

Towards an Allergy Ontology: A Utility-Based Contextual Approach

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Abstract: The aim of the present article is to report the construction of a medical knowledge organization system (MKOS) for the Allergy Unit of the Montpellier University Hospital in France, according to a *utility-based contextual approach*. The inputs from the analysis of information practices of allergy employees and of a corpus of documents used in the Allergy Unit, as well as validation meetings involving allergy professionals, patients, and KO specialists led to the creation of a multidimensional, multiviewpoint and user-friendly ontology. The ontology is potentially useful to support activities of allergy actors, even though its operational, conceptual, terminological and technical aspects still need to be improved. Such a result suggests that the utility of MKOs is the matter of the content, intentionality and operability, and should be constructed by designers through contextual interactions with potential users. The idea has been put into a methodological framework, and a Utility in Context Model has been proposed.

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1.0 Introduction

Healthcare and health-related topics have conquered the public space. After the mediatization and publicization of several sanitary crises, organized actions of activists, and the integration of information and communication technologies (ICT) in hospitals, biomedical edition, health libraries, and private sphere, discourses and communication related to health have multiplied and altered, sometimes going beyond the medical framework (Huber and Gillaspay 1998, Romeyer 2008). Therefore, nowadays, information in this field is produced, mediated, disseminated, shared, and mobilized not only by specialized actors, *e.g.* healthcare professionals, public institutions, but also by non-specialized ones, such as patients and people on the Web interested in health subjects. They all produce a massive number of documents in various forms. Their information practices become complex as well, *e.g.* health professionals use specialist documents, but also publish and search for wide-public

content to perform their activities; patients use generalized content, but also need specialized documents to inform themselves and make decisions regarding their care (Paganelli and Clavier 2012, Vivion 2018, Clavier and Paganelli 2019). Because of the complexity of information practices and produced documentation in health, knowledge organization (KO) specialists need to consider how to design medical knowledge organization systems (MKOSs) that would be able to represent and organize abundant and heterogeneous knowledge, while, at the same time, supporting various information needs in different contexts.

In numerous cases, MKOSs have been designed through ontological and techno-centric approaches, which have led designers to pay less attention to the human and socio-organizational environments. These methods might be reductive, and epistemological methods such as a *utility-based contextual approach*, developed in this work, should be considered to design complex and user-oriented specialized knowledge representation and organization systems. To put

such an idea into practice, a MKOS in allergy was designed for the Allergy Unit of the Montpellier University Hospital in France.

The present article will focus on MKOSs, discussing their typology, application, current needs, and design methods. It will also discuss the practical bases justifying the creation of the MKOS in allergy, its theoretical and methodological approaches, and its results. Finally, possible contributions and limits of the developed methodological approach will be discussed, providing some perspectives to improve the constructed system in allergy.

2.0 Medical knowledge organization systems (MKOSs)

2.1 Typology, users, applications

MKOSs, such as medical taxonomies, classifications, nomenclatures, subject headings, thesauri, semantic networks, consumer health vocabularies and ontologies, are structures consisting of concepts and their relationships, representing knowledge on different medical domains: neonatology, pharmacy, nursing, etc. (Trzmielewski and Gnoli 2022). Concepts in MKOSs correspond to terms that are derived from specialized terminology, *e.g.*, “Seasonal allergic rhinitis”, and/or lay vocabulary, *e.g.*, “Hay fever”. We distinguish general specialized systems: National Library of Medicine (NLM) Classification, Medical Subject Heading (MeSH), Unified Medical Language System (UMLS), etc., from systems dedicated to limited domains: Health and Aging Thesaurus, Ontology for Neurosurgery, Colon Cancer Treatment Ontology, etc. General classifications (Dewey Decimal Classification, Universal Decimal Classification, Library of Congress Classification, Bliss Bibliographic Classification, etc.) aim to classify all human knowledge but devote part of their schemas to concepts representing medicine as well. Many MKOSs represent and organize knowledge in specialties, pathologies and public health issues related to Western medicine. However, as complementary and alternative medicine is gaining popularity among the general public, “soft medicines” such as Ayurveda, traditional Chinese medicine, aromatherapy and herbal medicine are also expressed (Trzmielewski and Gnoli 2022).

MKOSs are used for organizing and searching physical and digital information resources in different spaces: hospitals, research labs, general and specialized libraries, catalogs, databases, and websites. They are used by health professionals, researchers, users of public and specialized libraries, patients and their families, and internet users interested in health topics (Trzmielewski and Gnoli, 2022). Even though the spread of connectionist artificial intelligence (IA) techniques to process health data, like machine learning (ML) or deep learning could mine the need for MKOSs (Reece

and Danforth 2017, Sidey-Gibbons and Sidey-Gibbons 2019), the numerous and various applications of categorization systems, developed and manipulated by humans, witness their continuing vitality, need and relevance. Nevertheless, a nice compromise could be played by hybrid IA, articulating symbolic MKOSs (such as ontologies) and connectionist techniques. Such an approach is currently particularly promising in processing health data (Chen et al. 2022, Hoehndorf and Gkoutos 2022). MKOSs are also still needed to represent and organize information in a new type of medical devices, notably in healthcare interface organizations (personal health records, telemedicine tools, etc.), intended for both public and private sectors, including patients and their families, to allow them to become a helpful solution for cooperation between different actors, and for sharing knowledge (Bourret 2018). MKOSs integrating such systems should support the informational practices of experts and laymen.

2.2 Need for an MKOS in allergy

The construction of the MKOS in allergy was raised from epidemiological and social issues. Allergies, originally perceived as rare diseases, have become a serious public health issue in terms of care and prevention, affecting nowadays more than 60 million people in Europe and probably almost one billion worldwide (Papadopoulos et al. 2012). These diseases significantly reduce the quality of life of patients and their families, hampering their personal development, career, and lifestyle choices. In France, allergy^[1] was only recognized as a medical specialty in 2017 (Demoly 2017), and currently, there is no specialized MKOS in French that allergy professionals can use in their work activities involving information use.

The construction of an MKOS in allergy is a documentary and strategic issue as well. Allergy knowledge, produced by different actors (allergists, researchers, learned societies, pharmaceutical companies, patients) is abundant and heterogeneous, and keeps increasing, in parallel with the massification of health data. Existing MKOS in allergy are not useful for processing and searching heterogeneous documents in French. To allow and provide access to this complex knowledge, it is crucial to identify and characterize it, first by focusing on what might be useful for professionals' daily activities and then by structuring it into a system of organization and documentary representation (MKOS), possibly linking the different ways of representing knowledge by the different actors of such domain. The Allergy Unit of the Montpellier University Hospital is a World Health Organization (WHO) collaborating center for the scientific review and representation of allergic pathologies in the 11th version of the WHO International Classification of Diseases. Specialists from this Unit developed, together with a Ph.D.

student in Information and Communication Sciences, the ALLERGIC project aiming to develop a specialized MKOS in allergy^[2]. The construction of such a MKOS could support document communication between different actors in this new specialty in France and give it some visibility.

We identified four existing MKOSs in allergy. Two of them are being currently developed: the Allergy Ontology (Yu et al. 2012) and the Allergy Information Ontology for Enlightening People (Velmurugan and Ravi 2016); and two of them are ready to implement: the AllergyIntolerance (HL7 FHIR) and the Allergy Detector II (Quevedo 2015). Attending physicians from the Allergy Unit of Montpellier assessed the usefulness of these systems for daily work and for the support of information practices. During non-directive interviews, they indicated that the existing systems are too generic (do not adequately represent their information targets), unclear, unscientific (except the Allergy Ontology), non-exhaustive and non-adapted for the specialist daily work practice. They also identified several problems relating to scientific and logical principles of division of subjects and some terminological concerns. They recognized that “we can see these systems are designed by engineers instead of doctors” as well. Moreover, none of the existing MKOSs in allergy are available in French, which makes them useless for French users. Furthermore, no system establishes a bridge between specialized and general-public conceptualization and terminology. Such an aspect is very relevant and necessary nowadays since allergy knowledge is produced, searched, and mobilized by various specialized and non-specialized actors. Therefore, existing MKOSs in allergy do not fit into the practices of allergy professionals and are not designed to represent and organize heterogeneous knowledge. Thus, the need to design new MKOSs for allergy has become evident.

2.3 Design methods

MKOSs design consists of collecting terms and concepts, relevant to medical domains, and representing them by organizing into semantic relationship. Conceptual and terminological data are collected through different methods: manual and automatic term extraction from documents, reusing existing KOSs, questionnaires, interviews, crowdsourcing (Trzmielewski and Gnoli 2022). Nevertheless, the first step the designer must take is to choose an approach that will lead the method of the construction.

2.3.1 Ontological and techno-centric approaches

Main ontological positions such as foundationalist pragmatism and realism (Tennis 2012) are frequently used in MKOSs design (Raj 1987, Huber and Gillaspay 1996, Na and Leng Neoh 2008, Raghavan and Sajana 2010, Khoo et

al. 2011, Das and Roy 2016, Almeida and Farinelli 2017, Tang et al. 2017, Iyer and Raghavan 2018). Considering this, designers focus on “what *lies behind* language” and mean “that content is unchanging, identifiable, and can be fixed in relation to other content” (Tennis 2012). Such an approach leads to consider “knowledge” as an object, *i.e.* recorded network of ideas and perceptions, represented in terms of formalization of data (Smiraglia 2014, Gnoli 2020). A foundationalist pragmatism is in accordance with the Domain Analysis Theory (Hjørland and Albrechtsen 1995, Hjørland 2017), inviting to understand each represented medical domain as “a body of knowledge, defined [both] socially and theoretically as the knowledge of a group of people sharing ontological and epistemological commitments” (Hjørland 2017, 441). Therefore, the representation of knowledge must be considered within a socio-cultural perspective. According to this view, designers develop MKOSs that are composed of facets specific to homogeneous subject areas, domain-dependent (Albrechtsen 1992), and based on consensus and validation of experts (scientific warrant principle, Bliss 1929). Huber and Gillaspay (1996), for example, created subject headings that “represent the multi-faceted body of HIV/AIDS knowledge”, as it is reflected in domain-specific textbooks, dictionaries, thesauri, and knowledge bases. Pieces of information provided from interviews conducted by Iyer (and Raghavan 2018), among professionals of Siddha medicine, gave indications on how experts categorize and designate relevant concepts of the domain, further represented in a developing ontology.

Another ontological position is a realist one, in accordance with Dahlberg’s (1976) Concept Theory, which claims that concepts representing medical domains are “units of knowledge” and have some essential characteristics. Concepts are extracted from specialized terminology (literary warrant principle, Hulme 1911), and classified through universal facets, such as “entity”, “disposition”, “agent”, “process”, “event”, “place” and “time”, and logical divisions. These facets and divisions are independent from language, cultural specificities, and time, and applicable to all medical subject areas. Systems developed in such a way are based on the theory of facet analysis (Raj 1987, Raghavan and Sajana 2010) or on the cava of conceptual formal structures extracted from top-level ontologies (Na and Leng Neoh 2008, Almeida and Farinelli 2017).

Ontological stances lead designers to pay less attention to the human and socio-organizational aspects, because they develop and assess MKOSs in laboratory methods and conditions, according to system-oriented KO paradigm^[3] (linked to information retrieval principles, Belkin and Croft 1987). Through this approach, potential users are not involved in the interaction with MKOSs, but only designers and domain experts are (Huber and Gillaspay 1996, Raghavan and Sajana 2010, Das and Roy 2016, Almeida

and Farinelli 2017, Tang et al. 2017, Iyer and Raghavan 2018). Moreover, designers often neglect users' cognitive factors and their information needs encountered in daily activities and environments. Instead of that, they target the correctness and technical efficiency of the content of developed MKOSs, which is supposed to provide users with better access to medical knowledge. They ask to experts to determine "completeness", "accuracy" and "relevance" of the proposed representations (Huber and Gillaspay 1998, Almeida and Farinelli 2017). They also perform automatic terminology extractions from specialized documents managed by different and not clearly identified information systems to verify whether the most frequent terms, obtained from the extraction, are present in the systems (Almeida and Farinelli 2017). Designers test medical ontologies through the ability of these systems to execute complex queries and to retrieve entities in knowledge bases made of these MKOSs (Das and Roy 2016, Iyer and Raghavan 2018) or in samples of typical documents to be processed, *e.g.* patient records (Raghavan and Sajana 2010, Tang et al. 2017). They calculate the relevance of MKOSs by different scores (*e.g.* recall and precision) (Tang et al. 2017), instead of assessing it through the cognition, affects, perception and behavior of users involved in utilization of systems in concrete situations (Mucchielli 2001). Therefore, designers simplify the reality, by testing the internal structure of MKOSs, or by working on limited samples that often are not part of collections that actually will be searched and processed by targeted users in concrete socio-organizational environments. Such technocentric approaches are in accordance with the dynamics of the integration of ICT in health. Since the 1970s, the implementation of systems like electronic health records (EHR) and document management systems (DMS) in health organizations has frequently been oriented by technical and economic reasons, with the aim to rationalize work and billing medical activities. Such a view implies technocentric designing approaches and systems built in this way do not fit into existing practices of health professionals and weakly satisfy existing uses (Grosjean and Bonneville 2007). Therefore, in some cases, professionals refuse to use these tools, and even workarounds or develop alternative parallel systems by themselves (Saleem et al. 2011, Park et al. 2012). The same technical and economic reasons arise when it comes to the integration of MKOSs to support automatic, quantified, and standardized processing of medico-administrative information that contributes to generating morbidity and mortality statistics. Such MKOSs are not user friendly, and healthcare professionals encounter problems with coding that affect drug marketing and entail public funding distribution (Trzmielewski and Gnoli, 2022). The design of MKOSs for information processing and searching frequently fits into techno-economic dynamic. Over the past ten years, specialists in computer and information science

have received funding from public and private stakeholders, allowing them to conduct and present research on MKOSs according to the system-oriented paradigm instead of focusing on actual users' needs (Trzmielewski and Gnoli, 2022).

2.3.2 Epistemological and user-oriented approaches

In epistemological positions, such as linguistic relativism/hermeneutics, antifoundationalist pragmatism and constructivism, "language is not conceptualized as a one-for-one match or as content (the best textual means to an end), but rather language in context is a tool for more symbolic interaction" of users and systems based on interpretation and situated in complex environments (Tennis 2012, Weiss et al. 2016). Therefore, "knowledge" is understood as a cognitive process of construction carried out by users (which from now will be also called "actors") according to the context of use of documents (Meyriat 1985; Jeanneret 2000). Within such approach, knowledge only exists "when there is interpretation, assimilation by an individual and when it is connected to a universe of defined knowledge" (Clavier and Paganelli 2012, 293). Thus, analogically, "information" is comprehended as part of a process of exchange and sharing, of finalized communication in a specific context, and understood as such as communicated knowledge (Meyriat 1985, Fondin 2001). The understanding of knowledge as a process leads to apprehending domain as context, a mean leading (to) a construction process, something to what Broudoux (2012, 6) refers to as a "prism from which we can interpret and act" in accordance with practices of involved actors. Thus, the main concern is shifted from the correct representation of data to the useful representation of the problems encountered by the actors in the context of MKOSs use. Therefore, epistemological stance fits into "actor-oriented paradigm" of KO (related to information seeking turn, Ingwersen and Järvelin 2005), claiming that "context" and human and social "activities" need to be considered when defining how documents should be represented and processed to satisfy users' needs (Soergel 1985; Albrechtsen et al. 2002, Clavier and Paganelli 2012, Pejtersen 2017).

In works carried out under an epistemological stance, the construction of MKOSs is user-oriented (Albrechtsen 1992), according to the user warrant principle (Lancaster 1977). Such a conception is based on an anticipation on the part of designers of possible user needs in a specific environment through user-specific facets, consumer health vocabularies, and image-based retrieval interfaces, aiming to support information searching and processing by users in their everyday practice (Cosgrove 1994, Soergel et al. 2004, Given et al. 2007, Iyer and Guadrón 2014, Oh et al. 2015, Choi 2016). Librarians from the California Pacific Medical Center developed a classification scheme to organize physical

and digital resources in a medical library, created in the center to provide health information to the general public (Cosgrove 1994). The classification relied on users-oriented facets (“Mental health/illness”, “Substance use”, “Life processes”, “Animal health”, etc.), based on information from users-librarians-experts interactions, instead of basing it on the Dewey Decimal, Library of Congress or NLM Classifications. The existing classifications seemed inadequate because they represented medical subjects unfamiliar to lay-person. They were not easy to use and not useful as well to this category of users. By conducting an online survey completed by 84 participants Oh et al. (2015) assessed facets that were preferred, easy to use, and useful to the general public in South Korea in accessing health information on websites. Given et al. (2007) examined, through 12 task-based interviews, senior’s health information behaviors and documented their search strategies using a prototype using similarity-based clustering of pill images for searching. Therefore, epistemological, user-oriented stances lead to the study of cognitive factors related to individuals, their information behavior, preferences, and activities occurring within informational and socio-organizational environments. Such approaches should be rather considered to develop complex and useful MKOSs, which has been indeed mobilized to design the allergy MKOS discussed in the present paper.

3.0 Theoretical framework

To characterize and structure allergy knowledge, a socio-constructivist approach was developed (Weiss et al. 2016) through the analysis of the processes that occur through mutual actions between allergy professionals and their informational and socio-organizational environments. Therefore, the elaboration of a MKOS in allergy was based on a contextualized approach (Clavier and Paganelli 2012) that relied, on one hand, on the analysis of the context of use of allergy knowledge, by the study of the information practices of professionals who seek, produce, and mobilize knowledge in the domain; and on the other hand, on the analysis of a corpus of documents that professionals use in their daily activities. By studying information practices, the goal was to comprehend “the way in which devices, formal or informal sources, tools, cognitive skills are effectively used” by allergy professionals “in the different situations of production, research, organization, processing, use, sharing, and communication of information” (Chaudiron and Ihadjadene 2010). The aim of such an analysis was inspired by studies of Clavier and Paganelli (2012) and Clavier (2014) on KO, led by professionals’ discourses, *i.e.* to take into account the way in which professionals seek information; what tools they use; what they do with the retrieved information; what is this information useful for; and why these ways of doing are indicative of socially rooted prac-

tices. A contextual framework was combined with an anti-foundationalist pragmatic approach (Tennis 2012), user warrant (Lancaster 1977) and cognitive systems engineering principles (Rasmussen et al. 1994). It led to giving major priority to the development of a useful symbolic interaction tool aiming to anticipate and support the information needs of allergy actors. Tennis (2012) suggests that systems designed for utility might be evaluated on their intentionality. Instead of providing some *a priori* criteria of usefulness to design MKOSs in allergy, the investigator aimed to inductively identify and construct them through his interaction with allergy professionals, involving interactions of professionals with developing MKOS, and situated within the context of their work. Such a method aimed to identify some cognitive elements useful to allergy professionals and represent them in a user-oriented symbolic representation.

4.0 Methodology

4.1 Information practices analysis

The study of information practices was carried out in 2020-2021 in the Allergy Unit of the Montpellier University Hospital. 39 participants of the study were supervising and apprenticing doctors, nurses, childcare workers, medical secretaries, and clinical study coordinators. 16 participants’ observations were included, from 8 journal club meetings, devoted to the presentation and critical analysis of recent scientific articles and conference presentations, and from 8 clinical meetings focused on the presentation and analysis of patient charts and records. Successively, 20 interviews were conducted, with different healthcare professionals working in the Allergy Unit, investigating their information and work practices. All participants signed an informed consent, and the study was officially accepted by the hospital Ethics Committee and registered on ClinicalTrials.gov. Personal data appearing in the survey corpus were anonymized, and the accuracy of medical concepts and terms in observation reports (in total: 19,470 words) and interview transcripts (121,203 words) was validated by professionals working in the Unit. To exploit collected data, a thematic content analysis was carried out, oriented by the Cognitive Work Analysis model (Rasmussen et al. 1994).

4.2 Document analysis

The document analysis was carried out in 2021-2022.

4.2.1 Creation of user-oriented facets

First, 453 terms were manually extracted from the corpus of observation reports and interview transcripts (in total 36 documents = 140,673 words). The investigator collected al-

lergy-related terms and classified them into user-oriented facets that were closely linked to informational targets of allergy professionals, discovered during the analysis of practices. The content of the reports and transcripts was useful to this task because it provided contextual information that permitted us to understand if some terms were to be classified in one category or another. The thematic analysis of these brought up 17 facets (Figure 1), further validated by 4 professionals, by checking whether they are useful for indexing of 8 documents used in the Unit (journal papers, slides, clinical protocols, questionnaires, and photos) and for characterization and searching for allergic cases. The content of validation reports led to the collection of 44 new terms and raised our terminological base to 497 entities. The assessment implied the identification of 12 facets of phenomena (Gnoli 2016), used by professionals to search for subject information. Facets of perspective dimension also were validated to express points of view on the contents. The investigator did not initially propose the document dimension, but during indexing, employees expressed a need for additional descriptors for representing features of production instances (authors' names and their affiliations), form (*e.g.*, "photography"), and function (*e.g.*, "prescription aid") of documents. They use such criteria to categorize and search documents in scientific databases, DMS and EHR.

| |
|-----------------------------------|
| Phénomènes^[4] |
| Allergène |
| Comorbidité |
| Facteur de risque |
| Maladie |
| Mécanisme |
| Méthode de diagnostic |
| Parcours de soins |
| Personne |
| Prévention |
| Qualité de vie |
| Symptôme |
| Traitement |
| Perspectives^[5] |
| Discipline |
| Méthodologie |
| Provenance des données |
| Documents^[6] |
| Auteur |
| Document |

Figure 1. A first version of allergy facets.

4.2.2 Terminology extraction

Then, the allergy-related terminology was semi-automatically extracted from a documentary corpus, composed of documents used daily by the Unit's employees, according to the results of the practices analysis. The date of collected documents was not older than 3 years before the time of the assessment, as professionals rather use recent documents^[7]. All selected documents were written in French, the work language used by all employees. Specific text parts were targeted as well, such as title, abstract, and categorization systems, which were identified as useful to professionals to interpret and represent the subject of documents. The corpus was divided into 3 textual sub-corpora: "Corpus scientifique", "Corpus généraliste" and "Corpus clinique" (Figure 2). All personal data that appeared in the corpus was manually anonymized. *Doctissimo* users and Allergy Unit patients were informed about data collection. The possibility to refuse to share their data was also given and communicated to them.

Each sub-corpus was separately processed with the TermStat Web 3.0 software, according to term appearance frequency (Figure 3). In total, 9,683 terms were extracted. Then, from each sub-corpora ("Corpus scientifique", "Corpus généraliste", "Corpus Clinique") 497 terms – the most frequently used ones – were selected to compare them to terms from the information practices and facets validation corpus ("Termes corpus pratiques et validation des facettes" in Figure 4). The aim of such selection also was to avoid making a representation (*e.g.* scientific or generalist) more prevalent than the others. As Figure 4 shows, each one of the 4 corpora was compared with the others, to erase redundant terms (in red), identify new ones (in green), and highlight those terms that were non-relevant (crossed out) to the conceptual frame given by the allergy facets. An allergist working in the Unit validated the results of the extraction. After the final analysis, and the doctors' assessment, 1,067 terms were included.

4.2.3 Terminology organization

Then, a thematic analysis of scientific, generalist, and clinical sub-corpora was performed to semantically assemble terms into allergy facets. A linguistic analysis helped characterize and structure terms by their morphologic and lexical form. Through a genus-species-free pre-categorization, a first draft of the MKOS was eventually elaborated. Existing user-oriented facets were not specific enough to represent the semantic scope of the extracted terminology. Therefore, 11 new classes had to be developed to refine the labels of the previous facets (Figure 5).

It was also important to notice different linguistic variations at lexical and morphological levels, as allergy experts

| Name of corpora | Corpus scientifique | Corpus généraliste | Corpus clinique | |
|--------------------------------------|---|---|---|----------------|
| Type and number of included elements | 864 titles and 761 scientific articles abstracts from the <i>Revue Française d'Allergologie</i> journal | 403 titles of threads and 2175 messages from <i>Doctissimo</i> generalist online health forum | 70 clinical activity documents, including models of standardized protocols, medical reports, standardized questionnaires, check and patients lists, 89 anonymized medical reports, and 1 text document containing terms used in a DMS to categorize documents | |
| Number of documents | 1.625 | 2.578 | 160 | 4.363 |
| Number of words | 229.973 | 333.384 | 45.553 | 608.910 |

Figure 2. Documentary corpus.

| Candidat de regroupement | Fréquence |
|--------------------------|-----------|
| patient | 1851 |
| cas | 1071 |
| allergie | 1031 |
| étude | 864 |
| résultat | 827 |
| asthme | 784 |
| réaction | 766 |
| test | 745 |
| enfant | 734 |
| méthode | 585 |
| conclusion | 569 |
| traitement | 546 |
| p | 510 |
| introduction | 490 |
| ige | 410 |
| allergène | 404 |
| anaphylaxie | 396 |
| diagnostic | 365 |
| sensibilisation | 349 |
| prise | 342 |
| âge | 314 |

Figure 3. A partial list of the terminological extraction of the “Corpus scientifique”.

and non-experts sometimes use different words to designate the same thing. Epistemological variations were identified as well, as different actors know/are interested in different aspects of allergy, and they may apprehend them differently. An allergist from the Unit clearly suggested us to distinguish such variations. 4 different kinds of representations of allergy knowledge were identified and structured:

- 1) terminological, phenomenal and conceptual accordance/similitude between expert and non-expert representations, e.g. as found for “Eczéma” or “Anaphylaxie”;
- 2) terminological discordance, e.g. “Rhinite allergique” (experts) and “Rhume des foins” (non-experts) to name allergic rhinitis, which was represented through synonymic equivalence relationships;
- 3) phenomenal and conceptual discordance between expert and non-expert points of view, e.g., some non-conventional treatments or sentiments, known and shared by patients or their families on the Web, are not mentioned in specialized documentation and are sometimes unknown by professionals. Also, allergens and symptoms are conceptualized differently by experts and non-experts

| | A | B | C | D |
|----|--|----------------------------|---------------------------|-------------------------------|
| 1 | Termes corpus pratiques et validation des facettes | Termes corpus scientifique | Termes corpus généraliste | Termes corpus clinique |
| 2 | Allergène | Patient | Allergie | Test |
| 3 | Acariens | Cas | Jour | Jour |
| 4 | AINS | Allergie | Bonjour | Réaction |
| 5 | Aliment | Étude | Problème | ml |
| 6 | Allergène alimentaire | Résultats | Peau | Traitement |
| 7 | Amoxicilline | Asthme | Merci | Allergie |
| 8 | Ana o3 | Réaction | Traitement | Test cutané |
| 9 | Anisakis | Test | Mois | Patient |
| 10 | Antibiotique | Enfant | Médecin | Produit |
| 11 | Anti-inflammatoire | Méthode | Fois | Bilan |
| 12 | Arachide | Conclusion | Eau | Provocation |
| 13 | Aspirine | Traitement | Main | Consultation |
| 14 | Augmentin | p | Eczéma | mg |
| 15 | Bétadine | Introduction | Temps | Surveillance |
| 16 | Bétalactamine | IgE | Chose | Prise en charge des réactions |
| 17 | Bevacizumab | Allergène | Cas | Test de provocation |
| 18 | Blattes | Anaphylaxie | Semaine | Heure |

Figure 4. A fragment of the terminological base.

The screenshot shows the ALLERGIDOC ontology interface. On the left, a 'Class Hierarchy' tree lists various classes, with 'IdentitéDeGenre' selected. The main panel displays the details for 'IdentitéDeGenre', including its IRI, annotations (rdfs:label, skos:definition, skos:altLabel), parents (owl:Thing), and relationships (estUtiliséPourDé... Sexe).

Figure 5. Principal classes (facets) and its properties, represented in ALLERGIDOC ontology.

perts. An allergist suggested representing such discordance by hierarchical relationships, e.g. treatments were divided into treatment validated by science and treatment not validated by science;

- 4) the use of the phenomenal and terminological non-specialized substitutes in the case of conceptual discordances, e.g. wide public designates food allergens, such as cows' milk proteins, through food products containing these allergens: "Comté", "Gruyère", "Fromage Blanc" (cheese types), which is also used by experts in medical documentation. As suggested by an allergist as well, these variations were represented by hierarchical relationships of "Allergène" (expert point of view) and "AllergèneDePointDeVueNonSpécialisé" classes (non-expert point of view).

Moreover, 8 existing MKOSs frequently consulted by allergy professionals were included: MeSH bilingue anglais-français, Classification internationale des maladies 11, Classification commune des actes médicaux, Vidal dictionary, Hypersensitivity Classification by Gell and Coombs, Classification of anaphylactic reactions by Ring and Messmer, Allergy nomenclature by Johansson et al., and categorization systems and nomenclatures from the e-allergie.fr website for professionals' education in allergy. Such analysis brought 423 new terms and useful relationships to organize terms in the MKOS.

Furthermore, an allergist provided several different suggestions on conceptual and terminological relationships and provided crucial phenomena definitions to the domain,

such as hypersensitivity, allergy, and intolerance. Also, academic and professional experts from online groups, forums, and mailing lists dedicated to KO and modeling helped add useful information for the project.

At last, a manual and semi-automated^[8] identification of 108 lexico-syntactic markers in the collected documents constituted the final part of the work. Associations of verbs and nouns, and nouns, verbs and data were assessed, and these linguistic patterns were used to create associative semantic relationships.

In total, 1,598 collected terms were organized by terminological and conceptual relationships in the first version of the MKOS in allergy. OWL and SKOS languages were used to specify and structure the complexities of the allergy knowledge, through a network of hierarchical, equivalence and associative relationships between entities expressed in an explicit and formal way. These languages gave some sense to the established relationships and made them technically operational (Bodon and Charlet 2020). By inserting these entities into the WebProtégé software, it was possible, through the web version of the software, to edit the MKOS in a collaborative way and to make it available online. Such a step perfectly fitted the project, allowing the sharing of the system with health professionals, KO specialists, and patients for both the validation phase and its daily use.

4.3 User-oriented validation of designed MKOS

The first version of the designed MKOS was validated in 2022 by 15 persons, representing different categories of potential users: 9 professionals from the Allergy Unit, 1 private allergist, 4 KO experts specialized in general and medical knowledge modeling, and 1 expert patient and director of an association for allergic patients. Participants consulted the system on the WebProtégé website and provided some comments about the terminology used and conceptualization, according to their work and information practices. They spontaneously expressed their opinions about the interest of the MKOS for existing uses and for future projects as well. Finally, they noted a total of 125 keywords expressing terms and subjects of their information searches. For this purpose, they used notebooks shared with them one week before the evaluation. They searched if noted terms had their equivalents in the MKOS database. Reports were written based on recorded data on participants' oral comments, navigation, and searching behavior. A content analysis of collected data was then performed.

5.0 Results

5.1 Characteristics and type of MKOS in allergy

The study on information practices led to the definition of a set of characteristics and types of MKOS in allergy needing to be designed. Several categories of potential users were defined, who should integrate the new MKOS in their activities: allergy professionals, KO specialists and patients who usually participate in document communication in allergy. The involvement of immunology labs, scientific societies, allergy working groups, general practitioners, and private allergists, who share documentation with allergy professionals, was found useful in supporting various information uses by the system, as well.

Furthermore, the analysis allowed to target concrete information-searching practices: querying by keywords, navigation, and sorting of results, and these related to information processing: semi-automatic indexing and text mining. The aforementioned practices of professionals should be supported by the MKOS to facilitate decision-making on allergic diseases and patients treated for their allergies in the Allergy Unit.

To represent and organize the information in EHR and in three DMSs parallelly used in the Unit, professionals use categorization systems of documents in files, which do not allow them to carry out information processing and searching in a satisfactory manner. Deprived of the possibility of indexing documents, professionals cannot finely describe the subject and other characteristics of the documents and, consequently, cannot perform keywords searches. In addition, the existing MKOSs complicate the access to the documentation because of the lack of specificity and numerous categories hampering navigation and leading professionals to "spend hours to find documents." Therefore, indexing will allow the creation of additional access to documents that are useful to professionals.

Moreover, info-communication devices used within the Unit were identified to integrate the MKOS in allergy, to carry out information practices. First, existing devices to which professionals should have access, to further organize and share clinical documents (protocols, questionnaires, medical reports and letters, etc.), generalist documents (documentation shared by pharma companies) and scientific professional documents (journal articles, books, education documents, etc.), especially in EHR and DMSs. Secondly, employees need to be allowed to share, organize, and analyze biomedical textual data and data from content produced and shared by patients and internet users on general public health forums and patient groups on social media. Generalist contents are complementing resources that professionals use to be informed on non-conventional therapies and beliefs related to allergies that cannot be obtained dur-

ing a physician-patient consultation. Also, allergists at the University Hospital of Montpellier are associated to a scientific research unit on epidemiology and public health, and they focus their research on the aforementioned data to generate epidemiological, socio-demographical, environmental and immunological markers. Thirdly, the investigator targeted devices for sharing, analyzing and mediating information and knowledge between professionals from the Unit and other actors involved in document communication in the domain: practitioners, pharmacies, laboratories, public health organizations, research institutes, the WHO, scientific societies and working groups, pharmaceutical companies, patients, and their relatives.

In addition, the analysis of practices allowed the language of publication to be settled. The MKOS in French was proven to be useful for all professionals in the Unit, because they all use the information resources and work in this language. Given the constant evolution in allergy knowledge, the analysis also drew our attention to the need for regular updates.

Considering all information obtained through the analysis of information practices, we proposed to construct an informatics ontology called “ALLERGIDOC”. This kind of MKOS will allow the representation and organization of complex knowledge structures that we may find in scientific articles and health records, containing specialized conceptualization and terminology, as well as different kinds of data: patients’ names, surnames, ages, sex, drug doses, etc. Ontologies are tools that are used for automatic indexing and semantic searching for information (Raghavan and Sajana 2010, Choi 2016, Almeida and Farinelli 2017, Iyer and Raghavan 2018). The ALLERGIDOC ontology will articulate multiple knowledge dimensions (phenomena, perspectives, documents) and points of view (experts and non-experts), as professionals will seek and process specialized

but also generalist contents, and as its users may be experts or laymen. The construction of such an MKOS, adapted to the work context in the Unit, was, therefore, the main goal of the research, together with the possibility of generalizing it for other uses and applications by various potential actors.

5.2 The first version of the ALLERGIDOC ontology

The first version of the ontology includes 155 classes, structured into hierarchical relationships, through disjointed classes (Figure 5). The system includes 940 instances of classes as well. Instances are the most granular concepts, e.g. types of symptoms (Das and Roy 2016), and named entities (Gnoli 2020): authors’ names, their affiliations and drug commercial names.

Moreover, the ontology contains 395 morphological and lexical synonyms, represented by “skos:altLabel”. The “Bétalactamine” class, for example, was expressed through 6 form variations (Figure 6). “Pneumallergène” class was connected to its lexical equivalents such as “AllergèneRespiratoire” and “AllergènesAéroportés”.

Furthermore, the designed MKOS represents 108 associative relationships. In first place, 80 object properties may be distinguished, such as “présente” (Figure 7). They allow to establish triples such as “Patient – présente – Symptôme”^[9] where “Patient” is defined as domain and “Symptôme” as range. Several concepts are linked by OWL inverse relationships (“InverseOf”). “ProfessionnelDeSanté” – “réalise” – “ActeMédical”^[10] has for example an inverse relationship “ActeMédical” – “estRéalisePar” – “ProfessionnelDeSanté”^[11]. Such a type of representation will support automatic inferencing.

20 data properties were also declared, to represent test results, dose of drugs and test agents, patient data, and temporality of allergy episodes (Figure 8). They are expressed by

| Class: Bétalactamine | | | |
|---|---------------|----------------|------|
| IRI http://webprotege.stanford.edu/RC8JzKeDh755bCzh5lkdh31 | | | |
| Annotations | | | |
| ⚙️ | rdfs:label | Bétalactamine | lang |
| ⚙️ | skos:altLabel | Bétalactamines | fr |
| ⚙️ | skos:altLabel | Bétalactamines | fr |
| ⚙️ | skos:altLabel | β-lactamines | fr |
| ⚙️ | skos:altLabel | β-lactamine | fr |
| ⚙️ | skos:altLabel | β-lactames | fr |
| ⚙️ | skos:altLabel | BL | fr |

Figure 6. An example of synonyms represented in ALLERGIDOC ontology.

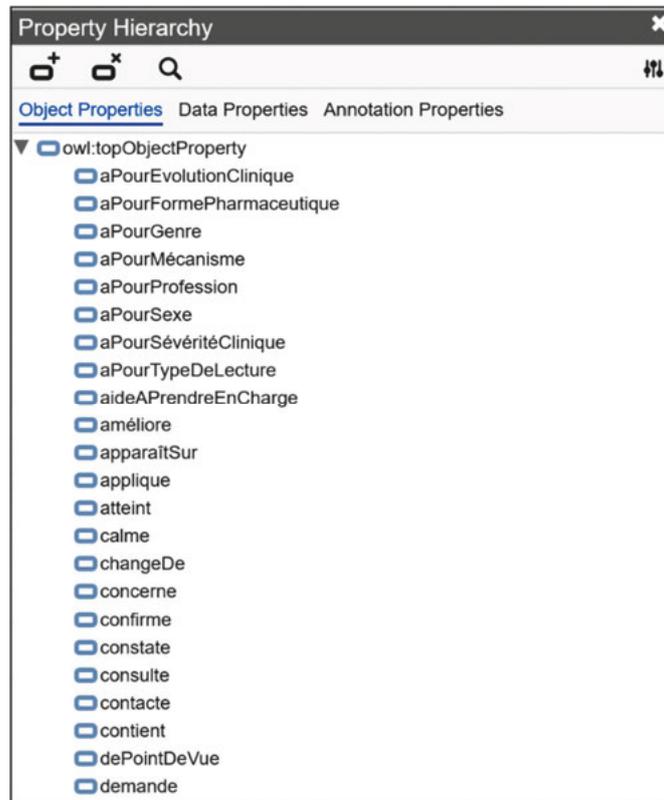


Figure 7. A fragment of object properties represented in ALLERGI-DOC ontology.

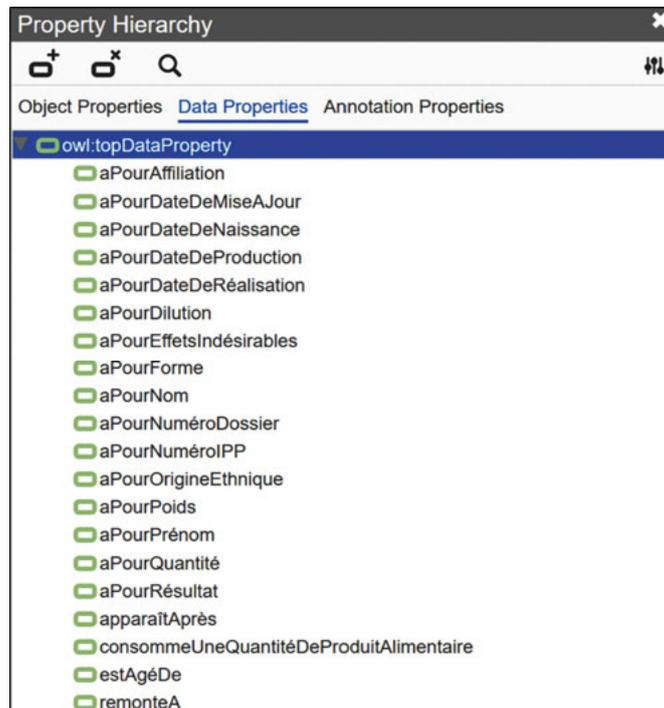


Figure 8. Data properties represented in ALLERGI-DOC ontology.

5.3 ALLERGIDOC ontology is potentially useful, but operational and content-related improvements are still needed

Allergy professionals appreciated the effort and the time dedicated to construct the ontology and the quality of this system as well. The representation seemed to them “clear”, “well done”, and “really well done”. Their comments concerned content, intentionality, and operationalization of the MKOS.

Regarding semantic coverage, five allergy professionals emphasized that the ontology reflects “well”, “largely” or even “completely” reality, knowledge, and professional activities in the domain. The represented terms cover a wide range of topics and are used “almost every day.” The expert patient noted that “the ontology faithfully reflected the patients’ discourses”. Such positive comments regarding the ontology also were given by KO experts. Furthermore, participants gave some conceptual remarks and suggestions concerning class division principles and terminology. They also identified errors in thematic classification, missing concepts, as well as problems at the subdivision and granularity levels. As criticized by KO experts, so far, the ontology is not conceptually coherent. Some concepts, such as “*Eczema*” appears in 4 facets, as it is considered by professionals as a “Disease”, “Comorbidity”, “Risk factor” and “Symptom”. Moreover, we placed classes representing subjects at the same level, with classes expressing document characteristics (Figure 5), which made the ontology content difficult to understand by validating actors. The second version of the ontology should include a distinction between these two different dimensions. Furthermore, some anomalies and inappropriate practices of formalization were found^[14], which made the ontology logically incoherent.

While consulting the ontology, interviewed actors suggested several applications and uses for which this system might be useful. The first proposed application was information searching and processing within medical records and scientific literature. An assistant highlighted that “it would be good to use the ontology to find all the patients who consult for rare diseases”. The second one was to use the ontology to represent allergy lexicon and topics. The private allergist said that “it’s good to have the synonyms. This is what was missing!”. A hospital practitioner claimed that “it could be useful as a training tool in allergy”, listing important topics. Nevertheless, all these possible applications cannot be done yet because only 47% of the keywords noted in the professionals’ notebooks were retrieved in the first version of the ontology. Participants also saw the potentiality of the ontology to be used in sharing health data between healthcare professionals and patients. An interviewed specialist in medical information architecture and semantic technologies claimed that “the articulation of the

specialist and generalist point of view in the ontology seems very interesting and essential for creating data sharing applications”.

While professionals initially had some difficulties using the ontology, after a few minutes, they easily navigated and searched for terms and relationships in the system. For the medical secretary, the ontology seemed too detailed, as she was used to dealing with file categorization systems. An assistant doctor claimed that “the ontology can be updated without problem” by professionals themselves.

5.4 The Utility in Context Model (UCM)

The design process of the ALLERGIDOC ontology was led by a utility-based contextual approach. The analysis of information practices and the validation meetings contributed to the identification of a set of human, informational, and socio-organizational elements that compose the context of use of knowledge in an Allergy Unit. At the same time, these methods led to the construction and assessment of the useful characteristics of ontology that needed to be built and encompassed by that context. For potential users, the utility of MKOSs was a matter of the content, intentionality, and operationality, and these dimensions were closely linked between them. The relationship between the context, actors, designer, and utility dimensions, developed through the reported inductive study, is shown in Figure 11 by the Utility in Context Model (UCM). This framework can be mobilized by KO specialists to build complex MKOSs but also systems in other domains, with the aim to support users’ needs.

In the present work, “Actors” in stake were central because they were understood as potential users of the ontology. Their cognitive factors, discourses, everyday conceptualization, terminology, information, and work practices were taken in consideration, with the intention of the designer that MKOS make sense to these actors and allow them to perform their activities. Therefore, the relevance and exhaustivity of the ontology “Content” were important as well. The “Content” was understood as a constructed and interpretative product of the ontology, *i.e.* as a document (Cotte 2004) including allergy reality phenomena, user-oriented facets, concepts, terms, semantic relationships, publication, and formalization languages, as well as different points of view on allergy knowledge. The representation of all these elements allowed the “Operationality” of the ontology, assessed by users’ manipulations: indexing, navigation, searching, and updating. The “Operationality” was linked to the “Intentionality” as well, *i.e.* targeted devices, information, and work tasks for which the MKOS might be useful, which also were represented by the “Content”. All these dimensions were situated in a concrete informational and socio-organization environment.

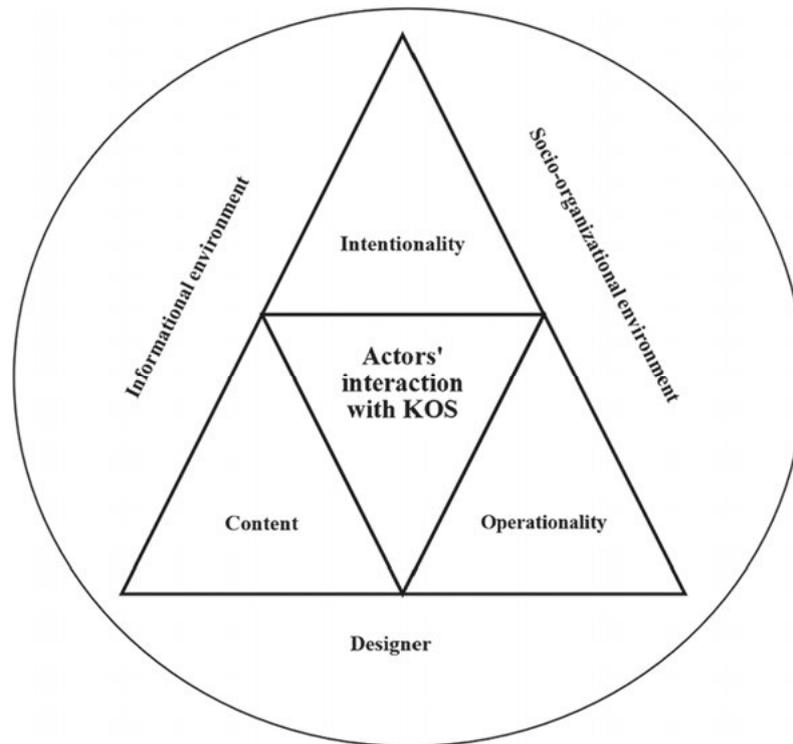


Figure 11. Utility in Context Model (UCM).

In the present work, contextual interactions of the investigator through the analysis of information practices and validation meetings allowed the collection of relevant terms to construct the ontology entities and to guide the gathering of new terms and discriminate redundant terms during document analysis. It also led to identifying documents daily used by professionals of the domain, which will be processed and searched by specific documentary tasks. Also, the same documents composed a documentary corpus that has been analyzed to identify, characterize, and organize domain terminology, as well as to represent the contents of useful documents and vocabularies of potential users. Therefore, the vocabulary of potential users, which might be used during their search for information, has a chance to be matched with terms represented in the ontology during information searching. Moreover, the contextual methods allowed all actors to be committed and gave them a central place during the design process.

6.0 Discussion and conclusion

This study led to the development of a utility-based contextual approach that allowed us to obtain a first version of a multidimensional, multifaceted, and user-friendly ontology, which is potentially useful to support practices of allergy actors, according to the context of use of knowledge in this domain. Indeed, as shown by the final validation, the content, intentionality, and operationalization of the ontol-

ogy are all connected to potential users' professional, informational, and everyday-life practices. Thus, such a design method can be considered "ecological" (Davenport 1997), as the comprehension and use of actors' practices and their environment were targeted. It may also be apprehended as "intelligent" (Le Moigne 2013), because it allowed to give some sense to the design process and conduct it in a significant way. The developed approach, expressed by a Utility in Context Model should therefore be considered in designing and updating the KOSs in medicine and in other domains. However, as shown by validation meetings, the proposed ALLERGIDOC ontology is still not ready to be used in concrete documentary tasks, mainly because of the timeline required to complete the work and the qualitative methods. These methods allowed us to consider human and socio-organizational aspects of the ontology design, but they were time-consuming and took away time from paying attention to the operational and content-related aspects.

Perspectives on the improvement of the ALLERGIDOC ontology are numerous. The anomalies and formalization problems, pointed out by KO specialists should be corrected to make the ontology logically coherent and technically operational. The ontology should also focus on representing documents (and not real phenomena) with the classical distinction between descriptive and subject representation facets. The place of a unique definition (Austin 1969) should also be reached, especially for those concepts assigned to several facets simultaneously. To reach this goal, a facet analysis

should be performed, with a parallel expression of poly-hierarchical concepts through different object properties. For the same purpose, existing top-level and domain conceptual frameworks could possibly be consulted as well. The ALLERGIDOC ontology could also be mapped to existing general and allergy MKOSs, to make it interoperable with other systems. By doing so, the ontology would become a boundary mediation object (Albrechtsen and Jacob 1998) articulating individual user's access and collective knowledge structures. It would bring together the epistemological approach and the ontological approach to the representation and organization of knowledge, under an umbrella of a methodological eclecticism (Dousa and Ibekwe-SanJuan 2014). How such a reconciliation could be possible? At which point could the results obtained in this study be generalizable? How to represent and keep the terminology and conceptualizations of allergy actors? Also, the distinction between expert and non-expert points of view should be more emphasized in the ontology. Instead of the proposed hierarchical relationships, ontology properties could manage this distinction (Zhitomirsky-Geffet et al. 2017). Finally, as ALLERGIDOC ontology only covers about 50 % of everyday terms used by allergy professionals, the system should thus still be completed with new terms coming from extracted documents and other specialized health resources. Translating terms into English should also be considered to support the activities of allergists who consult and organize articles in English. The aim is also to make the ontology freely and openly available to any other person who wishes to develop info-communication devices for allergies.

Interns in information science and a postdoctoral student specialized in knowledge engineering will continue developing the ALLERGIDOC ontology. They will edit the system's content, refine its applications, and test the validity and operationalization of the MKOS to support document processing and searching tasks by allergy professionals in real-life settings. Indexing medical reports with ontology support is already planned.

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Endnotes

1. In French: *allergologie*.
2. The PhD thesis was funded by the Occitanie Region (2019-2023).
3. System-oriented paradigm is abundantly criticized by Chaudiron and Ihadjadene (2002).

4. In English: "Allergen", "Comorbidity", "Risk factor", "Disease", "Mechanism", "Diagnostic methods", "Healthcare circuit", "Person", "Prevention", "Quality of life", "Symptom", "Treatment"
5. In English: "Discipline", "Methodology", "Data source"
6. In English: "Author", "Document"
7. Scientific articles that professionals present during journal club meetings rarely are more than 3 years old.
8. Termostat options called *bigrammes* were used.
9. In English: "Patient" – "presents" – "Symptom"
10. In English: "HealthProfessional" – "performs" – "MedicalAct"
11. In English: "MedicalAct" – "isPerformedBy" – "HealthProfessional"
12. In English: "Trophallergen" – "hasTheForm" – "{ "Raw", "Cooked", "Extract", "Uncooked", "Undercooked" }
13. In English: "Trophallergen" – "hasQuantity" – "xsd:string"
14. The identification of inappropriate practices of formalization was supported by OOPS! tool.

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