



***Workshop:
Communication and ICT in Healthcare:
Theory and Practice***

**Enhanced Communication between Care Professional and Patients
with Hemophilia by Using a Web Enabled Electronic Logbook**

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Abstract

Hemophilia

Hemophilia is an X chromosome linked disease characterized by an increased and life-long tendency to hemorrhage due to a deficiency or functional defect of coagulation factor VIII or IX. Treatment has shifted from administering clotting factors on demand, i.e. when a hemorrhage occurs to prophylactic care to prevent hemorrhages from occurring. Clotting factors are a scarce commodity and very expensive. Since clotting factors are still mainly produced out of human plasma, an accurate registration of use and distribution of the medicine is not only vital but also compulsory by Dutch law. Ongoing scientific research is needed to improve the accuracy of doses needed to prevent complications of the disease.

Patient demographical data

In the Netherlands we have approximately 1500 patients with hemophilia. 600 of them have a serious form and need frequent care. At present there are 16 centers where the patients can get their treatment. The Dutch government wants to reduce the number to about 6 centers. Naturally patients do not live in the vicinity of a treatment center.

The Van Creveld Kliniek, National Hemophilia Center, University Medical Center Utrecht, takes care of 350 of the serious cases. At present a patient notes down on paper when and why he administered clotting factors. The doctor only gets an overview when the patient comes to the center, usually 2-3 times a year. If a patient has a serious complication or is otherwise in need of acute medical care, doctors in other hospitals have no insight in the current treatment of the patient at hand.

Problems with in the current on paper registration

- It is time-consuming to get a quick overview on the recent use and cause of administering clotting factors
- No monitoring of the home use of clotting factors in between consultations
- Data are not available for research to optimize the current best practice in hemophilia care
- Data for reporting to the Dutch ministry of health is not easily available
- The paper version of the logbook is physically vulnerable due to possibility of loss or damage
- The patient at all times has to carry a paper copy of his treatment plan on him

Web enabled electronic logbook

Many patients are very computer literate since they have limited choice of a professional occupation due to the disease. To facilitate improved patient care The UMC Utrecht has build an application where the patient as well as the doctor and other care professionals can register and review the treatment and reason of treatment. The application has been tested during a 3 month long pilot. Patients and doctors are very enthusiastic about the use of the application and together with a software developer the application will be improved to facilitate also other treatment centers.

We will give a demonstration of the application and the technical background. The application can run on a PC, PDA or GMS.

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Advantages of the electronic logbook

- Place and time independent registration possible
- Improved communication between patient and -doctor or other healthcare professionals
- Quality improvement of treatment
- Data always available
- Data collection of a minimal dataset for the patient population can be realized and used for research
- Insight in stock of clotting factors at patients home leads to more efficient use and distribution of clotting factors