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Holistic health: Predicting our data future (from inter-operability among systems to co-operability among people)[☆]

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ABSTRACT

Data depend on processes; processes depend on organizational models; organizational models depend on regulations and policies. This position paper envisages the future data scenarios and the related research needs by addressing this whole logical chain.

A 'smarter health and wellness future' requires the proactive engagement of citizens and of their caregivers, and the cooperation of health professionals across care facilities, with intense usage of mobile communication and connected devices. This ecosystem of people and organizations is currently extremely fragmented. Technology offers the possibility to mediate among the different actors in order to build a functional care team around the specific needs of each individual, i.e. a 'virtual facility'.

However, this requires policies and regulations in every jurisdiction that motivate providers and their organizations to collaborate among themselves and with citizens according to explicit individual plans of care provision, to share their goals and negotiate their respective roles with respect to each citizen.

Once a collaborative organizational context is established within integrated care models, policy makers could identify a critical mass of relevant shared processes and isolate a set of 'Attention Points' with predictable actors, concerns, activities, and thus highly precise information needs. For each Attention Point, a template for a Context-Specific Profile of the patient could be produced, e.g. as an HL7-CDA schema that fully specifies the mandatory and optional (clinical) data useful to support the care processes and to manage governance indicators. In relation to these predictable Attention Points data sources can be aligned to achieve reasonable coherence and consistency. Attention to data quality can be improved in a context of systematic re-use of the same data by different actors in different contexts.

From a collection of profiles it could be possible to set up the core of a multi-purpose "Policy-Oriented" Health Record (POHR), shared by the functional care team in the citizen's ecosystem. In fact, the shared management of selected clinical data should be no more based on the a posteriori extraction from the personal notes of each professional, but on the cooperative construction of a systemic resource, together with the administrative and organizational data, able to support the management of innovative, integrated care models.

[☆] This paper originates from the Discussant Presentation in the session "Predicting our data future" at the OECD-NSF Workshop "Building a smarter health and wellness future", Washington, February 2011 [1].

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In addition, the policy-oriented focus on routine data within a set of predictable situations makes it possible to stratify an appropriate number of citizens into homogeneous classes and to produce timely indicators of processes and outcomes from routine data for governance purposes, e.g. to optimize the allocation of resources, to drive continuous education, or to promote epidemiological studies.

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1. Introduction

Most countries and regions are entering the “connected health” era. Information and communication technologies (ICTs) affect all sectors of our lives, through a range of communication devices and infrastructures (such as mobile phones and Internet) and through selective access to data, information and knowledge. Progress in eHealth research is needed to enable the introduction of dramatic changes in the organization of health and social care; in fact eHealth solutions could assist the move toward more sustainable care systems and effectively further transfer care provision to the community, by supporting home care and reducing unnecessary hospitalizations [1–5].

E-Health policies could become a crucial component of economically sustainable healthcare strategies through the introduction of advanced organizational models enhanced by appropriate ICT solutions. The European Commission is increasingly stimulating eHealth research toward the challenge of promoting a holistic health perspective in order to build a smarter health and wellness future [6], by integrating the various ICT initiatives within the overlapping fields of healthy aging, e-inclusion, ambient assisted living, and social care informatics [7–11].

This position paper deals with the future role of routine clinical data, their usage in the care provision and their quality to support the optimal behavior of the various actors around the patient. We expect that the routine capture and sharing of clinical data will be strongly affected in complex ways: (i) the role of data depends on their intended usage in the actual citizen-specific care process; (ii) within that process, the attitude of the actors toward data capture and sharing depends on the organizational model; and (iii) agreements among organizations and facilities to introduce an organizational model depend on the jurisdiction’s regulations and policies. Therefore, to discuss the data future, we must discuss the relations among these different layers.

The change management related to eHealth, which originally concentrated on standards and infrastructures, should in future also encompass collaborative care processes and innovative organizational models, and the regulatory and cultural background. We argue that to try to achieve a complete coverage of semantic interoperability, by precisely formalizing the (clinical) data elements needed for all the potential situations, is an endless and useless task; successful and effective solutions can instead be progressively obtained in a large but enumerable set of contexts, where data nature (with admitted values, constraints and cross-relations) can be carefully defined.

To meet this goal, we suggest that the initial focus should be on the most frequent and predictable ‘Attention Points’,

defined according to health policies so that a critical mass of carefully structured data may be captured, shared, and used by different actors in different processes not only to provide care but also for governance, epidemiology, and research.

1.1. Organization of the paper

In Section 2 we first describe the new challenges to eHealth research coming from the current evolution of health and social systems toward innovative and sustainable care models, with a particular attention to disease management, citizen engagement, long-term care. Then in Section 3 we analyze the need to create a shared substrate of structured data, information and knowledge to support the integrated care processes in the citizen’s ecosystem, with particular emphasis on the issues of the aging society and long-term care. In Section 4 we further elaborate on the requirements for an effective semantic interoperability, namely to assure the timely availability of *all the specific data elements* needed to each actor to perform his/her tasks, at least in a limited set of situations.

In Section 5 we claim that a general solution is not viable, and thus policy makers should concentrate on a critical mass of ‘Attention Points’, i.e. predictable situations concerning shared care or the risk of non-appropriate behaviors, where it could be possible to predict the involved data elements. We also emphasize that an effective data harmonization is a consequence of (i) the organizational integration of the processes for each citizen, and (ii) the level of engagement of the citizen and his/her caregivers. Both factors affect the coherence of the services to promote and maintain holistic health in a daily routine and thus the coherence of the routine data and their re-usability.

Finally in Section 6 we argue that organizational harmonization and process integration – prerequisites to identify the Attention Points and thus to work out which data need to be captured and shared – should be a structural component of a policy to deploy innovative care models in a jurisdiction, based on the cultural background and suitable regulations. It emerges as a central tenet for the comprehensive deployment of a holistic approach to health and cannot be achieved casually by spontaneous evolution or by initiatives limited to the eHealth sector.

2. Technology-enhanced innovative organizational models

The health systems worldwide are looking for more sustainable care models, which could improve quality of care and make an optimal usage of the resources. In this section we discuss the potential role of the technologies in the diffusion of innovative care models and, vice versa, the influence of the

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