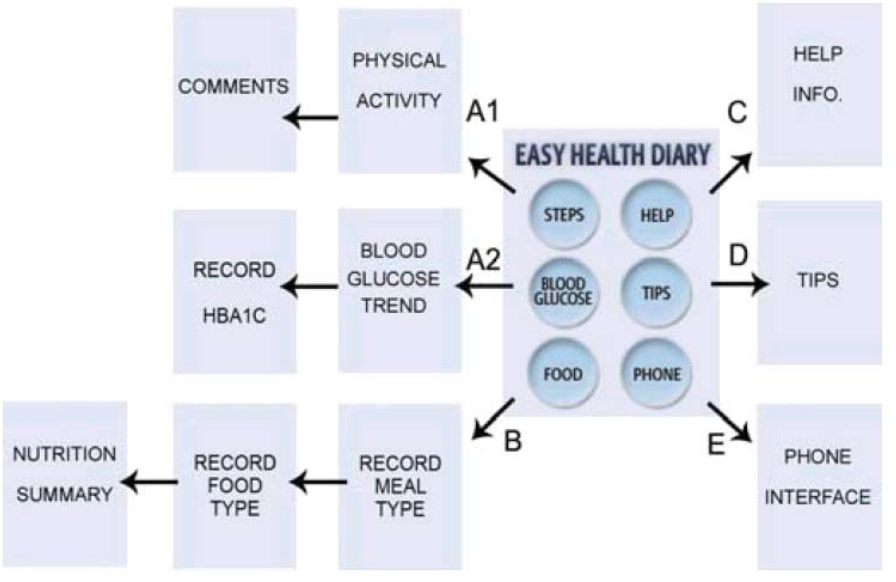

Figure 2. *Diabetic self-help tool user interface and main functionality*

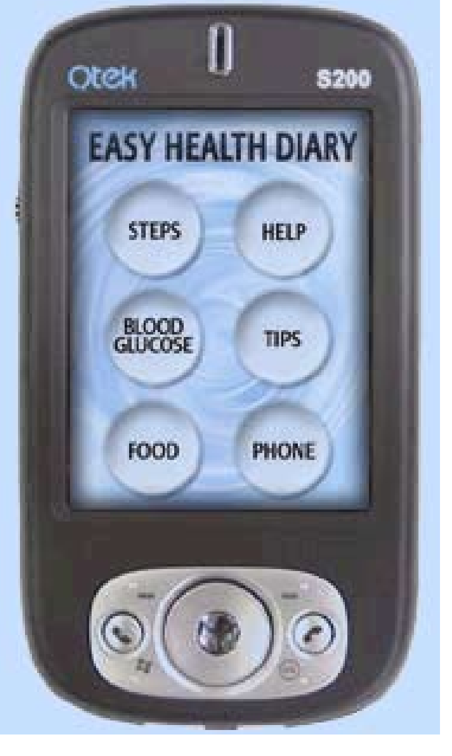

Figure 3. *Smartphone used in the diabetic self-help tool*

The sensors communicate wirelessly with a smartphone (Figure 3)[5,7] which holds an electronic diary (eDiary) and thus up to date data is always available in the eDiary (Figure 3)[1]. Data can be sent from the smartphone to be stored in the patient's Electronic Health Record (EHR) which is maintained by their general practitioner.

The Snow Agent System

The Snow Agent System is named after John Snow, a British physician who pioneered epidemiology by correctly identifying the source of an outbreak of cholera in London in 1854. The system has been developed to automatically extract data from electronic patient record systems and other healthcare information sources such as laboratories, and after processing the data to make it available as statistical data to GPs, community doctors and public health institutions[7–9]. For example the number of influenza cases can be analysed per day, week, district, etc. An example of a disease outbreak taken from "The Snow Agent System" is shown in Figure 4. The data can be interpreted in conjunction with other data.

Electronic Disease Surveillance System

In the electronic disease surveillance project, we have attempted to develop a system (electronic Disease Surveillance System – eDSS) that is capable of early detection of

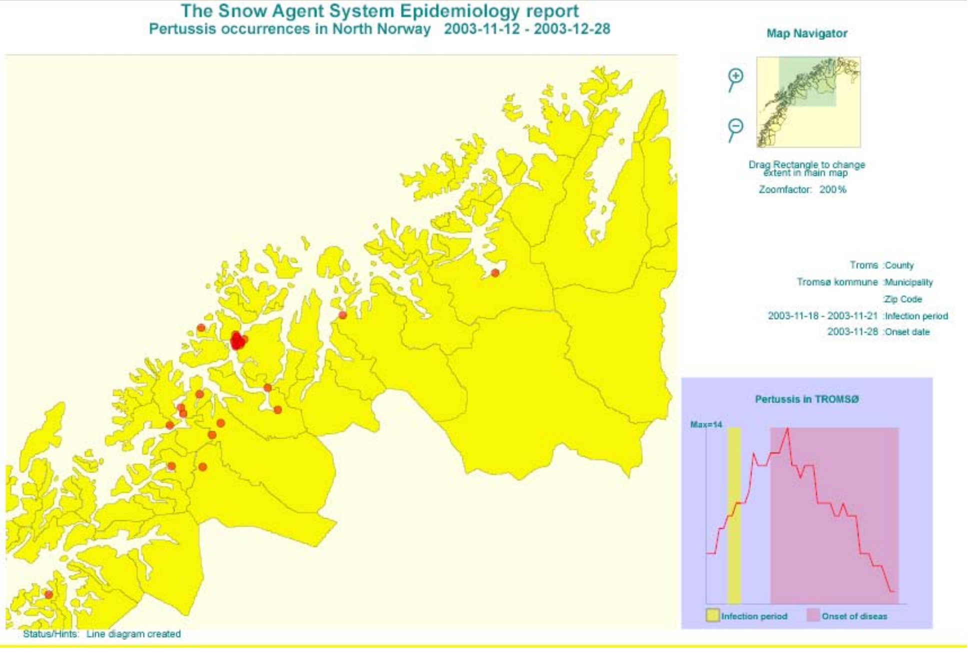

Figure 4. *Display from the Snow system of the spread on Pertussis in North Norway in late 2003*

infectious disease cases[10–16]. Most current disease surveillance systems only target the period after the onset of symptoms and frequently only when a diagnosis is confirmed (Stages t4 and t5 in Figure 1). However, as for the majority of infections a contagious period precedes the onset of symptoms, current surveillance systems are not effective for enabling early action to be taken to curtail the spread of an infectious disease and also to initiate early treatment for infected patients. The objective of the eDSS is to detect the disease in the incubation period (before stage t3 in Figure 1), i.e. before any signs or symptoms of the disease appear.

The key challenge with this approach is to identify an appropriate marker that could facilitate the detection of infectious diseases during the incubation period. Our approach is based on the assumption that some physiological indicators are altered immediately after infection in the first stages of the incubation period. For example, the white blood cell (WBC) count is altered when a person is exposed to a pathogen and such a marker could be used as an input to an eDSS. This, however, produces the logistical problem of measuring the marker in the general population. To circumnavigate this problem we have chosen to evaluate the eDSS model in diabetic patients who perform regular blood glucose tests since a high correlation has been demonstrated between elevated blood glucose levels and infections in diabetic patients[13].

Electronic Disease System (EDS)

In our proposed Electronic Disease System, blood glucose readings made by diabetic patients are automatically passed to their EHR. From here the data is pulled by the Snow communication infrastructure and passed for analysis and returned as statistical data. The data is also passed to the eDSS for analysis to identify any potential infectious cases and to inform the authorities as appropriate.

RESULTS

All 3 systems have been individually implemented and evaluated. How the 3 systems interact in the EDS is shown in Figure 5. Data can be inputted into the EDS either directly from the glucose sensor and/or other electronic sensors, the patient's eHealth diary or the patient's EHR. The Snow system facilitates transmission of personal health data to the general practitioners' electronic health records, the extraction of diagnoses codes from EHRs and transmission of patient data between different EHRs. The outputs of the EDS are:

- Electronic disease surveillance that works both on a micro and macro level
- Comparison between patient groups
- Early detection of infections

As part of the project, 15 Type 2 diabetics aged between 40 and 70 years participated in a 4 month study. The users met in focus groups where relevant topics in the treatment of diabetes were discussed. The user feedback clearly indicated

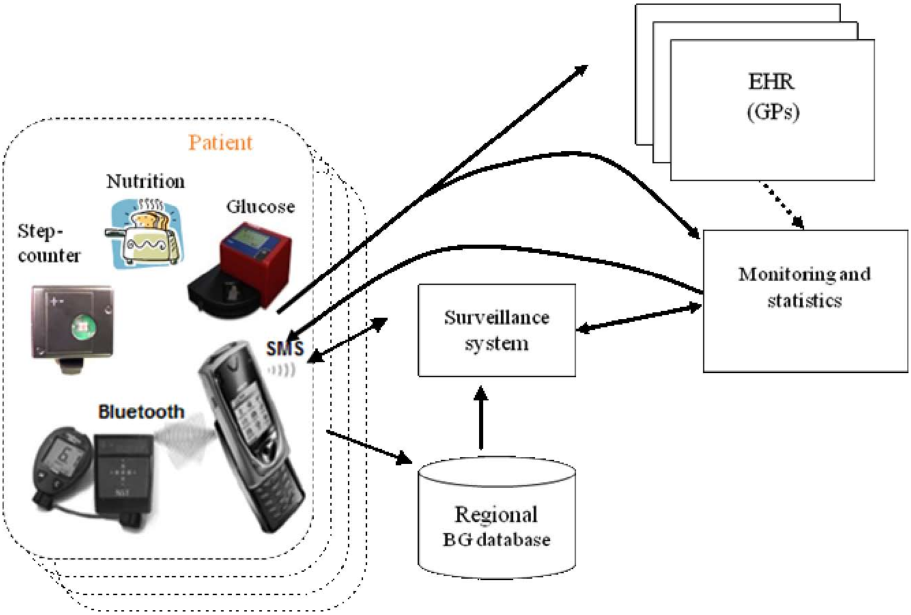

Figure 5. *Electronic disease system (EDS) based on reuse of patient data.*
BG = Blood Glucose, EHR = Electronic Health Record, GP = General Practitioner, SMS = Short Message Service.

that patients felt that more data on their diabetes, both on an individual as well as group level, would help them better control their diabetes. The combination of data on blood glucose levels, physical activity and nutrition habits, was regarded as being very important in helping them achieve the goal of adapting to a healthier lifestyle.

DISCUSSION

A key benefit of electronic health records is that data only has to be collected once and can then be reused several times. This principle applies both to patient demographic data and clinical data. The Electronic Disease System that we have developed aims to enhance reuse of clinical data for the benefit of both individual patients and healthcare services.

Physiological data is collected on a daily basis by many patients with chronic diseases, e.g. blood glucose levels in diabetics or peak expiratory flow rates in asthmatics. However as most personal health monitoring systems use proprietary systems to store and interpret the data, the data usually remains confined to the patient. The patient may share the data with their general practitioner, but this rarely involves all the data being entered into the patient's EHR which is maintained by the GP. The data consequently cannot be used for other purposes. We have addressed this problem through the development of the Diabetics self-help tool and the Snow system. The former allows data captured by electronic sensors to be automatically entered in the patient's eHealth diary (held in a smartphone). From here the data is automatically sent and entered in the patient's EHR. This data in turn can be extracted by the Snow system along with data from other patients and analysed. The analysed data is returned and enables patients (and their GP) to determine how well they are managing their diabetes in comparison to other diabetic patients of their age and gender. When the system is implemented in a health network with a large number of diabetic patients (or patients with other chronic diseases), the system should produce a positive effect not only for individual patients but the general population as well.

In this project we have extended the use of patient-collected data for electronic infectious disease surveillance. As part of the body's response to an infection, blood glucose levels tend to rise[12–14], but in non-diabetics this is quickly compensated for and glucose levels are maintained at normal levels. Diabetic patients do not have this same level of control and their blood glucose levels become elevated for some time. As a consequence this can be used as an indicator of infection. It should however be appreciates that elevated blood glucose levels is a non specific marker of infection, i.e. blood glucose levels can rise in diabetics for other reasons than an infection. There are other more specific markers of infection, e.g. C-reactive protein (CRP) or the white blood cell count and the latter can be measured by some home testing systems.

Inevitably patients will become aware when their blood glucose levels become elevated, but the electronic disease surveillance module will perform reliable and consistent analysis. In addition the surveillance system can also use other data provided by the Snow system to heighten its sensitivity. For example if the Snow system shows there are a number of cases of community pneumonia in an area, the first rise of a small elevation of blood glucose in a diabetic patient living in that area could be interpreted by the electronic surveillance system as an early indicator of a chest infection.

We believe that reusing patient clinical data will be an important component of future healthcare systems. At present, much clinical data is collected in primary and secondary care as well as by patients, but remains confined to the clinicians caring for the patient or the patients themselves. Enabling access to these data (in anonymised format), and then processing it through appropriate algorithms offers the opportunity to both enhance patient empowerment and benefit the healthcare system and the population it serves.

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