

# Patient summaries in Paediatric Emergencies: Policy, Standards, Prospects

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**Abstract.** Patient summaries defined as the minimal set of health information that needs to be conveyed for patient safety in the context of emergency or unplanned care were initially introduced in a European context in the cross-border setting across member states of the European Union. Quite complex and high impact emergency situations involve young children and their parents. Then, shifting to a patient-centric perspective, patient summaries make sense in the hands of active and empowered parents and carers. This workshop builds on the work of the Trillium-II project that aims to scale-up use of patient summaries and the work of the MOCHA project which is analyzing health policies for children in 30 European states. The expected outcome of the workshop is to identify challenges and propose recommendations for further coordinated action where digital health policies interface with standards, with clear objectives, actions and intended benefits.

**Keywords.** eHealth policy, emergency care, children, pediatrics, patient summaries

## Introduction

The Trillium-II project ([www.trilliumbridge.eu](http://www.trilliumbridge.eu)) aims to scale up adoption of International Patient Summary (IPS) standards extending the patient summary concept beyond the cross-border setting addressed by the eHealth Digital Services infrastructure [1], which considers minors out of the initial scope. Trillium-II analyses use the IPS components namely problem, medications, allergies, etc., in digital health communities of practice, facilitating synergies and sharing of experience and knowledge. Situations addressed are refined and move beyond the typical ambulatory case of unplanned visits.

The MOCHA project ([www.childhealthservicemodels.eu/](http://www.childhealthservicemodels.eu/)) addresses the full spectrum of primary care policies for children in the 30 European countries, including looking at the practice of Electronic Health Records and public health system use for children including also digital health. MOCHA has reviewed policies for urgent child care in schools across Europe and compiled use cases simple and complex, from a policy view [2]. Interviews with children and parents provide insights into their expectations, and the MOCHA project is linking with the European Center for Disease Control,

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regarding that agency's vision on Immunization Information Systems. MOCHA has ascertained each country's policies in linking primary care and school health service records and assessed the policy in each country with regard to accessing medical records when a child needs urgent care during the school day. The rights of older children to autonomy in confidentiality and in record access, also under new Data Protection Convention and patient summaries provide illustrative examples.

University Hospitals of Geneva are piloting a mobile app to reduce waiting time for pediatric emergencies, prepared before and after the emergency visit. Starting from this example, and examining key use cases identified by MOCHA from a social, technological, and financial perspective linked to the patient summary, will help understand the challenges and the benefits of using patient summaries in daily clinical practice [2-4].

## 1. Topic Rationale

The challenges associated with the use of digital health tools, despite their promise of productivity and safety, are frequently overlooked [5]. This workshop aims to change that. The workshop brings leading professors in medicine, pediatrics and informatics together with engineers to discuss digital health tools and the pediatric patient summary within the backdrop of differences in health care and public health policy.

**Catherine Chronaki**, institutions officer on the Board of EFMI, secretary general at the HL7 Foundation, and scientific lead of Trillium-II, will present patient summaries as developed and extended in the Trillium-II project, and introduce the speakers. She will focus on how standards can help build trust in the data and shape expectations on supported functionality.

**Frédéric Ehrler** will present a mobile app, developed by his team at the University Hospital of Geneva, assisting young patients and their families in the management of pediatric emergencies. His presentation aims to inspire the audience to imagine how the patient summaries can support the patient journey and initiate the discussion on how different policies in Europe can be bridged. PhD in Computer science, Frederic is specialist in improving healthcare system efficiency and user experience through innovative IT solutions. He aims to foster the integration of evidence based methodology in the implementation of IT solutions in hospitals. Frederic has a strong experience in user centered design and evaluation of patient centric interventions. He is using a wide range of technology going from gamification to IoT to implement innovative solutions improving the efficiency of the whole healthcare ecosystem.

**Rianne Oostenbrink** will present views on young patients with complex needs i.e., what info should be essential in the patient summary, and what would be the role of parents in managing, maintaining and using them. Moreover, Rianne will discuss how to provide parents essential information they can share as a summary in the perspective of continuing care from discharge from the ED to potential revisit to subsequent caregivers, and how to support parents in reevaluating their child and to decide upon new health contact. Rianne Oostenbrink is pediatrician at the dept. of general pediatrics of the Erasmus MC – Sophia in Rotterdam, The Netherlands and chair of the REPEM European research network pediatric emergency medicine.

**Professor Michael Rigby** will address the “*disparity in national policies on availability of key emergency clinical information in school time*” drawing results directly from a MOCHA project survey. Michael is visiting professor and senior research fellow at the Section of Paediatrics in Imperial College London, and Emeritus Professor

of Health Information Strategy, School of Public Policy and Professional Practice, Keele University, UK. He is the deputy principal investigator for the Models of Child Health Appraised (MOCHA) Horizon 2020 project. He also member of the IMIA Working Group on Technology Assessment and Quality Development.

**Professor Simon de Lusignan** is a general practitioner, professor of primary care and clinical informatics, head of the department of clinical and experimental medicine at university of Surrey, director of the Royal College of General Practitioners research and surveillance centre, member of the BCS Health and Care executive and the UK national representative to EFMI, and the Publications Officer on the EFMI Board. Simon will address the use of big data, especially routinely collected data to support better clinical care focusing on looking at the data flows between primary and secondary care using exemplar conditions such as asthma and diarrhea. These conditions are used to investigate the interface of primary and secondary care to compare data flows in primary care systems. In addressing the role of patient summaries, Simon will explain how improved data flows may be facilitated by patient summaries and result in better quality data for research and policy development.

**Professor Dipak Kalra** is President of the European Institute for Health Records and of the European Institute for Innovation through Health Data. He undertakes international research and standards development, and advises on adoption strategies, relating to Electronic Health Records. He leads the work of Trillium-II on Context, role and adoption of the International Patient Summary in the global ecosystem and he will address how pediatric patient summaries can meet the goals learning health systems.

**Tarik Derrough**, senior expert in vaccine-preventable diseases, at the European Centre for Disease Prevention and Control (ECDC), leads a project in the area of electronic immunisation registries and will share EU experiences in collecting individual level data on immunisation to better support immunisation services and programme monitoring. The sharing of standardised immunisation data across borders and linkage with other health outcome databases are among areas of interest to be addressed.

## 2. Expected Outcome

The workshop will be organized as a sequence of brief 5 minute position statements followed by interaction with the audience using sli.do. Then, there will be a second round of discussion and 30 minutes of Q&A and interaction with audience. In the closing, key results of the workshop will be summarized, and next steps will be identified. Questions will aim at capturing insights from the audience and prioritizing a set of topics to be presented in a workshop report which will guide follow-up activities on child health to be organized in the second part of 2018.

## References

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