

# E-health in youth care

An overview of the main social-cultural impacts of digital patients records in youth healthcare.

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## ***Draft version***

*This version of the paper is only a sketch of the main storyline. More references need to be included and better fitted into the text. Furthermore a large part is only worked out in bullet points.*

## Abstract

*Situation, Complication,*

*Approach, Results,*

*Next steps*

Keywords: E-health, Youth healthcare, information systems, social-cultural impact

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## Introduction

In our digitalizing world, all kind of healthcare services are adopting more and more information systems. In the youth healthcare, this process is also going on. (Ludwick & Doucette, 2009). The fact that (1) children are not (yet) capable of standing up for their own rights and that (2) the maturation of children can be seriously harmed when information about treatments is misused makes this a special case in comparison to the digitisation of 'regular' healthcare (e-health) received by adults. Therefore this paper will focus on the following problem statement:

*What are the main social-cultural impacts of the implementation of electronic patient records and digitisation of the administration for youth care and what can designers of information systems learn from this?*

In order to get an overview of the current social-cultural influences of e-health in youth healthcare, first the main concepts will shortly be introduced and defined. After that, in order to give some context of the importance of youth healthcare, the article concerning youth healthcare of the Convention on the Rights of Children (United Nations) is shortly discussed.

Since the involved people are in this case mainly the children receiving the care, their parents and the doctors providing youth care, in the next section the social-cultural impact of E-health on them is

discussed. In this section the impact on (1) children and their parents, (2) youth healthcare providers and influence on society in general are being discussed.

In an attempt to cope with the social-cultural impacts on the different parties, the role of designers of information systems will be discussed and how they can deal with the impact of E-health in youth healthcare while designing information systems.

The insights of this paper will hopefully help the youth care to digitise its patient records and administration in a responsible way, while aware of the socio-cultural impact this might have.

## Definition of the main concepts

In this section, the main concepts used in this paper are introduced and defined in order to avoid confusion. After the main concepts are defined the scope of this paper is also shortly discussed. The main concepts defined are:

- E-health
- Youth healthcare
- Information systems

### E-health

Within this paper, E-health is used as a concept to catch the digitisation of the *administration* of the healthcare (and youth healthcare in particular). All other kind of trends in the digitisation of health, like telecare (as described by for example (Barlow, Singh, Bayer, & Curry, 2007)), the use of apps in healthcare (Boulos, Wheeler, Tavares, & Jones, 2011) or e-health by any other means of changes in healthcare by using information and communication technology (ICT)(like (del Hoyo-Barbolla, Arredondo, Ortega-Portillo, Fernández, & Villalba-Mora, 2006)). The reason to focus on the administration part is twofold; (1) these changes are a trend (not a hype)<sup>1</sup>; it is quite certain that the digitisation of the administration systems used in healthcare are not going back to 'old-school' hardcopy card catalogue. (2) The literature available in this field is less exploratory then in the other fields; this means that in this field less uncertainty about the findings are and stronger recommendations can be drawn from this.

### Youth healthcare

All health provided to persons younger than 18 years old. This include also mental healthcare and regular school healthcare. Excluded is child protection, because in this kind of care has a lot of other dimensions then 'regular' youth healthcare.

### Information systems

In this paper, we use the 'information layer' and the 'business layer' from the model created by (Bouwman & Janssen, 2010). This means that details about practical implementation will be avoided and the focus will be on design principles and how they should be chosen regarding the social-cultural effects of e-health in youth healthcare. By using a known enterprise architecture framework, confusion about the level of abstraction is hopefully being avoided.

### Scope of this paper

This paper focusses on the social-cultural impacts of two aspects of e-health; (1) the social-cultural impacts of the implementation of electronic patient records and (2) digitalisation of the administration

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<sup>1</sup> Note that we use 'trend' here to describe a phenomenon that lasts, while a 'hype' is seen as something that is booming/trending only for a short while and then disappears again.

in the youth care. Although legal aspects differ a lot per country, a general view on the youth healthcare in the western world (especially Europe) is attempted.

## Children rights concerning (E-)Health

To sketch the context in which the digitisation of healthcare is taking place, article 24 of the Convention on the Rights of Children of the United Nations is shortly discussed.

*"[24.]1. States Parties recognize the right of the child to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health. States Parties shall strive to ensure that no child is deprived of his or her right of access to such healthcare services." (United Nations, 2014)*

This article states that every child in the world has the right to gain the best medical attention possible. Regarding E-health, this means that improvements/changes can only be implemented if it is a clear improvement for the quality of the healthcare (or at least neutral). With the healthcare turning more commercial last years, this is even more important; an E-health implementation aimed at the improvement of the business model of a healthcare provider is only allowed if it doesn't bring the quality of the healthcare provided in danger.

*The next section is only worked out in bullet points.*

## E-health; what is the impact of digital patient records

The impact of e-health on the different involved parties will shortly be discussed here. The privacy of the children involved is taken into account at each separate party.

### Influence for the children & their parents

The fact that records are kept digitally has a lot of influence on the children and their parents.

- Privacy
- Right to see own/child's record?
- advantages

### Influence on healthcare providers

In this section the influence of e-health on healthcare providers is discussed. This is split up in a part about the influence on medical personnel and the organisations they are working for.

#### Influence on medical personnel

- Influence on privacy
- Influence on time spending to do administration vs real treatment time
- Advantages

#### Influence on organisations providing youth healthcare

- Influence on efficiency
- Influence on managing possibilities
- Influence on (digital) security measures

## Influence on society

- Discussion about the balance between privacy and preventing incidents
- The right to be forgotten?

## How to design for information systems for youth healthcare

- Formulation of design principles for designing information systems in youth healthcare
  - Privacy by design (Cavoukian, 2009)

## Conclusion

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