

# Towards Ontology Co-creation in Institutionalized Care Settings

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**Abstract**—In this paper, we describe how we have, thus far, conducted ontology co-creation in institutionalized care settings (i.e., a care residence and a hospital). We describe the goal and procedure of the co-creation workshops that we have already held. Through this paper, we want to start a discussion on ontology co-creation’s merits and on appropriate co-creation methods within these settings. In return, we offer what we have learned from our ongoing research.

*Co-creation; methods; care; ontology; e-health*

## I. INTRODUCTION

In this paper, we describe ontology co-creation work that is part of the interdisciplinary project ACCIO (Ambient Aware provisioning of Continuous Care for Intra-mural Organizations). What ontology co-creation stands for can be best understood by considering its constituent terms.

*Ontologies* formally capture what domain experts commonly understand about a domain [3]. They make explicit the concepts that are assumed to exist in that domain and the relationships between these concepts [4]. In engineering, they are used for knowledge sharing between applications. Logical and constraining rules [1, 2], defined in or on top of an ontology, enable software to reason about the knowledge contained in the ontology and derive new knowledge.

*Co-creation* has been described as “any act of collective creativity that is shared by two or more people” ([8], p.2). When integrated in a design process, it is also called co-design. Co-design has its roots in participatory design, an approach towards computer systems design in which the people destined to use the system also play a critical role in designing it [9].

Ontology co-creation then refers to a creative, continuous involvement of stakeholders - (in)direct users, ontology engineers, ... - in ontology engineering [6]. The rationale behind this approach is that it increases the acceptance of ontology-driven technologies and facilitates their appropriation.

It encourages users to feel in control of the ontology, continue to adapt it and to thus increase its accuracy.

Kuziemsky and Lau [5] see ontology co-creation as the key to the challenge of creating an ontology that is both accurate and useful. They observe how little research has been done in a field that nevertheless greatly benefits from high-quality and practical ontologies: (health)care. Indeed, caregivers are faced with a vast amount of information that they need to integrate and prioritize. By implementing a context-aware, ontology-based framework, certain care tasks could be automated to alleviate caregivers’ workload.

Ontology co-creation in the healthcare domain is the focus of ACCIO. The goals of this project reflect its interdisciplinarity. From an engineering perspective, we aim to develop and demonstrate an ontology that supports quality of continuous care in institutionalized care settings such as care residences and hospitals. Through our complementary social-scientific work, we explore and implement co-creation methods to ensure the development of a human-centered ontology.

A particular type of ontology-based healthcare support that will be demonstrated in ACCIO is a dynamic nurse call system that can find the most appropriate nurse to handle a particular patient based on the context information in the ontology such as nurses’ profile information, risk factors of patients or location information. For more information concerning the ontology-based nurse call application, see Ongenae et al. [7].

In what follows, we will focus on ontology co-creation methodology, starting with a description of how ontology co-creation fits in the project’s research process. We then elaborate on how we have conducted ontology co-creation, thus far, through a number of workshops and conclude with lessons learned from doing so.

## II. RESEARCH PROCESS

Within ACCIO, ontology co-creation is embedded in a research process that integrates observation, scenario development and co-creation. At the start of the research process, we conducted observations of care giving practices (e.g. providing medicine, helping people get out of bed) in two settings to cover two main forms of institutionalized care: residential and hospital care. Observations were systematically represented in mind maps.

As a next step, a use scenario was written that balanced our research interests with our observations from the field. It describes how residents/patients and staff use an ontology-based ambient-aware continuous care platform in the two settings under scrutiny (i.e., a dynamic nurse call system). It communicates our research results in a way that generates empathy with the users of the platform.

The scenario is updated iteratively according to the outcome of co-creation workshops with stakeholders. These workshops serve to further specify the scope, requirements and general rules of the ontology under development. Thus far, we have conducted three co-creation workshops with selected stakeholders.

Our stakeholder group has been composed in such a manner that ontology engineers, concerned with (the methods for) building the ontologies can interact with domain experts and social scientists. It consists of the following subgroups:

- Ontology engineers with a computer science background that have been involved in e-health projects
- Potential end users (i.e. staff from the observed settings and related settings) such as nurses, doctors and residential caregivers
- Professionals working for the healthcare industry (e.g. representatives of a furnishing company and of a company that makes communication systems)
- Social scientists experienced with conducting co-design

## III. CO-CREATION WORKSHOPS

In what follows, we describe each workshop in detail, specifying its goal and procedure. See Table 1 for a summary of the number and kind of participants in each workshop.

TABLE I. PARTICIPANT SUMMARY

Workshop	Participant information
1	22 pp.: all stakeholder subgroups represented, users represented by management staff only
2	18 pp.: members from all subgroups, users represented by both management and caregivers from different healthcare settings
3	16 pp.: members from all subgroups, users were caregivers and management from the care residence that we observed

### A. Workshop 1: Introducing ontologies

In this workshop, stakeholders learned what ontology means and what ontology engineering is about. In addition, we aimed to generate a discussion on how we could jointly design ontologies in the domain of institutionalized care.

At the start of this workshop, participants were given descriptions of ontologies from a social science and an ontology engineering perspective. An ontology engineer then helped them to construct a simple ontology through exercises. Participants based their ontology on their view of a bedroom, which they were asked to describe prior to the workshop.

Once participants had created their own ontology, they were encouraged to reflect on how ontologies can be used to automate processes. Again through exercise, they were made aware that ontology-based automation relies on reasoning both in and on top of the ontology.

At the end of the workshop, participants were presented with existing ontology engineering methods and we discussed our vision of ontology co-creation with them. We feel that the goals set for this workshop were met. Participants considered especially the hands-on exercises and the discussion that ensued to be particularly useful.

### B. Workshop 2: Role-play

The goal of this workshop was to construct a high-level ontology. Within this high-level ontology, we tried to capture those concepts and relations, which are used with the same meaning across different institutionalized care settings. Hence, we specifically invited staff from both care residences as well as hospitals to participate.

A first version of our use scenario, visualized in a storyboard, formed the common thread in this workshop. Participants took turns in playing out the scenario within a high-fidelity mock-up of a patient room. Each participant received a persona card, stating something about the character they would be playing. Also, prior to each ‘performance’ participants received a situation card that gave them an extra piece of contextual information (e.g. ‘it is very busy and multiple nurse calls are made’).

While certain participants were role-playing, the others watched their performance on monitors outside the patient room. This audience was asked to note down issues they perceived. At the end of each performance, a moderator inquired into these issues during a group discussion and they were added to the storyboard by means of post-its and drawings. Two ontology engineers followed this process in the background, and constructed a high-level ontology based on it.

Although this workshop did help us to validate and extend the proposed scenario, the process of constructing a high-level ontology was not satisfactory. Discussions went very broad and a consensus was rarely reached. This made it hard to evaluate if a certain concept was used and whether it had the same meaning for the different stakeholders. It was also difficult to formalize or pick up the different relations that existed between concepts that arose. In sum, it seems that this type of workshop is more suitable for validation than conceptualization.

### C. Workshop 3: Decision-making

In this workshop we discussed with stakeholders what constitutes a meaningful way of prioritizing and assigning care requests or nurse calls to caregivers. The goal was to capture the decision process that stakeholders proposed for this type of assignment in a decision tree. Ontology engineers would then be able to translate decision factors and prioritization into, respectively, ontology concepts and reasoning rules.

Because we were looking for context-dependent factors, we specifically invited caregivers from one particular setting. In this case, this was the care residence in which we did our initial observations. We plan to conduct a similar workshop with hospital staff.

At the start of this workshop, participants were asked to describe on paper a complex situation involving care requests or nurse calls. A few situations were selected to further discuss, per situation, how the care requests or nurse calls should best be prioritized and assigned.

Participants were asked to suppose that they were an intelligent system that had a complete overview of the institution. This was illustrated by putting up a layout of the institution they worked for in the middle of the table. The participants, playing at the system, could collect information for making a sensible decision by asking a question (e.g. ‘who made the care request?’).

Each question from the group was first returned with in-depth questions from us: ‘Why do you feel that the answer to this question is pertinent?’, ‘Does everyone agree on this?’ and ‘Can you give examples of answers to this question?’. Once this was handled, we answered the initial question and illustrated the answer on the layout so that it could be remembered.

Ultimately, we could derive a lot of concepts on which decisions were based. For most of these, consensus was reached as to whether they were important to take into account. Prioritization turned out more difficult, as this was situation-dependent and it was hard to derive what about the situation influenced it.

## IV. LESSONS LEARNED

In this section, we discuss what we learned with regard to ontology co-creation. These lessons are based on our experiences as social scientists and on stakeholders’ written evaluations of the workshops.

### A. Moving from practice to ideation

During the workshops we observed that it was difficult for caregivers to look beyond their current situation. It was evident that simply bringing them together with stakeholders from other disciplines was not sufficient.

For example, in Workshop 2, participants tended to play out the scenario as if they were in their natural setting with the tools available to them there. In Workshop 3, it took a while for caregivers to get into the notion that they now had a bird’s eye view on their institution.

From these experiences, we have learned that participants need to be explicitly triggered to think out-of-the-box. For instance, in Workshop 2, offering persona and situation cards were good elicitation tools. Similarly, one could provide mock-ups of ‘futuristic’ sensors and communication technologies to get participants thinking on how to use these technologies.

### B. Connecting engineers and other stakeholders

One of the challenges we experienced during the workshops was how to facilitate communication between ontology engineers on the one hand and other stakeholders on the other hand. It became apparent to us that in order to connect ontology engineers and domain experts we needed to build bridges. We did this in various ways across the workshops.

In Workshop 1, we familiarized stakeholders with ontologies by starting from a common area of expertise: the bedroom. In Workshop 2, the storyboard was the link between the domain experts’ activities (doing and watching role-play) and the ontology engineers’ activities (modeling the high-level ontology). Finally in Workshop 3: the layout of the domain experts’ care setting and the decision tree visualized by the ontology engineer were updated simultaneously.

We noted that some ways of building bridges were more successful than others. Mutual interaction seems to be key. In Workshop 2 there was no interaction between the two ontology engineers and the other stakeholders. Ontology engineers observed the others’ work but not the other way round. The stakeholders became oblivious of the ontology engineers’ task and ontology engineers could not get feedback on the model as it was being constructed.

### C. Giving it time

Our workshops lasted 2 to 3 hours and duration was communicated in advance. In their evaluation, participants often remarked that the sessions seemed too short to get to the bottom of the issue at hand.

While we shared the participants’ desire for an in-depth exploration of the workshop’s topics, we did not want to overburden them or lose potential participants because they cannot make themselves available that long.

In line with a suggestion of one of the participants, we believe that explicitly coupling a follow-up session to each workshop could be a solution to this issue. Not only would we be able to address pressing issues that could not be handled in the workshop, we could also present the output of the workshop and what we did with that output to illustrate how it was time well spent.

### D. Getting the language right

At the start of the project, the question was put forth in which language the ontology should be created: Dutch (the mother language of the stakeholders) or English.

Clearly each option has benefits. Dutch would make it easier to let stakeholders evaluate the ontology. It does not require command of a foreign language and may more easily invoke intuitive understanding. Furthermore, words used

within the domain of interest could be inserted directly into the ontology.

An English ontology, however, would make it easier to reuse existing ontologies and to reach an international audience. Also, the search for an appropriate translation would force stakeholders to have a thorough discussion of what the concept means to them and facilitate a truly shared understanding.

Ultimately, we chose to have the best of both ‘ontologies’ by making the ontology in Dutch and annotating it in English.

### E. Learning by doing

Throughout the workshops, we have followed a hands-on approach. Participants were stimulated to actively reflect on sometimes highly complex issues.

In Workshop 1, participants were guided into making an ontology through exercises. In Workshop 2, stakeholders participated in role-play as the starting point for reflection. Finally, in Workshop 3, participants had to find a solution for a complex care request situation through a question-and-answer process.

We found that participants much appreciated our approach of action and reflection. It enhanced their understanding of the topic. In the case of caregivers, it provided them with new insights in their own domain.

## V. CONCLUDING REMARKS

While the benefits of ontology co-creation have been identified in the literature, as a methodological approach it has largely remained elusive. By elaborately describing our own methods and the lessons we learned from applying them, we hope to generate discussion on what constitutes ‘good ontology co-creation practices’.

In our view, user participation can go beyond collecting requirements for ontology specification (through observation and interviews), without actually pushing users in the role of ontology engineers and overburdening them.

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## REFERENCES

- [1] S. Bechhofer, F. Van Harmelen, J. Hendler, I. Horrocks, D. L. McGuinness, P. F. Patel-Schneider, and L. A. Stein, OWL Ontology Web Language – Reference, W3C Recommendation, 2004.
- [2] J. J. Carroll, I. Dickinson, C. Dollin, D. Reynolds, A. Seaborne, and K. Wilkinson, “Jena: Implementing the semantic web recommendations,” in Proc. 13th Int. Conf. World Wide Web, New York, NY, 2004, pp. 74-83.
- [3] A. Gomez-Perez, O. Corcho, and M. Fernandez-Lopez, Ontological Engineering: with examples from the areas of Knowledge Management, e-Commerce and the Semantic Web, 1st ed. London, UK: Springer-Verlag, 2003.
- [4] T. R. Gruber, “Toward principles for the design of ontologies used for knowledge sharing,” Int. J. Hum.-Comput. St., vol. 43, pp. 907-928, November/December 1995.
- [5] C. E. Kuziemyk and F. Lau, “A four stage approach for ontology-based health information system design,” Artif. Intell. Med., vol. 50, pp. 133-148, November 2010.
- [6] F. Ongenae, A. Ackaert, A. Jacobs, A. Veys, M. Van Gils, P. Verhoeve, and F. De Turck, “User-driven design of an ontology-based ambient-aware continuous care platform,” in Proc. 4th Int. Conf. Pervasive Computing Technologies for Healthcare 2010, Munich, 2010, pp. 1-4.
- [7] F. Ongenae, D. Myny, T. Dhaene, T. Defloor, D. Van Goubergen, P. Verhoeve, J. Decruyenaere, and F. De Turck, “An ontology-based nurse call management system (oNCS) with probabilistic priority assessment,” BMC Health Serv. Res., vol. 11, pp. 1-28, February 2011.
- [8] E. Sanders and P. J. Stappers, “Co-creation and the new landscapes of design,” Co-design, vol. 4, pp. 5-18, March 2008.
- [9] D. Schuler and A. Namioka, Participatory Design: Principles and Practices. Hillsdale, NJ: CRC / LEA, 1993.