

Children's Immunisation in Europe – a Vision of using the HL7 International Patient Summary to transform local Data into Child-specific Information and Population Health Knowledge

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Abstract. Immunisation is a key preventive health measure for children. E-health applications have been used for over 50 years, yet still there is no harmonization or standardization, while uncoordinated policy initiatives proliferate. Two EU research projects (Trillium II and MOCHA) have come together with experts and stakeholders, and used EU-wide situation analysis research to seek to stimulate development of data and process standards as a harmonizing force in a supporting policy environment, putting the child as the central data collation unit.

Keywords. Child health; immunisation; data standards; summary record

1. Introduction

Immunisation is a key component of preventive health services for children. However, as health systems are a national competence, immunisation is delivered and recorded by different means in each country, and often by different agencies within a country. In this disparate process, information about an individual child can be fragmented and not always linked. Consequently, some children may not be fully protected because of lack of continuity in their receipt of planned protections, while there is also a risk of over-immunisation. Thus, from a child-centric perspective, data at the encounter level may not be aggregated to the crucially important and core purpose child level information.

Secondly, not only is analysis of the overall level of protection for children important to ensure their immunity – witness recent concerns about population vulnerability to measles due to reduced child population immunity levels [1, 2] – but there is also much that can be learned about immunisation related delivery and population behavior if this case-level information is aggregated effectively to a level of population-based knowledge. For instance, in the current climate of concern about the harmful effects of vaccine resistance, there is little understanding of how many children's immunizations are deferred because of a short-term illness (or holiday) but then not completed due to

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follow-up failure, how many times vaccine supply or other organization problems are to blame, and how many parents are genuinely hesitant, but are not identified as such for more personalized explanation and reassurance.

More recently, within the European Union, several well-intentioned proposals have arisen to increase immunisation protection, but these too are uncoordinated. This paper reports a follow-on to a recent initiative instigated by the Trillium II [3] project of the HL7 Foundation, and the Models of Child Health Appraised (MOCHA) [4] project, both funded by the European Commission’s Horizon 2020 Research and Innovation programme, through events hosted by CEN and WHO, to seek to instigate some cohesion based on information management and use of data standards and an International Patient Summary dataset as the core [5].

2. Digitization of Immunisation Records and Scheduling

Use of computers to schedule and record immunisation is a very early European digital health application, having started more than a half-century ago [6], and even at that time evaluated as being cost-effective [7]. That led to a series of local and national implementations in many countries, but then also a lack of continuity as policies vacillated between innovation, devolution to localities, and integration with generic and adult focused records and commercial EHR systems [8]. The net result is a lack of European standards or functional specifications, and a fragmentation of immunisation delivery. However, many countries have their own case-based child public health records, with a split between those which actively schedule, monitor uptake with identification of those out of schedule, and passive recording (Figure 1).

System Directly Schedules Appointments	System advises Provider of Children Overdue	Passive Record
Czech Republic Denmark Estonia Iceland Spain UK (Northern Ireland and Scotland) (SA)	Czech Republic Denmark Estonia Hungary (SA) Iceland Ireland (SA) Italy Norway Romania Spain UK (England) (SA)	Croatia (SA) Finland Malta (SA) UK (Wales)
All use a form of automated data exchange unless marked Stand Alone (SA)		

Figure 1. Functionality of Child Public Health Systems in Europe (Source: [8])

At the same time, the European Centre for Disease Control (ECDC) has called for countries to develop Immunisation Information Systems, which record and produce person-centered summaries of immunisation, including travel and other vaccinations, and for all ages [9]. There is strong synergy between the objectives and survey findings between MOCHA and ECDC. One key element of this is the lack of formally agreed data standards, or functional specification for proactive functions. In short, in 50 years little progress has been made on building on validated foundations.

3. A Confusion of Initiatives

Recognizing the importance of immunisation for children, and aware of falling rates and of vaccine hesitancy, several European agencies have recently proposed initiatives.

The World Health Organization Regional Office for Europe, in its European Vaccine Action Plan (EVAP) 2015–2020, stated priority areas for action, so as to ensure that all countries are able to “provide equitable access to high-quality, safe, affordable vaccines and immunisation services throughout the life course” [10]. The Council of Europe has proposed a range of immunisation supportive information projects including a European Vaccination Card [11]. The EU Expert Panel on Effective Ways of Investing in Health (EXPH) has recommended more activity to address vaccine hesitancy but not looking at investing in record or delivery systems [12]. WHO globally issued guidelines on home-based records to include immunisation data without specifying the data items [13]. The WHO-linked organization TechNet-21 advocated home-based records primarily as an immunisation support but again without more detailed content specification [14].

Significantly and of concern, particularly in an era of digital health, none of these initiatives suggests how data may be created, managed, linked, or progressed to child-specific information or system knowledge, though those objectives are implied.

4. The Trillium II and MOCHA Initiative to seek Digital Harmonization

Given this agitation of interest and confusion of concern, the Trillium II and MOCHA initiatives saw a need and also an opportunity to work in tandem, based on the hypothesis that data standards, and the International Patient Summary [15], might provide a way forward. A collaboration protocol was signed.

First, an analytic workshop was held in September 2018 in Brussels [16]. This meeting proposed a stakeholder workshop, for which it set an agenda of issues for discussion. This Stakeholder Workshop was then held at the WHO Regional Office for Europe in November 2018. Five immediate short-term actions were agreed as important, and six longer-term actions which should be explored if resources could be identified [5].

Within the context of health informatics, key issues were:

- Boosting the International Patient Summary (IPS) immunisation component with an indicator of reason for non-immunisation.
- Addressing gaps in health data standards for child health; autonomy and consent in patient summaries for adolescents; common interface to immunisation registries; and child patient summaries for children at school.
- Examining the feasibility of supporting the European Vaccination card as part of the roadmap for CEF eHealth DSI, addressing coding issues.
- Exploring the support of patient summaries to children with complex needs, developing further the care plan component for the IPS
- Developing the Application Programming Interface (API) to retrieve patient summary immunisation component with Immunisation Registries to extract up-to-date information.
- Exploring validation of patient summaries in Portuguese community Pharmacies (where immunisations are given in Portugal)

5. Conclusion

Childhood immunisation is an important public health concern. Despite 50 years of experience, digital health is not being used optimally, while in a wide policy context numerous initiatives are being proposed without either cohesion or consideration of Data, Information and Knowledge as the foundation. This two-project initiative seeks to bring some standards-based harmonization, to the potential benefit of Europe's children.

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