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E-health stakeholders experiences with clinical modelling and standardizations

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Abstract. Stakeholders in e-health such as governance officials, health IT-implementers and vendors have to co-operate to achieve the goal of a future-proof interoperable e-health infrastructure. Co-operation requires knowledge on the responsibility and competences of stakeholder groups. To increase awareness on clinical modeling and standardization we conducted a workshop for Danish and a few Norwegian e-health stakeholders' and made them discuss their views on different aspects of clinical modeling using a theoretical model as a point of departure. Based on the model, we traced stakeholders' experiences. Our results showed there was a tendency that stakeholders were more familiar with e-health requirements than with design methods, clinical information models and clinical terminology as they are described in the scientific literature. The workshop made it possible for stakeholders to discuss their roles and expectations to each other.

Keywords Information storage and retrieval/standards, Semantics, Health planning

1. Introduction

Implementation of a future-proof interoperable e-health infrastructure is a challenge which requires stakeholders on many different levels to co-operate, especially in the domain of clinical modeling where both technical and clinical insight is needed. It is a pre-requisite for co-operation that the responsibility and competences of other stakeholders is clear and that knowledge gabs are identified.

In Figure 1, we present a theoretical model based on the scientific evidence of the different aspects of clinical modeling and standardization. We use this model in a workshop as a point of departure to identify stakeholder's familiarity with each of the aspects, the perceived knowledge gabs and differences between groups of stakeholders. The two columns represent the basic contrast in health IT development between the close–to-user setting, where support of local complexity is the priority, and the e-health authority setting, where sharable and therefore uniform information is the priority. We named these two positions the de-centralized and the centralized view. In the following the aspects: requirements, design methods, information models and terminologies are presented from a de-centralized and centralized view respectively.

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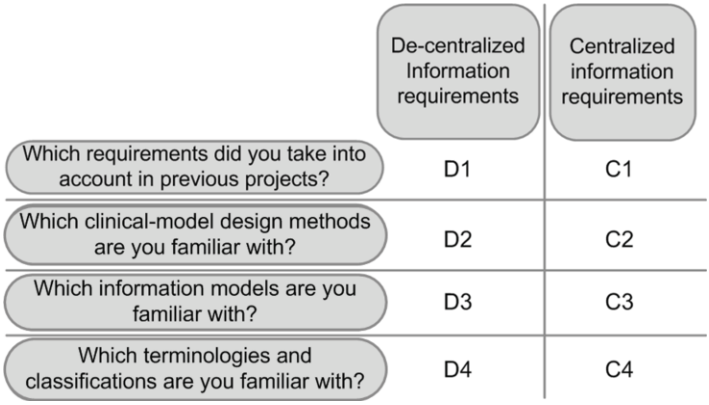

Figure 1 - A theoretical framework for assessing clinical modeling aspects

In the de-centralized requirement aspect (D1), systems should be tailored to the context, in which they are intended to work. The close-to-user requirements include that the day-to-day clinical documentation and workflows should be supported and that it should assist clinical decision making by providing links to clinical evidence such as guidelines [1]. From a centralized viewpoint (C1) the aim is a semantic interoperable framework that supports patient mobility and professional communication as well as information needs in administration and research [2]. To capture different views from stakeholders we asked: *Which close-to-user and information sharing requirements did you take into account in previous projects?*

In clinical modelling, several different design methods have been explored for different use cases. In a de-centralized view, clinically guided system development is the most common including methods such as participant interviews and surveys, participatory design meetings, rapid prototyping and formative evaluation e.g. [3,4]. The risk of such methods is that adoption may be dependent on whether a user was involved in the design of the system [3]. Another approach that may hinder the "not invented here" syndrome and avoid duplication of effort is to actively use other organizations models or accepted clinical knowledge when designing. For example, Buch et al. used existing openEHR archetypes when designing an information system for premature infants [5], and Garde and Knaup included an analysis of trial protocols in their design method [4]. In a centralized view, where models are developed to allow information sharing, multi-site collaborative development is often the preferred method. E.g. a web interface can be used to support collaboration between stakeholders at different sites [6]. This is also an approach used in international modeling initiatives such as openEHR, where international collaboration is supported using the clinical knowledge manager [7]. To capture different views from stakeholders we asked: *Which clinical-model design methods are you experienced with?*

Semantic interoperable frameworks require unambiguous representation of clinical data, which can be obtained through the adoption of standardized information models and terminology [2]. However, even in research projects conducted in controlled environments, the coordinated use of models and terminologies remains a challenge. Standardization is a challenge because many different models and terminologies exists e.g. HL7 information models, ISO13606 information models, SNOMED CT, LOINC, and ICD [8], and overlap of functionality makes harmonization difficult [9,10]. This situation leaves decentralized stakeholders with the choice of implementing standards that seems immature [11], or designing systems that relies heavily on proprietary

information models and terminology with exception of the information where regulations require a specific model or terminology e.g. for reimbursement purposes. To capture different views from stakeholders we asked: *Which information models are you experienced with? And, which terminologies and classifications are you experienced with?*

2. Methods

We organized a workshop at the end of a one-day conference on e-health standardization in a Danish context. The conference was organized by the Danish Centre for Health Care Informatics (DaCHI) and was structured in a morning session with international keynotes and an afternoon session where we gave a 20 min presentation of our theoretical model before the workshop. The purpose of presenting the model was to provide a common reference for discussions in groups. From the list of participants, it was possible to categorize the participants into three types of stakeholders and the 73 participants were in advance of the conference divided into 8 groups of 6-10 participants:

1. Vendors: Employed in private companies – mostly consultants and developers from health-IT vendors. (2x10 participants)
2. Governance: Employed in the public sector – working with health- and IT-governance at a national level in Denmark or in Norway. (2x6 participants)
3. Clinical e-health implementation: Employed in the public sector – working with IT in hospitals, in one of five regions and in some municipalities. (4x8 participants)

Each group was appointed a facilitator. The facilitators received the method for the group discussions in writing in advance of the conference. The main role of the facilitator was to chair and document the discussion by adding stickers on a pre-printed overview of different types and levels of standardization.

All participants were provided a printed copy of the model presented and each group had copies in A3 format for the facilitator to fill in with green (experiences) and red (challenges) stickers based on contributions from each group member. After 45 minutes of discussions each group was asked to hand over their A3 model to one of the other groups. The idea was for the groups to compare views and reflect on similarities and differences. Finally, the reflections of each group were presented orally for the other groups.

In the analysis of the result from the workshop, we wanted to explore which of the areas from the theoretical model that a stakeholder was most familiar with. Consequently, we analyzed where the density of marks were highest regardless of their color. We also analyzed knowledge gabs and challenging areas in clinical modeling as experienced by the participants. We defined challenging areas as places in the model where a group did not place any marks or where the number of red marks exceeded the green marks. Lastly, we wanted to explore whether there were differences between the groups in terms of centralized or de-centralized aspects being in focus.

After the workshop, the authors compared experiences from being group moderators in terms of how the theoretical model worked as a point of departure for discussing views on clinical modeling.

3. Results

In Table 1, the distribution of stickers placed during the workshop is presented. The total number of stickers differed between groups; see N values in the table.

Table 1 - Normalized marks placed during workshop

	Vendors				Governance				Clinical IT implementation							
	A N=12		B N=9		A N=24		B N=35		A N=18		B N=29		C N=10		D N=26	
	g	r	g	r	g	r	g	r	g	r	g	r	g	r	g	r
D1	0.0	25.0	11.1	11.1	4.2	0.0	8.6	8.6	22.2	5.6	10.3	10.3	0.0	0.0	23.1	15.4
D2	0.0	0.0	0.0	0.0	4.2	0.0	5.7	2.9	11.1	0.0	13.8	3.4	0.0	10.0	15.4	0.0
D3	0.0	0.0	22.2	11.1	0.0	4.2	8.6	2.9	5.6	11.1	6.9	3.4	0.0	0.0	11.5	3.8
D4	0.0	16.7	0.0	0.0	0.0	8.3	5.7	5.7	5.6	0.0	6.9	6.9	0.0	10.0	11.5	0.0
C1	16.7	0.0	0.0	11.1	20.8	4.2	8.6	11.4	16.7	5.6	10.3	13.8	0.0	30.0	3.8	0.0
C2	16.7	0.0	0.0	0.0	4.2	12.5	2.9	2.9	5.6	0.0	3.4	3.4	10.0	10.0	3.8	0.0
C3	8.3	0.0	11.1	22.2	16.7	4.2	8.6	5.7	5.6	5.6	0.0	0.0	10.0	10.0	0.0	0.0
C4	16.7	0.0	0.0	0.0	4.2	12.5	11.4	0.0	0.0	0.0	3.4	3.4	0.0	10.0	3.8	7.7

Consequently, the numbers shown in the table are normalized using the total number of stickers that a group placed on their model, we refer to this as normalized marks. The grey areas in the table are identification of knowledge gabs. The dark grey areas are aspects where no stickers were placed by a certain group and light grey areas are where the number of red stickers exceeded the number of green stickers.

It has been tested, using a t-test that the number of normalized marks in D1 and C1 is significantly different from the number of normalized marks in each of the other aspects, $p=0.0007$. There is no significant difference between the numbers of normalized marks placed on the centralized compared to the decentralized aspects. When tested separately, the only stakeholders which have a statistically significant difference between centralized and decentralized aspects are the governance groups which place more normalized marks on the centralization aspects than on the decentralization aspects.

4. Discussion

We noted in the workshop that discussing the requirements of e-Health systems is possible and familiar for stakeholders and this is supported by the fact that most stickers were placed in this area. Stakeholders are well-aware of both centralized and decentralized requirements.

We expected that it would be clear from the workshop where groups of stakeholders had their strengths and weaknesses with regard to clinical modeling competences. However, the knowledge gabs are distributed throughout the different aspects, and no conclusions could be drawn.

Before the workshop we anticipated that local health IT implementation personnel would be more de-centralized and governance related persons more centralized in their views toward clinical modeling both when it came to identified experience and

challenges. Whereas the governance participants placed their stickers consistent with this hypothesis this was not the case for clinical IT personnel. With their role in-between clinical users and governance related demands, they placed their marks evenly between the de-centralized and centralized aspects. In conclusion, our study did not show big differences between groups or serious knowledge gaps across all groups, which is positive in terms of future collaboration projects. However, we did see a tendency that stakeholders were most familiar with the requirement-aspects of the theoretical model, which may indicate that in the aspects of development methods, information models and terminologies practitioners can still learn from the available evidence.

In the evaluation of the results, it became clear that stickers were placed with different strategies by different groups, which can most clearly be seen by the differences in number of stickers used which ranged from 9-35. We believe that there are three main reasons for this. Firstly, in the workshop, participants questioned the definition of "a challenge". Secondly, some groups expressed that they did not understand aspects of the model, and even though the facilitators were provided with background material in advance, they could not fully explain the model for the participants. Thirdly, different strategies could be explained by group dynamics and negotiations. This is the reason why the results are analyzed carefully and that red and green marks are not separated in any of the statistical tests. We merely use the marks as an indication of where the discussions went. After the workshop, we concluded that despite the above mentioned methodological challenges, the theoretical model provided a point of departure for well-organized discussions that made stakeholders discuss their own role compared to others.

References

[1] Kalra D, Ingram D. Electronic health records. Information Technology Solutions for Healthcare 2006:135-181.
[2] European Communities. Semantic Interoperability for Better Health and Safer Healthcare. 2009.
[3] Garde S, Knaup P. Requirements engineering in health care: the example of chemotherapy planning in paediatric oncology. Requirements Engineering 2006;11(4):265-278.
[4] Nowlan WA. Clinical workstations: identifying clinical requirements and understanding clinical information. International journal of bio-medical computing 1994 Jan;34(1-4):85-94.
[5] Buck J, Garde S, Kohl CD, Knaup-Gregori P. Towards a comprehensive electronic patient record to support an innovative individual care concept for premature infants using the openEHR approach. International journal of medical informatics 2009.
[6] Hoy D, Hardiker NR, McNicoll IT, Westwell P, Bryans A. Collaborative development of clinical templates as a national resource. International journal of medical informatics 2009;78 Suppl 1:S95-100.
[7] Clinical Knowledge Manager. Available at: http://www.openehr.org/ckm/. Accessed 8/8/2014, 2014.
[8] Knaup P, Bott O, Kohl C, Lovis C, Garde S. Electronic patient records: moving from islands and bridges towards electronic health records for continuity of care. Yearb Med Inform 2007:34-46.
[9] Pape-Haugaard LB, Rasmussen AR, Rosenbeck KH, Andersen SK. Pitfalls when integrating terminology systems and EHRs. In: Ann Bygholm, Pia Elberg, Ole Hejlesen, editors. SHI2010 Proceedings,: TAPIR Akademisk Forlag; 2010. p. 34-38.
[10] Goossen WT, Goossen-Baremans A. Bridging the HL7 template - 13606 archetype gap with detailed clinical models. Studies in health technology and informatics 2010;160(Pt 2):932-936.
[11] Anne Randorff Højen, Pia Britt Elberg and Stig Kjær Andersen. SNOMED CT adoption in Denmark: why is it so hard? European Medical Informatics Conference, MIE; 2013.