

# Personalized Health Care Record for Children: Where Needs of Parents, Children and Health Professionals Meet

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## ABSTRACT

In this paper, we describe our project proposal involving the development of a solution for the creation and upkeep of children's personalized health care records. The project envisions the creation of a mobile-cloud platform that would enable parents to collect, keep, and track the personal health records of their children, as well as make them available (fully or partially) to external parties, such as health care specialists. The main motivation lies in the currently dispersed nature of health records issued by various institutions and in various forms. Providing a platform where all these data would converge, would give parents and health care specialists better insight into the health of their children and enable the specialists to quickly find relevant information about their patients in order to give them proper treatment.

## Categories and Subject Descriptors

J.3 [LIFE AND MEDICAL SCIENCES]: Health

## General Terms

Keywords: healthcare, children, personalized health care record (PHR), informatics

## 1. INTRODUCTION

The Slovenian healthcare system is funded by compulsory health insurance paid for by employers and employees. Children's healthcare is fully funded. The system enables modern healthcare facilities available to all citizens. In healthcare, overall well-being is stated of equal importance as general health. The system is divided into primary, secondary, and tertiary health care systems. The first contact is usually through the primary care settings. According to the rule-book, children health care is divided into curative and preventive part. Healthcare for children is declarative taken care by general paediatricians (GP) who are trained according to the highest international standards [1].

However, with the demographic, economical, and social changes, health care system needs an organizational reform. Currently, clinical information technology is used only in the tertiary and the secondary centers, with incompatible platforms. The primary care is left rather unsupported with paper-oriented records with some rare exceptions. Binders and lots of paperwork still can be used

efficiently; however in the era, where almost everyone uses a smartphone, this can be changed.

## 2. VISION

### 2.1 Parent's Needs

Child healthcare is as subject to the fads and fashions of the era as is the nurturing process. In planning primary care we need to think about parents and parenting, about societal influences, and about workforce issues [3]. Over the past years, the GPs have seen enormous changes in parental behaviour, both in respect of the sick child and the well one. The pattern remains one of significantly higher consultation rates in children [4]. The trend is to call on primary care earlier in the evolution of a child's illness. As hospital admission rates for asthma in young children have increased, the mortality rates have declined [5]. Case fatality rates for meningitis have shown little change [6]. This can be interpreted as the need of easily accessible, personalized guidelines for parents. Despite vast number of literature, e-sources, information technologies, etc., the parents feel insecure. Legitimate question they are asking is: "Is this applicable to my child?" Personalized contact is needed even more when the child is ill.

The parents are currently viewed as partners during the treatment of their child. Hence their role becomes more demanding and they face some problems, which are listed here as cases.

#### CASE A:

My child has epilepsy. Every time we come to the doctor's we need to describe the seizure. When seizures are ordinary, such as always, this is no problem. Otherwise we describe it infinitely. I hate explaining this to every single doctor. I would prefer to show them a video. Best solution would be to send the video to our paediatric neurologist instead of meeting doctors who do not even know what kind of rare epileptic syndrome our son has.

#### CASE B:

As we moved to another city, we had lost our immunization booklet. When we enrolled our children in summer camps, we had big problems of getting our health records data since our paediatricians retired in addition to the fact that we have moved to another city. Also not all data were recorded. So I was searching through papers and memories to get data, though not everything I recalled was accurate, I am afraid.

#### CASE C:

Every time we are admitted to the hospital or emergency department, there is some new doctor. Repeating child's milestones: first smile, first step, last check-up, latest vaccination is quite annoying to me. If possible, I would prefer that the doctor already knew these things.

#### CASE D:

Our child is chronically-ill. She has cerebral palsy. We visit doctors very often and believe me – we have seen everything. We, the parents are expected to keep tabs on our children's medications, height and weight, allergies, milestones, and doctor visits. It's a huge undertaking! So I have developed my own system: a fat folder, bulging with scribbled doctor notes, insurance statements, receipts copies, and appointment reminders. Why can they not do it by themselves?

## 2.2 Vision

As individual items that compose a complete personal health record are issued by a variety of institutions (e.g. records from different doctors, labs, hospitals, and pharmacies), an integrated top-down solution that would encompass all relevant actors and give a complete overview of a (digital) personal health record, seems far away. This is especially true if we consider that even individual institutions do not have a centralized digital evidence of their patients and interventions.

Therefore, our vision lies in providing an inverted bottom-up process, where we entrust the creation of such health records to parents. The goal is to create a unified platform, which would enable easy upkeep of children's health record with all relevant information, and give access to these records to health care specialists.

## 3. EXPERIENCE

The project involves the paediatrician who has worked in both, tertiary as well as the primary settings (Paediatrics Clinics Ljubljana, University Clinical Centre Ljubljana, and Health Centre Ljubljana) and collaborates with National Institute for Public Health (NIJZ). Given the experiences with Slovenian health system for child health care, some of the solutions were already proposed in the form of school for parents, education for kindergarten and school professionals, as well as some commercially available video-clips and written materials (e.g.: Babybook, magazines Moj malček, Mama, etc.).

Members of Laboratory of Computer Graphics and Multimedia, Faculty of Computer and Information Science, University of Ljubljana, are experienced with developing mobile and web solutions in the area of eLearning and Multimedia. Currently they are involved in the following development oriented projects:

- PerceiveConceive: an application for ICT-supported inclusion of blind and visually impaired youth in society;
- EtnoFletno: Slovenian folk song and music on mobile devices;
- eExperiments - Modern teaching of natural sciences using flexible open source measuring system;
- CREA - Network of summer academies for the improvement of entrepreneurship innovative sectors.

## 4. PROPOSED PROJECT

We propose the development of a mobile-cloud platform that would enable parents to collect, keep and track the personal health records (PHRs) of their children, as well as make them available (fully or partially) to external parties (health care specialists).

The proposed solution would offer the parents a secure location to store all the relevant health data of their children and give health care specialists more opportunities to find all relevant information about their patients and give them proper treatment according to their needs.

PHRs would combine records from doctors, labs, hospitals, and pharmacies. Parents' notes, observations, questions, and wellness goals could be added. As good record-keeping begins with good record-taking, it is important the data are recorded and updated accurately. Some data would be mandatory and some optional, the latter could make PHRs more appealing to use by parents.

Through the use of flexible mobile and web interfaces, the solution would offer a *secure* environment, where parents would collect all relevant information on their children's health. The mobile interfaces for major mobile platforms would primarily enable the capture of relevant medical data, e.g. keeping track of doctor's visits, capturing (taking photographs) and adding medical records, prescriptions etc. All data would be stored in the cloud, where they would also be indexed (photographed/scanned documents put through optical character recognition) to enable flexible searching of all stored contents. The fully featured web interface would enable a complete overview and upkeep of PHRs, as well as options to share the data with selected external parties. All interfaces would include necessary security mechanisms to prevent unauthorized access to data, as well as keep relevant audit trails.

PHRs within the proposed project should provide an integrated overview of the following data:

- Name, birth date, and contact information (name of both parents or care-givers, address, e-mail, and home- and cell-phone numbers);
- Emergency-contact information;
- Phone numbers and addresses for the primary-care paediatrician, dentist, eye doctor, and preferential specialists;
- Insurance information;
- Daily medications (both prescription and OTC) and supplements, including dosages, frequency, and reason for taking (diagnosis is optional if the parents want it);
- Family history of physical and mental-health conditions. Include parent and sibling information as well as close relatives with notable, inheritable illnesses (e.g.: an aunt who had breast cancer; grandmother who died at age of 50 due to myocardial infarction). Family tree can be created up to 3 generations.

Additionally, data important to health care workers should include:

- List of chronic health conditions (such as asthma, ADHD, and diabetes), including treatments, prescription names, and dosages and history of hospitalization, surgical procedures;
- Allergies and sensitivities to medications, foods, and materials;

- Dates and types of immunizations;
- Specific data about birth (weight, height, head circumference, Apgar score);
- History of breastfeeding; any special diets;
- Blood typing (if known);
- Lab results, which were recorded during the last systematic review, and blood-pressure readings;
- Results of recent checkups, including height, weight, and body mass index (BMI) with children's growth-chart percentiles. Individual growth chart can be drawn from the data;
- List of chronic health conditions (such as asthma, ADHD, and diabetes), including treatments, prescription names, and dosages and history of hospitalization;
- Allergies and sensitivities to medications, foods, and materials.

Optional data, which could make the use of PHR more appealing for parents could include:

- Photo of the child (one photo/child year with date);
- Video clips of major milestones (e.g.: smile, walking, talking, running with date);
- Parents' notes and observations;
- Questions for health care professionals.

#### 4.1 Partners

The project consortium already has the necessary knowledge to successfully develop the proposed solution, however we are interested to expand with interested parties from medical and IT domains.

## 5. CONCLUSIONS

We proposed the development of a personalized health care record, based on a mobile-cloud platform that would enable parents to collect, keep, and track the personal data of their children, which are relevant for their health and well-being. As the data could be available to health care specialists, the procedures in which children and their parents are involved could be shortened and made easier. The application would therefore represent a hub – meeting point of all participants: parents, children, as well as health care specialist, making the otherwise unpleasant interactions easier, friendlier, and more reliable.

## 6. REFERENCES

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