Why Are Children's Interests Invisible in European National E-Health Strategies?

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Abstract. Harnessing the power of IT solutions in child primary care requires strategic thought at national level, and good health care delivery needs this support. The aim of this study was to investigate whether children's needs are considered in national e-health strategies in Europe. In 2016, a survey was carried out in all 28 European Member States plus 2 European Economic Area countries. Sixteen countries fail to mention children's needs at all. Only eleven of 27 countries mention children and adolescents in their national e-health strategy documents ranging from mere data protection concerns to comprehensive IT approaches for the improvement of child primary care.

Keywords. e-health strategies, Child primary care, Europe, informatics, policy

1. Introduction

In May 2012, the Estonian President Toomas Hendrik Ilves, Chair of the independent high-level European Commission's e-Health Task Force said: "*We know that in healthcare we lag at least 10 years behind virtually every other area in the implementation of IT solutions. We know from a wide range of other services that information technology applications can radically revolutionise and improve the way we do things*" [1].

In child health the issues are even more important for a number of reasons. Infants and young children cannot speak for themselves, give their own history, or supply past health information, thus an up-to-date health record is therefore vital. This is even more essential where parents may not know the full details (such as clinical factors at birth), are themselves stressed or confused, or in those cases where for whatever reason the parents neglect their child's best interests. In these cases, as Rigby has previously indicated, the record acts as the child's advocate [2]. Electronic health records give a modern effective way of ensuring that accurate, timely data is available at the point of clinical contact, or in ensuring that all preventive services have reached a child. However, not only is the pattern of implementation of e-health very varied across Europe, but in many cases systems are designed and implemented to a generic model

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based on adults' needs, without awareness of the particular issues of child e-health records – ranging from the need to link records even before the child has a formal name or civil citizen status, through to the child-specific data items which are important to record such as accurate preventive care (screening and immunisation), growth analysis and developmental status, child protection concerns, and interface with dedicated adolescent health services.

E-health is a complex field, which at the same time should be harmonised and compatible between installations and applications. A strategy to direct planned multi-agent investment is a necessary tool to ensure orderly and efficient progress, focused on clear health benefit objectives. WHO encourages the development of national strategies. In 2012 the WHO and the International Telecommunications Union (ITU) published a national e-Health Strategy Toolkit to offer support to those countries developing an e-health vision and strategy as well as for those where there is a necessity to revitalise available strategies [3]. According to WHO and the ITU, such strategies should be based on national health priorities, available and potential resources, and the current e-health environment. In practice, however, a considerable number of countries are struggling with meeting these requirements. In order to ascertain the currency of national policies, the WHO holds for each country a repository of e-health policies and claims this to be a collection of current national e-health strategies [4].

This paper provides a locally informed view as whether these policies are up-to-date and whether children have been considered in the national e-health strategies. It is based on a study to identify to what extent European countries have defined the health needs of children and adolescents in their national strategies and to what extent ICT solutions have been considered as possible means for the implementation of these strategic goals.

2. Methods

The Horizon 2020 funded project Models Of Child Health Appraised (MOCHA), running from 2015 to 2018, is charged with identifying optimal models of primary care for children, including the role of electronic records to support care delivery [5]. In February 2016, in order assess how well children were supported in national e-health policies, the project carried out an analysis of available national e-health strategies as contained in the WHO depository (http://www.who.int/goe/policies/countries/en/, (access dates 8 and 9/02/16). A key methodological feature of the MOCHA project is the retention in each study country of a part-time Country Agent – a local expert in child health services – who acts as the informant for obtaining data requested by the principal scientists in the project, using local indigenous sources. Questions asked of Country Agents have passed through internal and external scientific scrutiny to confirm their rationale, relevance, and clarity.

To investigate whether children and e-health are considered in national e-health strategies, data were gathered between 21st March and 29th April 2016 through the MOCHA country agent network, thus ensuring local analysis in national languages. The questionnaire was designed as a semi structured survey instrument and asked whether the e-health strategy available in the WHO depository was the current document for each country, and whether it was the only one. MOCHA country agents were asked to list any other relevant e-health document, and to ascertain the presence

of content of each document regarding e-health and children, or the total absence of mention of children.

At the time six out of 30 national e-health strategies were readily available in English with a working link, for 16 countries the documents were available in the countries' own languages only and for eight countries the document was not accessible at all either because a false link was provided or the document was not available at the link provided.

3. Results

Replies were initially received from 27 countries. Eleven out of 27 countries' MOCHA Country Agents replied that the e-health strategy contained in the WHO depository (as of April 2016) was the latest. Twenty said that beside the documents contained in the WHO depository there were other national strategies. Only eleven countries - Cyprus, Germany, Hungary, Ireland, Latvia, Lithuania, Norway, Poland, Portugal, Spain and the UK - mentioned that their countries' e-health strategy contained considerations on children and adolescents. Sixteen replies stated that their national e-health strategy did not consider children and adolescents. Data for 3 countries are still outstanding. Details are given in table 1 and Figure 1.

Table 1: Overview on document currency and context (April 2016) [1,2]

Is the WHO document the latest?		Is the WHO document the only document?	
Yes	No	Yes	No
Bulgaria	Austria*	Finland*	Austria*
Cyprus*	Belgium*	Hungary	Belgium*
Finland*	Croatia	Italy	Bulgaria
Hungary	Czech Rep*	Latvia	Croatia
Italy	Estonia	Romania	Cyprus*
Latvia	Germany	Slovakia	Czech Rep*
Lithuania	Greece*	Sweden	Estonia
Portugal*	Iceland*		Germany
Slovakia	Ireland*		Greece*
Spain*	Luxembourg		Iceland*
Sweden	Malta		Ireland*
	NL		Lithuania
	Norway		Luxembourg
	Poland*		Malta
	Romania		NL
	UK		Norway
			Poland*
			Portugal*
* WHO update since June 2016			Spain*
			UK
11	16	7	20

[1] Independent of the analysis in this paper, the WHO has updated the repository on national e-health strategies in June 2016. Because field work had been completed in May 2016, it has not yet been possible to update the paper.

Only eleven of 27 countries mention children and adolescents in their national e-health strategy documents, ranging in some cases from mere reflections of data protection concerns, to other countries' comprehensive approaches covering a broad variety of potential areas for the improvement of child primary care through information and communication technology. Whether this weak coverage is due to lack of awarenss of the importance of specific data items and healthcare delivery processes for children, insufficient prioritisation of child healthcare, a lack of appreciation of ICT solutions in the healthcare context, or a lack of resources to sufficiently address challenges linked to a possible implementation, can not be answered at this stage. It is, however, astonishing how little strategic thought is currently spent on the potenial of ICT approaches to make child health care safe and efficient. Clear descriptions of current child health needs, definitions of goals for improvement in child health care, stakeholders to be involved and aligned ICT measures as means of improvement are largely missing.

Figure 1 provides an overview on countries considering children and adolescents in national e-health strategies and those that do not, independent from the actual implementation status of the strategies. This is based on the content analysis of national strategy documents and the MOCHA country agents' evaluation on whether children and adolescents were considered in theory. In cases where national e-health strategies do not refer to the needs and vulnerability of children and adolescents, this has to be considered a potentially serious gap given children's dependence on effective modern systems as being a necessary prerequitie to making child and adolescent health care safe and efficient.
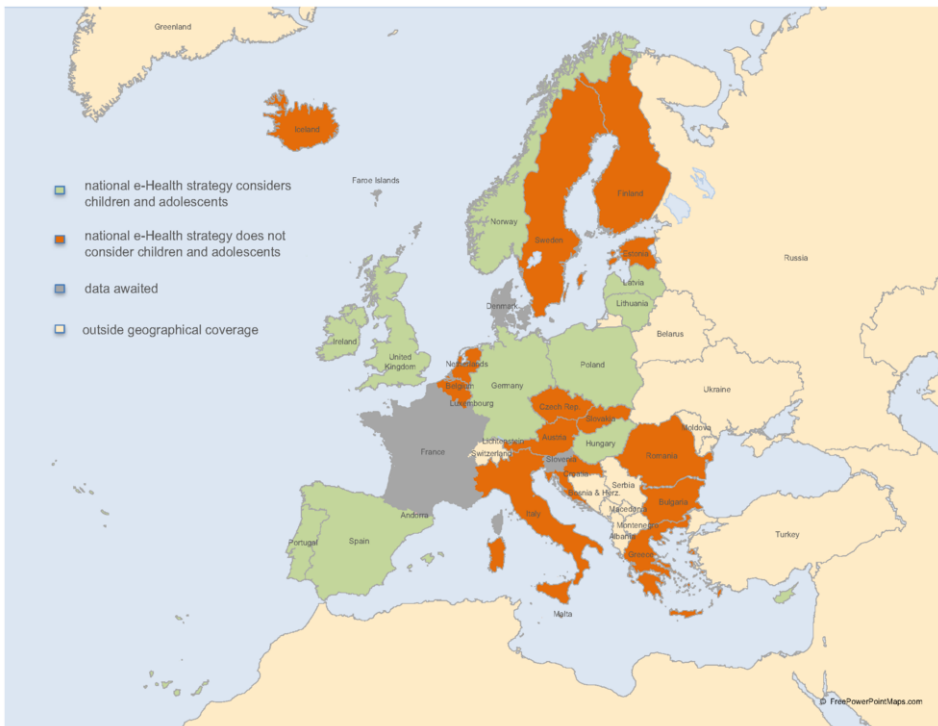

Figure 1. Overview on national e-health strategies

4. Conclusion

Sixteen (59%) of the 27 reporting MOCHA countries fail to give any consideration of children in their national health strategies, and of the 11 (41%) which mention children, seven are in a stage of early adoption of e-health solutions to child health. This underpins how little strategic thought is spent on child health interests and the ICT solutions for more effective and safer child health care, even though IT applications in child health have been a proven cost-effective European innovation for over 50 years [6, 7].

The appropriate development of electronic health records and e-health services for children is severely compromised if under 50% of reporting countries have any mention of the particular needs of children and adolescents, their health, and equitable efficient and effective modern health delivery and monitoring. The findings of this study do not accord with the societal and health system duty of care to children who are dependent on them and cannot advocate for themselves.

This work will be progressed through an inventory of system availability (in hand), and matched to other MOCHA work on patterns of healthcare provision and optimal future models of delivery of children's primary care. Enhanced e-health support will be part of that visioning, and this first policy analysis will help formulate the degree and direction of strategy development needed, as well as initiating discussion on the issues.

Acknowledgements

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