

# Towards Safe and Efficient Child Primary Care – Gaps in the Use of Unique Identifiers in Europe

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**Abstract.** In order to provide for best possible child health care, timely access to all relevant medical data is of vital importance. The aim of this study is to investigate the use of unique identifiers, a key instrument in this regard, in the countries of Europe. A survey was carried out in all 28 European Member States plus 2 European Economic Area countries in 2015, and refreshed in 2016. In 23 countries unique identifiers are used to link children's health records. Five countries indicated they currently do not link child health records, and two have no such plans. There is variety as regards the type of number and the issuing process.

**Keywords.** Child health; Intersectoral health care; eHealth and intersectoral documentation, health telematics; Health Data Management and networking

## 1. Introduction

The UN Convention on the Rights of the Child (to which all European Union (EU) and European Economic Area (EEA) Member States are signatories) defines the highest attainable standard of health care as a fundamental right of every child [1]. The extent to which this requirement is met in practice by national health care systems varies considerably among the countries of Europe, and is the core purpose of the Horizon 2020 funded project Models Of Child Health Appraised (MOCHA), running from 2015 to 2018 [2]. This reported study embedded within MOCHA is focussed on appraising the variations of national health care record linkage systems to identify optimal possibilities, bounded by the ethical and legal concerns regarding the linkage of personal clinical data.

One aspect of the MOCHA study is to examine the role of record keeping in support of primary care, especially electronic child-centric health records, since a precondition for delivery of safe and efficient quality health care is effective and timely access to reliable and inclusive records. Some children, for example neonates, are particularly vulnerable to fragmented clinical information over a comparatively short time, and thus risk receiving sub-optimal care: they are born in one location, supported thereafter by the

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primary care system and possibly by post-natal midwifery follow-up, may be referred to paediatric specialist services in the event of a health problem, and finally may be taken to emergency services in the event of accidental injury or sudden onset illness. Subsequently, clinical (and social) conditions may change rapidly, necessitating access to timely and complete record systems to ensure that the treating health professional has the full picture of their health history.

However, the reality is often that such vital data are fragmented and locked in different provider-based silo systems. Linked health records can provide the complete picture including possible causes of disease, prior health problems or reactions to previous treatments. Thus they provide information in a far more comprehensive manner than can be expected from a child or parent, or from a single provider record [3].

This is of particular importance for those patient groups who are not themselves in a position to provide this kind of information because of a lack of capacity, be it for reasons of age or illness or because of the intrinsic complexity of multi-provider health care provision. Parents may not always know, or give, a full picture, or may not be present. The importance of record linkage in children's health care has been recognised for over 30 years, e.g. [4-6]

The use of a unique record identifier (URI) is a key instrument in this regard. A URI is a nationally organised number (alpha-numeric or numeric) allocated to each citizen, including children, to link their health records. To be effective for children's record linkage it needs to be given at the time of birth to link all records from that time, though in practice in some countries it is given some time later, compromising safe care.

The URI may be a national citizen ID and used in health, or it may be specific for health only. It is national, in that it follows the child if he/she moves internally. The aim of this study is to investigate the variation in the use and application of time of birth URI systems in the countries of Europe, and possible factors hindering implementation.

## **2. Methods**

A key methodological feature of the MOCHA project is the retention in each study country of a local expert in child health services, who obtains data from local indigenous sources. Questions asked of these Country Agents are passed through internal and external scientific scrutiny to confirm rationale, relevance, and clarity.

Within this frame of the project a survey of unique record identifiers for new-born children was carried out between 14th October and 11th November 2015 (and updated for new data). The questionnaire was designed as a semi structured survey instrument. MOCHA Country Agents were asked to complete the questions on the basis of their expertise, or in cases where this was not possible, to gather data from other sources or national experts on individual questionnaire items. The replies of all participants were analysed using descriptive statistics.

The questionnaire asked whether the country had a specific unique record identifier for children, when this was issued, the structure of the number and what type of records it linked (e.g. was it solely for health, or also a unique citizen identifier for all services). The study also enquired whether the identifier, if it existed, was issued to the parents or to the health system. The questionnaire also asked about whether there were on-going plans or policy debates on strengthening children's record linkage.

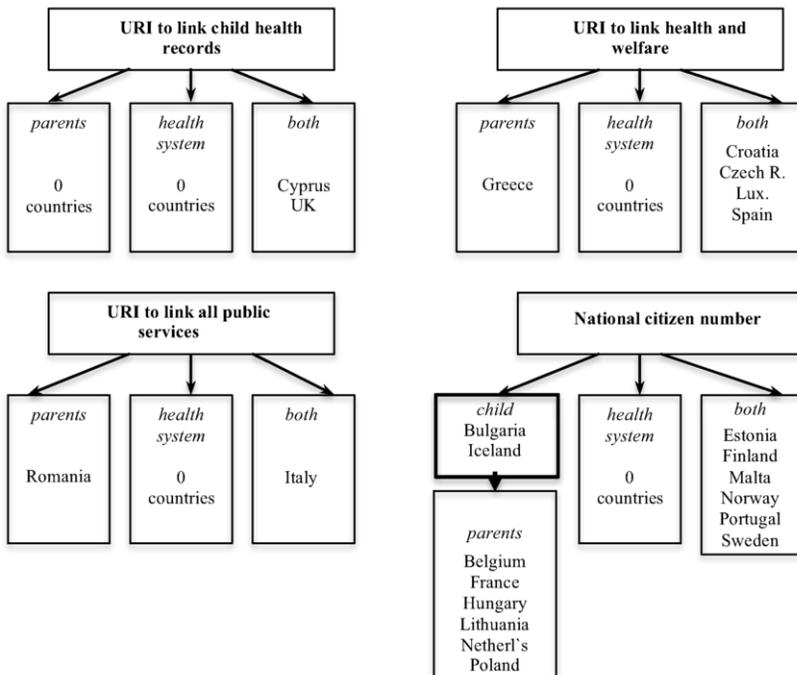
### 3. Results

Replies were initially received from 28 countries. The majority of European countries use a number mechanism to link child health records. Eight of these issue the URI right at birth, the other counties at a later stage. In nine European countries health-specific URI are applied and in 14 more general citizen numbers are used for health record linkage. These 23 countries all use the URI for all records, electronic as well as paper.

Five countries - Austria, Germany, Ireland, Latvia and Slovakia - currently do not link child health records. These five countries differ, however, in the extent to which there are plans for URI implementation. Whereas in Austria, Germany and Ireland there are concrete plans and a set timescale for implementation of a URI including for children, their possible implementation is under debate in Latvia. Slovakia has a number mechanism in place but currently does not use it for record linkage.

Among the countries that link medical records, there is variety as regards the type of number used, the issuing process and details contained as well as the application of URI. Three countries out of 28 reporting differentiated between the application of URI regarding public and private health provision; these are Croatia, Cyprus and Malta.

Figure 1 illustrates the different functionality of URI in different countries, and to whom the number is issued.



**Figure 1.** Overview on national functionality and to whom issued

None of the countries issues the identifier only to the health system, which means in all countries with a URI there is awareness, if not full involvement, of parents. Thirteen countries issue the URI to both health system and parents simultaneously, while ten countries issue it to the parents or child, giving them a key role in ensuring linkage.

Whether this is a hindering or supportive factor as regards healthcare access or health record linkage if parents cannot or do not want to provide the URI has not been included in this study.

The assumption that the overall functionality of the number would have an effect on who the identifier is issued to holds true, in that for those countries where the URI is restricted to health, or health and welfare, linkage it is likely to be issued to both the health system and the parents simultaneously (6 out of 7 such countries). By contrast, where it is a national identifier or citizen number, only 6 out of 14 such countries issue it to the health system directly. This adds another step, and thus potential source of delay or error, when seeking to link records swiftly in times of healthcare need.

The Bulgarian and Icelandic policies are exceptional in this respect as the unique identifier is issued to the new-born child directly. Although this at first sight seems unusual as a child will for their first years need adult representation, upon reflection it is an implicit progressive statement that the child is the focus of care, and that the adults are agents for the child, not controllers of the child's health data. Normally parents will act as agents for the child, but this system aids continuity in times of family restructuring.

In Bulgaria, Estonia, Finland, Iceland, Lithuania and the Netherlands the URI is a numerical code issued at birth, in all other countries at a later stage. What was not ascertained in this initial study is how, and how effectively, data about the delivery and early days of the child are linked to ongoing health records if the unique identifier is not available from the start of the child's life. This suggests a potential risk of treatments or preventive measures being based on incomplete data, and requires further study.

Data protection approaches show conflicting attitudes across a spectrum. In some countries data protection is given such gravity that it is a barrier to introducing record linkage, or linkage of clinical items, even if this creates a treatment risk. In some countries a firm middle ground is taken, with linkage only for health, or health and social care, purposes, and an identifier itself containing no data items. At the other end of the spectrum a more liberal approach supports linkage for all public services, use of a general citizen number, and inclusion in the URI of data items (such as date of birth) which stricter countries rate as personal data not to be revealed openly. This study has not considered in more depth the impact and value of these alternative views, and though local values are important further discussion would seem merited.

All these responses provide an insight to the extent that the patterns of record keeping mean that medical decisions in child primary care can be based on timely, accurate and reliable health data. This will aid the MOCHA project in considering how future models of children's healthcare might be optimised.

#### **4. Conclusion**

Based on a variety of historic and traditional factors, and the lack of a common vision or standard, there continues to be significant variation in achieving the essential quality enablement of good child health delivery through linkage of early health records. The safety and efficiency of child primary care, as well as trust and convenience for children and parents, is at stake. In every country, this is a national health infrastructure policy determining practice for all citizens including children (and parents). Despite the importance of rapid record continuity, only 8 countries out of 28 enable record linkage from the time of birth, with 3 more planning this. Two countries have no plans for linkage, while 15 have an issuing system implemented some time after birth. These 17 countries

appear prepared to let lack of timely and complete record linkage impede safe care to their children, even in a modern e-health age.

Data protection concerns are deeply rooted and paradoxical. In some countries data protection seems to over-ride safety of health and care. At the other extreme, other countries allow identifiable personal information to be embedded in the identifier. The construct and intrinsic characteristics of the URI also vary considerably between countries. While key criteria are utility and acceptability, the current variation does beg further consideration of whether certain characteristics should prevail. However, and criteria to guide the implementation and properties of URI in child primary care in Europe need to be tailored to the special needs of children and cannot simply be transferred from adult-based systems.

The results obtained within the frame of this first phase of the MOCHA study mark a preliminary insight into the use of unique identifiers in child primary care in Europe. They will serve as a building block for further research on the facilitators and barriers to the development and maintaining effective models of electronic health record support to the delivery of optimal models of child primary care, and will be integrated into the final conclusions of the project in 2018.

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