

Patient Summaries: An International Perspective

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Abstract

Patient Summaries, excerpts of Electronic Health Records used most frequently for emergency or continuity of care, have received a lot of visibility in the context of eHealth strategies and standardization efforts. Interoperable patient summaries that can be exchanged safely and accurately across borders of organizations, health systems, regions, and countries, are perceived as the key for patient safety, as well as efficient and effective care. In the European Union (EU), the eHealth Network established under Article 14 of the directive on patient rights to cross-border care 2011/24/EU [1], adopted in 2013 the guidelines on minimum non-exhaustive patient summary dataset [2] triggering attention to patient summary specifications throughout Europe. These patient summaries should include inter-professional dimensions to attend to complexities of care across the patient's longer-term trajectories. In the United States, the Blue Button initiative aims to empower citizens giving them the opportunity to download their patient summary after a medical visit. Japan and Brazil proceed with standardization projects for discharge summaries, offering the opportunity to compare and contrast different approaches. This workshop brings together speakers from Europe, the United States, Asia, and Latin America to discuss key aspects, types and uses of patient summaries, how they are produced and maintained overtime, and point out challenges of standardization, consolidation and harmonization in an increasingly mobile global world. The attendees will learn about initiatives surrounding patient summaries to gain awareness of key issues and associated problems around the globe. Such opportunities to engage in active discussion on how local standards relate to global interoperability of patient summaries can pave the way towards international standards.

Keywords:

Electronic Health Record; Patient Summary; Interoperability, discharge summary, continuity of care, global standards.

Workshop Description

Nowadays, leading a life increasingly digital and mobile, we rely and depend on technology for key activities of daily living. In this setting, availability of up-to-date emergency health data online is an issue of patient safety and quality of care. However, emergency data is just one type of patient summary. Other popular types of a patient summary are discharge summaries, the so-called continuity of care record, lab reports, encounter reports, etc. Considering the clinical

summaries addressed to specific medical specialties and medical problems as chronic diseases, the number of patient summary types increases dramatically and calls for interdisciplinary collaboration. Even when using the same underlying standards and terminologies to express a specific type of patient summary, e.g. discharge letter, differences in language, care and treatment, culture, and policy lead to essentially different clinical elements and value sets. Such differences are important, but sharing information can be instrumental in informing local initiatives and expanding interoperability.

Another lens to view patient summaries is the way they are constructed, maintained, and shared. Some countries or regions in Europe have the patient summary automatically generated from the most up-to-date available health information. Providers may prepare a patient summary when the patient is transferred. In other countries the assigned General Practitioner serves as a gatekeeper and maintains the patient summary. There are pros and cons in these strategies that merit reflection, particularly in the context of health information technology infrastructures for longitudinal health records.

In this workshop, speakers from Europe, the United States, Japan, and Brazil will present different activities and projects related to patient summaries that effectively and efficiently communicate information at the place of need. Key topic in the discussion will be how to strike the right balance between local and global patient summary standardization efforts and the role that professional societies are invited to play.

Workshop Speakers and Topics

European Patient Summary and Trillium Bridge

Catherine Chronaki, MSc will present the main elements of the European Patient Summary Guidelines and the ways in can be maintained and exchanged. She will address findings of Trillium Bridge, a European project to compare patient summaries in Europe and the US and to investigate the feasibility of transforming patient summaries in ways that make them fit for use across the Atlantic and potentially globally [3]. She will describe different types of patient summaries and infrastructure to construct and maintain them.

Catherine Chronaki is Secretary General of the European HL7 Foundation. She has engaged in eHealth projects since the early 90's. Co-author to 100+ scientific papers, she is member of the European Federation of Medical Informatics (EFMI)

Council, the European Society of Cardiology (ESC) e-cardiology WG, and the HL7 Hellas Board.

Headings for a consultation summary, United Kingdom

The Royal College of Physicians (RCP) worked with patients and other professional bodies to produce the first version of generic medical record keeping standards in 2008 [4]. In 2010, the Department of Health appointed a Joint Working Group to resolve the governance of multi-professional standards for the content and structure of patient records. The Joint Working Group noted that “Technical standards alone do not ensure the ability for information systems to transfer interpretable health data around the NHS” [5]. The Professional Records Standards Body for health and social care (PRSB) was formed in 2013 as a collaboration between the medical and nursing royal colleges, patient groups, and the professional bodies for allied health professions and social care.

The Professional Records Standards Body for health and social care (PRSB) was formed in 2013 as a collaboration between the medical and nursing royal colleges, patient groups, and the professional bodies for allied health professions and social care. During 2014, PRSB ran a proof-of-concept project to determine whether, and if so how, selected PRSB standards could be verifiably implemented as conformant technical artefacts [6]. This work demonstrated how the outpatient headings could be used as the basis for a consultant summary letter to the referring general practitioner. The project included a comparison between the data content of the outpatient headings and the epSOS extended patient summary data set [2]. The two definitions have very different use cases, so their divergence is unsurprising. The comparison highlighted some gaps in the generic medical record headings and some significant differences in information structure, notably in the Medication Summary. There are also differences in perspective between a longitudinal summary and a ‘transactional’ outpatient letter. The learning from the proof-of-concept project is now being applied to the modelling of Discharge Summary.

Dr Philip Scott MSc PhD is a Senior Lecturer in Information Systems in the School of Computing, University of Portsmouth, and the Chair of HL7 UK.

Discharge Summaries in Japan

Michio Kimura, MD, PhD will provide an update on patient summary activities in Japan. So far, HL7 v2 orders and Patient Referral documents in HL7 CDA R2 are standards adopted by the Ministry of Health in Japan. Currently, updated referral documents, discharge summary, other types of specialized reports from diagnostic radiology, cardiology, and pathology in HL7 C-CDA [7] are in the process of receiving approval by the Ministry. In Japan, main efforts of standardization is not on the medical record contents, but on document exchange between healthcare providers.

Michio Kimura is a professor of Medicine, and Medical Informatics, and director at Medical Informatics Department of Hamamatsu University Hospital, Japan. He is currently IMIA vice-president for membership, President of Japan Association for Medical Informatics (JAMI), HL7 Japan chair, ISO TC215-WG2 vice convener, and IHE (Integrating the Healthcare Enterprise) International board member. Prof. Kimura was past-president of APAMI, the Asian Pacific Association of Medical Informatics.

Discharge summary proposed standards in Brazil

Beatriz de Faria Leão MD, PhD will provide an update on discharge summaries in Brazil. The Brazilian ISO TC 215 mirror committee (ABNT - CEE-IS) has been working in the proposal of a national standard for the Hospital Discharge Summary. The work was led by more than experts from WG1 - Architecture, Frameworks and Models of ABNT-CEE-IS, from different backgrounds: public and private sector, academia and government. The proposal took into account the international experience, especially from UK and Australia as well as national information requirements both from the public and the private sector. The main objective was to define an information set to support the continuity of care of the patient after the hospital discharge. The main sections of the Brazilian Discharge Summary include patient, provider and health professional identification elements, which are linked to associated national registries. Additional elements include [8]: Reason for admission, relevant diagnoses and/or comorbidities developed during the hospital admission; List of current health problems; Diagnostic / therapeutic procedures; surgical procedures performed; Textual description of the hospital admission; Allergies and adverse reactions during hospital stays; Hospital Discharge Prescription; Patient and Family Orientation. The Discharge Summary proposal is currently under national public consultation for one month, till mid February 2015. It will be revised and published as a national standard at the most in April 2015. This is the first national standard that aims to support the continuity of care through the different levels of healthcare attention.

Beatriz de Faria Leão MD, PhD, has been active in health informatics since 1982 and co-founded the Brazilian Health Informatics Association (SBIS). Beatriz is with the Hospital Sirio Libanes in São Paulo, where she coordinates the Graduate program of Health Informatics. Beatriz is the convener of WG1 Frameworks, Architecture and Models of the Brazilian Mirror ISO TC 215 Committee and Vice-Convener of this same WG at ISO TC 215. She's also the coordinator of IMIA Standards WG and President Elect for the Brazilian Health Informatics Association (SBIS 2014-2016).

Patient Summaries for Telemedicine in Denmark

In Denmark ITC strategies for the Health Sector has been formulated in the past 25 years. The strategies have been a valuable tool for agreement and ensured incremental development of ITC solutions and services to support the workflow and collaboration in a fragmented health care system. In Denmark, Patient Summaries can be created to “fit the purpose” by accessing selected data in the many different solutions and repositories where new solutions are added every year. Currently, the area with highest priority in Denmark is telemedicine services and collecting health data from citizens. The purpose is to set a framework for Danish-profiled standards for the collection, communication and storage of data from devices in the patient's home, as well as sharing of data from existing ITC solutions and repositories.

In recent years, several pilot telemedicine projects have been completed and have provided the various healthcare providers with greater knowledge about the possibilities for using telemedicine. However, many of the projects have been established as separate, independent projects that have not been linked to the overall use of eHealth. Each project has ended up with its own solutions and architectures and has applied different technologies. The fact that the various

solutions do not 'speak the same language' (i.e. that the semantic content has been perceived differently) has obstructed the dissemination of solutions.

A new strategy have been formulated, with the goal to establish a new national telemedicine infrastructure, to accelerate the dissemination and to reduce the costs of establishing and further developing telemedicine solutions. It is high time that the solutions developed during the past 25 years together with a new telemedicine infrastructure will enable access to correct and valid data for point of care.

Morten Bruun Rasmussen is an engineer, computer scientist and CEO in MEDIQ. He has been working with Medical Informatics and Quality Development for more than 25 years within it-strategies, procurement, evaluation, interoperability testing, and health care networks.

Meaningful Use and Blue Button in the United States

Douglas Fridsma MD, PhD will bring the United States perspective with Meaningful Use and a system of incentives [9], and will reflect on the implications of continuity of care on the design and operationalization of patient summaries. Under the stimulus bill (American Recovery and Reinvestment Act), congress authorized the Office of the National Coordinator for Health IT to certify electronic medical records to certain standards and capabilities, and then offer incentive money to physicians who demonstrated the use of health IT to achieve certain quality and process objectives. As part of the certification program, electronic medical records in the US are required to have the capability of generating a clinical patient care summary using an HL7 standard format. That same format is used to electronically share health information with the patient through an initiative called "the blue button". As the meaningful use program has matured, document-centric ways of exchanging information using the care summary standard is giving way to more data-centric ways of exchanging information that lever the patient summary data elements.

Dr. Douglas Fridsma is the President and CEO of the American Medical Informatics Association. Dr. Fridsma has spent four years in the Office of the National Coordinator for Health Information Technology, most recently as the Chief Science Officer where he was responsible for the scientific and technical strategy for the ONC portfolio of technical resources to support the meaningful use program and health information technology interoperability.

Interdisciplinary, longitudinal dimensions in the summary

Anne Moen, RN, PhD will address the importance and necessity to account for interdisciplinary collaboration, contributions and responsibilities in the discharge summaries to ensure continuity of care across settings. This is particularly important for complex care and treatment of patients with chronic conditions and multiple co-morbidities, like the elderly.

Dr. Anne Moen is professor at the Institute for health and society, Faculty of Medicine, University of Oslo. She has been active in health informatics research for the past 30 years. Representation of information and knowledge, in particular the ageing to assist their health information management and self-care. She serves as president of EFMI (2014 – 2016).

General Organization of the Workshop

Organization

Catherine Chronaki and Douglas Fridsma will co-chair the workshop. Following a 5 minute presentation by each of the presenters and a Questions and Answers session, the audience will engage with the speakers to elaborate the challenges of leveraging local insight and global vision in standards development and adoption. At the end of the session, the speakers will articulate main insights from the discussion and jointly formulate a call for community engagement to advance understanding of clinically relevant patient summaries fit for local purpose, leading to effective global interoperability standards.

Audience

The expected audience of the session are clinicians, medical informaticians, terminologists, eHealth advocates, project managers and policy makers.

Expected Results

This workshop aims to bring international perspective to the notion of patient summary to: (a) inform of ongoing initiatives related to patient summaries and in particular their creation and maintenance; (b) reflect on the common elements of patient-summary related activities; (c) discuss on going standardization efforts in the area and the prospects and challenges of developing an international patient summary standard.

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