Clinical practice guideline management information systems: Cancer guidelines as boundary spanning transformable objects of practice

Demosthenes Akoumianakis, Giannis Milolidakis, Anargyros Akrivos, Zacharias Panteris, Giorgos Ktistakis
Department of Applied Informatics & Multimedia
Technological Education Institution of Crete
Heraklion, Crete, Greece

e-mails: {da, milolidakis, epp2063, epp1110, ktistakis}@epp.teicrete.gr

Abstract—The paper elaborates on the concept of transformable boundary artifacts and their role in fostering knowledge-based work in cross-organization virtual communities of practice. The domain of investigation is clinical practice guidelines development for cancer. By reviewing the social worlds involved, we claim that guideline development is a boundary spanning activity which can be facilitated through social networking tools of a Guideline Management Information System. Such a system is then described, focusing on the way it appropriates ‘plasticity’ to make guidelines cross social, institutional and technological boundaries. Contrasting earlier efforts, a key contribution of the research presented is that it emphasizes the dialogue and the intrinsic properties of developing (rather than interpreting) guidelines in collaborative settings.

Keywords-component: boundary artifacts, collaborative work, distributed collective practice

I. INTRODUCTION

Clinical practice guideline development entails professional and knowledge-based work to consolidate best practices in a health care domain. The primary outcomes of guideline development are textually mediated artifacts such as manuals and scripts which aim to represent a complex of cognitive, material and rhetorical activities leading to the proposed guideline [1]. This is not always effective or possible, as static narrative descriptions may not capture the social dynamics (i.e., perspectives, negotiation, conflicts) that arise in the course of developing a guideline. Furthermore, narrative description of guidelines does not assure compliance by practitioners. To respond to the issue of complying with guidelines, the biomedical informatics community for several years now seeks representation formats (e.g., ProForma, GLIF3) to facilitate computer-supported interpretation of clinical practice guidelines. Nevertheless, the issue of capturing and representing the dialogue leading to or the rationale behind a guideline remains a challenge.

The present work concentrates precisely on this challenge and proposes a computer-mediated method to capture the social dynamics of articulating clinical practice guidelines. Although, the reference domain of the paper is specific and targeted, the analysis aims to advance a more general insight on how collaborative technologies can facilitate consensus-based decision making. To this end, we seek to explore how online groups of peers can engage in emergent knowledge processes whose outcome cannot be predicted in advance. A distinct orientation of the present research is that it frames clinical practice guideline development as an emergent process spanning physical, social and cognitive boundaries of a cross-organization workgroup. The analysis builds upon the concept of boundary objects [2] as used in Computer Supported Cooperative Work and revisits the notion of transformable boundary artifacts [3] as first class design objects. Boundary objects represent codified knowledge (i.e., documents, sketches, repositories, etc) having potentially different interpretation across social worlds, but common enough structure to make them distinctively recognizable in each social world separately. The notion of transformable boundary artifacts is an extension of the basic concept of a boundary object. The extension covers tractable information-processing properties intended to facilitate computer-mediated cross-organizational collaboration which is a typical case in clinical practice guideline development where multiple organizations, social worlds and perspectives co-engage to reach consensus on a designated agenda.

Recent research reveals the complexity of building and sustaining cross-organization virtual workgroups and the demands placed upon the underlying organizational and technological set up [4]. It turns out that successful handling, manipulation and interpretation of information, as well as use of technology to communicate perspectives among and across distributed workgroups, depends on knowledge being captured, codified, articulated and transferred among people performing related-but-different work, located in different places and belonging to different communities of professional practice [5, 6]. This is further complicated when the task at hand is boundary spanning, requiring contributions by different social groups and/or perspectives. Clinical practice guideline development is an example of a boundary spanning endeavor as it emerges from contributions by several social worlds: the ‘science’ social world (made up from health service researchers, biomedical experts, pharmacists, etc); the ‘practitioners’ social world (made up from general practitioners, nurses and patient representatives); and the ‘politics’ social world (made up by health care managers, consultants, insurance organizations, etc). In such cases reaching consensus and common ground entails negotiation of multiple domains of knowledge by members who may only partially contribute within their own domain of professional practice [7, 8].

The present work sets out to shed light to the design of collaborative technologies for emergent knowledge
processes targeted to clinical practice guideline development. To this end, we develop the concept of transformable boundary artifacts as digital abstractions exhibiting collective awareness, plasticity and social translucence so as to facilitate accountability in shared and collaborative information spaces. In earlier work [3], the term transformable boundary artifact was used to refer to plastic social proxies, in the sense of Erickson & Kellog [9], which either cross or transform community boundaries to support collaborative work tasks while making visible the status of the contributors. The concept was applied to drive collaborative assembly of information-based products and services for tourists. In this paper the intention is to expand upon earlier experiences by illustrating the concept’s applicability in emergent knowledge processes, such as negotiating clinical practice guidelines.

The rest of the paper is structured as follows. The next section presents the theoretical grounds of the present work by elaborating on common information spaces, boundary artifacts and socially translucent systems. This allows us to establish basic requirements for transformable boundary objects in cross-organizational contexts, thus setting the focus of the current research. Then, we formulate engineering and information-based properties of transformable boundary artifacts. The case study reveals how this concept can re-shape the way in which clinical practice guidelines are constructed, negotiated and agreed upon in distributed collaborative settings. The paper is concluded with a discussion of recent experiences and an outline of ongoing research work.

II. THEORETICAL MOTIVATION AND RELATED WORKS

Since the introduction of the notion of a virtual community of practice, researchers have questioned its computational constituents, substance and operation in virtual settings. One key concern relates to the tools through which members of a virtual ensemble become co-engaged in a designated practice in virtual settings. Scholars from different disciplines have tried to address this issue by proposing theoretical and engineering concepts to coin different aspects and desirable features for community-oriented practice-based systems. In what follows, we provide a critical discussion of related works, identifying shortcomings and open issues, thus leading to an elaboration of intrinsic qualities of transformable boundary artifacts.

A. COMMON INFORMATION SYSTEMS

The term ‘common information system’ or CIS was introduced in [10] to characterize a virtuality whereby cooperating actors can perform their individual and collaborative activities. The rationale of CISs is that actors engaged in interdependent work activities of need to coordinate their tasks so as to accomplish a collective objective using shared repertoire of computer-mediated resources. Such coordination entails articulation work, which designates a set of dedicated activities to manage the distributed nature of cooperative work [11]. Subsequent studies aim to systematize the analysis of CIS by defining parameters and dimensions that can be used to position a CIS. Bossen’s [12] parameters allow a CIS to be classified in terms of (a) distribution between employees that need to collaborate, (b) the extent to which tasks need to be articulated and the diversity of frames of meaning that exist for articulating activities, (c) the means of communication that exist, (d) the immaterial and material mechanism of interaction that support coordination. More recently, Rolland et al. [13] revisit critically the notion of CIS following an empirical lens and develop a dynamic perspective emphasizing how CIS is malleable, open and achieved in practice. Furthermore, the authors argue that large-scale CIS efforts inherently tend to re-produce fragmentation as an unintended consequence of integrating heterogeneous sources of information.

Despite these efforts, very little is known about the design concepts that drive the development of a CIS and foster the makings of new knowledge. Instead, the vast majority of the relevant works report on experiences with groupware systems emphasizing sharing of knowledge codified as documents, repositories or social interaction. However, in complex knowledge-intensive domains entailing articulation work and heavy negotiation, classical groupware technologies do not suffice.

B. BOUNDARY ARTIFACTS

Recently, there have been efforts in the direction of extending analytical frameworks for building CIS with accounts of their anti-factual properties. This has established a research scholarship on qualifying CIS engineering base in terms of concepts such as boundary objects [2] and intermediary objects [14]. Boundary objects are ‘plastic’ objects capable of being interpreted differently by different communities, while appearing stable enough to maintain their integrity as ‘common’ objects (across these communities). Since the introduction of the boundary object concept [2], research has matured in several different directions, indicating different types of boundary artifacts such as diagrams, drawings, and blueprints, workplace timelines and schedules such as Gantt and PERT charts in project-based work [15] and digital documents [12]. Moreover, several studies have analyzed the role of boundary artifacts in domains such as translation [7], new product development [16], software development and HCI [17, 18] and organizational memory systems [19].

Despite its wide recognition, the boundary object concept has also attracted critiques from various perspectives. Recently, HCI researchers [17, 20], management scientists [16] and CSCW scholars [19] have emphasized the need for a broader connotation for boundary artifacts framed in workflows and/or embodied in tools such as organizational memory systems, social software and community support systems (i.e., Blogs, Wikis, portals).

C. SOCIALY TRANSLUCENT SYSTEMS

Another concept attracting attention of researchers studying distributed collective practices is social translucence. Erickson and colleagues [9] introduced social translucence as a key requirement for supporting computer-mediated communication and collaboration. They coined as
‘socially translucent’ systems that make use of perceptually-based social cues which afford awareness and accountability [21]. They use the term social proxies to coin artifacts that support work tasks, while at the same time maintaining a visual overview of collective interactions (i.e. the status of the collaborators’ professional activities). In effect, their work concentrates on qualities of artifacts used in collaborative work and the mechanisms that facilitate and support making of sense and coordination of work.

Although social translucence is clearly important and promising, current implementations offer limited insights as they cover domains such as online discussions and social interaction, while framing social translucence as a property / affordance of a single tool. Nevertheless, professional activities persist across tools, environments and organizational settings, entailing knowledge-based work assigned to user roles. Social translucence should therefore be revisited in the context of virtual collaboration spanning across boundaries defined by management information systems, organizational systems and user roles. Specifically, as collaboration may take place at various levels including the organizational level, collaborating partners may employ different information systems and individuals may fill more than one role at a time, socially translucent systems should employ novel features to encapsulate boundary crossing distributed collective praxis.

III. TRANSFORMABLE BOUNDARY ARTIFACTS

In this section our primary interest is to synthesize elements of the concepts presented earlier and discuss the intrinsic design properties of transformable boundary artifacts and how they foster virtual partnerships while maintaining the members’ local autonomy. In this context, common information systems, boundary objects and socially translucent systems clearly bare implications, but none by itself can facilitate the reach design and engineering challenges that emerge. The ‘glue’ between these concepts is the notion of transformable boundary artifacts that exhibit the required properties making them accountable across organizational, technological and community boundaries.

A. Properties

For virtual alliances – developed either as inter-organizational partnerships or external communities of practice [22] – the prominent challenge relates to designing the repertoire of resources through which partners make sense of the shared space, assure awareness of collective (virtual) assets and carry out articulate work so as to expand social capital. Due to the digital nature of the alliance these challenges may be further complicated by impediments to collaboration such as lack of trust, weak sense of community and a compelling need for accountability. For such alliances to sustain recurrent co-engagement in practice, it is critical to establish a model of collaboration, which capitalizes upon collective intelligence and facilitates emergent artifacts of high-added value through knowledge-intensive processing. Attaining these goals demands complex coordination mechanisms unlikely to be accomplished by social interactions, online discussions and/or document sharing practices. Consequently, it is of paramount importance to devise a suitable frame of reference to understand and facilitate such collaboration.

To this end, we use the term transformable boundary artifacts to refer to a class of objects of practice possessing certain tractable information-processing properties:

- **Multiple affordances:** The artifact should afford alternative presentations (not necessarily visual) so as to capture community-oriented activity and collective actions.
- **Polymorphic instantiation through flexible assembly:** A mechanism allowing alternative enactments of the artifact by assembling primitive components.
- **Unified presentation:** Multiple possible interactive manifestations according to the intended context of use.
- **Unified specification:** A single specification encapsulating all possible enactments of the artifact and the way in which they are instantiated.

Designing artifacts to adhere to the above properties turns out to be non trivial and a challenging endeavor. The complexity arises from the fact that such properties represent complex quality attributes with conflicting requirements. For instance, plasticity may conflict with flexible assembly and unified specification. Moreover, such requirements are to be encapsulated into a single unified specification that drives all alternative enactments. Phrased differently, transformable boundary artifacts should be designed so as to (concurrently) foster multiple interpretations (as in the case of boundary objects), asynchronous and synchronous manipulation (as in the case of CIS objects), collective awareness (as in the case of socially translucent systems) as well as plasticity in use so as to suit not only the radically different social perspectives and work practices of members of the alliance, but also the different contexts of use of the intended customer base. It follows therefore that these requirements are to be satisfied rather than fulfilled. Irrespective of how this is to be achieved the important feature of transformable boundary artifacts is that they should provide a language or protocol for collaboration, allowing members of the alliance to make sense of and co-engage in a designated linguistic domain. Such a linguistic domain and the activities defined upon its elements constitute a virtual micro-practice concurrently recognizable by all members (irrespective of profession) but interpreted differently across different professional communities.

Figure 1. Architecture for transformable boundary artifacts

Collectively, these features characterize a type of digital objects (see Fig. 1) – referred to as transformable boundary
artifacts – which shift the focus from the information processing characterizations of traditional boundary objects (e.g., repositories, diagrams, work schedules, maps, etc) to the design-oriented quality attributes that should characterize artifacts and systems capable of crossing organizational fields and transforming boundaries to support virtual collaboration.

B. Building transformable boundary artifact

Transformable boundary artifacts comprise two basic components, namely flexible templates and social widgets to present collective features and to invoke user input. A template can be conceived as an abstraction which is assigned certain access rights and it is populated by primitive elements. Elements are interactive components hosting a designated content. Collective use and/or user input can be invoked by assigning social widgets to templates or to individual elements. Such an assignment is carried out by the ‘owner’ of the template or the moderator, while it can be revised as the need arises. Schematically, the structure of a template and its constituting elements are summarized in Fig. 2. The figure represents the template devised for our case study (see next section) while the prefix ECCS used is the acronym for EuroCancerComs (see Acknowledgement).

Social widgets invite collaboration at the level of elements or entire documents. At present, we have implemented the following widgets:
- **Tag widget**: Allows users to create their own tags by defining keywords as well as to assess the relative frequency or popularity of tags amongst the user community of each ECCS_Element.
- **Rate widget**: Allows users to evaluate the content of the associated ECCS_Element.
- **Word cloud widget**: This is a visualization widget depicting the number of occurrences of each word in a designated ECCS_Element. It can be used as a word frequency index with each entry word being a hyperlink that facilitates web search of that word.
- **Twitter widget**: This is a communication mechanism whereby short messages regarding a designated ECCS_Element can be exchanged. It is useful for getting / posting updates. The widget could also be augmented with notification policies, thus determining recipient lists (if needed).
- **Comment widget**: This is similar to the Twitter widget except that it allows longer messages to be posted and it is useful for storytelling.
- **Voting widget**: The widget is deployed to facilitate short polls and surveys.
- **Dispute widget**: With this widget, users can encode argumentation and rationale related to the ECCS_Element. Specifically, the widget allows the management of an issue i.e., raising and justifying an issue, seeking contributions to the issue (by posting solutions) and reaching consensus.
- **Uploading widget**: The widget allows experts to contribute e.g., in an issue by uploading relevant documents such as sample data and multimedia objects.
- **Questionnaire / assessment widget**: This is a ‘plastic’ component allowing on the fly development of electronic questionnaires from XML specifications.

Widgets can be assigned to an ECCS_Element when creating the ECCS_Document. Through this mechanism, moderators assign intentions to ECCS_Element, thus determining both the type of input required and the role of the ECCS_Element in the document. For instance, ‘Dispute’ widgets may not be associated with ECCS_Element presenting non-negotiable facts. Consequently, by assigning social widgets to ECCS_Element - of an ECCS_Document - moderators define what is subject to negotiation or social interaction and which user views are to contribute. In effect, this establishes the boundaries each ECCS_Element is allowed to cross during the development process.

In contrast to the widgets described above, which effectively ‘invite’ user input there are widgets that present collective praxis at the level of an ECCS_Document. Their primary role is to compile statistical accounts of community traffic, thus making explicit the community’s history of co-engagement in the development of the guideline.

IV. CASE STUDY: CANCER GUIDELINE DOCUMENTS AS BOUNDARY-SPANNING OBJECTS OF PRACTICE

Medical guideline documents consolidate proven and established practices in medical domains such as cancer management. A clinical guideline is a document that contains directions for medical practitioners such as nurses, doctors, etc. It is intended to support decisions that need to be taken regarding diagnosis or treatment in health care. Different stakeholders, including insurance companies, professional organizations and medical societies may be involved in the development of such guidelines. Depending on its source, a guideline aims to make health care more reliable, less variable and efficient. Consequently, the task of developing guidelines spans across several constituencies and perspectives. Managing these perspectives and the respective socio-logics turns out to be of critical importance to the quality of guidelines.
Several authors have identified a number of shortcomings in the process of developing and using guidelines. Of particular interest are the limitations resulting from the narrative form in which guidelines are expressed. Narrative guidelines seldom allow recommendations to cross over institutional boundaries, information systems or the patients' social worlds. Recent works sought to improve upon this by devising methodologies for clinical guideline development [23] as well as representation formats (such as GLIF3 [24], templates and design patterns [25, 26]) for sharing computer-interpretable clinical practice guidelines. Although these efforts demonstrate the feasibility of turning narrative guidelines into data repositories for crossing institutional or health care information systems boundaries, they offer very little to make guidelines meaningful to patients. Our current effort aims to address this shortcoming by exploring social networking technologies as an approach for raising the patients' voice during the development of clinical practice guidelines. To this end, our case study revisits the process of developing guidelines (related to cancer) in an effort to allow their graceful transformation into forms that invite collaboration between professionals and patient communities. However, before presenting details of how such collaboration is achieved, it is important to briefly analyze the boundary properties of clinical practice guidelines and the constituent user communities that are involved. Then, we will turn to the issue of how transformable boundary artifacts can foster and facilitate the boundary spanning role of guidelines using social networking and collaboration technologies.

A. Reviewing guidelines and their boundary properties

In order to gain insight to how clinical practice guidelines are compiled we reviewed (a) methods deployed in governmental (i.e. NHMRC) or professional (i.e. SIGN, NHG) organizations worldwide, (b) available literature regarding guideline development / evaluation and (c) online guideline databases (e.g. http://www.guideline.gov/, http://www.nice.org.uk/). Our primary focus has been cancer guidelines as this was the primary domain of investigation. Initial analysis focused on four criteria, namely the scope of guidelines (i.e., screening, diagnosis, prevention, etc), the types of outcomes (i.e., flowcharts, tables, balance sheets, etc), the target users (i.e., physicians, nurses, health researchers, patient representatives, etc) and the guideline evaluation (data sets, audits, published materials, etc). In an effort to analyze the boundary properties of guidelines, the present work draws upon Moreira’ classification [27] of the social worlds implicated during the development of guidelines and uses related theories, such as the sociology of situated judgment and the social studies of technology and medicine to explore how the diversity of knowledge is important in the development of medical standards.

It turns out that three social worlds become predominant during clinical practice guideline development. Each is briefly discussed using an analytical lens formulated around four criteria, namely: (a) aim/perspective of social world (b) means of attaining (c) primary instrument and (d) role of actors.

1) The 'science’ social world: The ‘science’ social world is typically expressed by health researchers, professors and pharmacists. Their primary concern amounts to the technical robustness of the statement or the guideline. The effort of the members is to assess the relative value or position of the statement or the guideline against prevailing perspectives, popular opinion or relevant research findings. The goal is attained by collaborative construction of a robust argument. When guidelines are negotiated from the ‘science’ world view, health researchers are the dominant actors. General practitioners and patient representatives mostly listen and reconstruct the argument on the grounds of personal records and experience. Frequently, consultants may act as mediators, doubting the strength of the evidence by health researchers.

2) The ‘practice’ social world: The world view is represented by General Practitioners, patients or patient representatives. Their primary aim is to consider the usability of the statement or the guideline. This is attempted by assessing the usefulness of the statement in typical healthcare practices. Story telling is frequently the means through which a proposed statement is measured against cases encountered by doctors or situations experienced by patients. Specifically, General Practitioners present cases and experiences. Patients corroborate the stories presented by GPs. Health researchers make use of these stories to ground data and clinical need or relevance.

The ‘politics’ social world: This social world comprises policy makers, health care managers and consultants, insurance companies and/or private establishments that may have an interest in the guideline or parts of it. The primary concern is on the acceptability of the statement being negotiated which is assessed by examining how the guideline affects the political stability and distribution of power in institutions in which the guideline is to be implemented. Consequently, the group engages in collaborative assessment of the available evidence and recommendations supporting or inscribed in the guideline.

B. Clinical guideline management information system

The analysis presented earlier reveals that guidelines qualify as a boundary artifact which needs to be abstract enough so as to be identifiable across different social worlds and plastic enough to make sense in each separate social world. The next relevant question is how such boundary role can be manifested and facilitated during the development of the guideline. As already mentioned earlier efforts have invested in formats that capture the details of guidelines at several levels, but seldom address the rationale behind the guideline or the social dynamics leading to the consolidation of the statement and its recommendations. To alleviate this shortcoming, guidelines are framed as transformable boundary objects and become accountable and amenable to the practice of an online community using a clinical guideline management information system. This is a web-based collaborative tool combining community support functions (i.e., registration, sub-groups, moderation, etc) with practices relevant to clinical guideline development.
Figure 3. The desktop version

Figure 4. Collective praxis and community traffic widgets
In what follows, we briefly describe the second of these components as the community support functions are rather standard. Fig. 3 depicts an example of a guideline document, the different elements and the associated widgets for user input. As shown the guideline is a multi-part document following the template in Fig.2. Parts can be explored by selecting from the top-level toolbar. Each part comprises a set of elements laid out vertically. Users may select an element by clicking anywhere within the element. In our reference example the currently selected element is the top level. By selecting the appropriate element users can tag, comment or rate the element. Additionally, they can utilize widgets such as word cloud to obtain brief overviews of the contents of the element or the search widget to launch web search query respectively. Fig. 4 presents the community traffic widgets. These serve to colocalidate the collective praxis for an ECCS_Document by revealing details about the history of co-engagement of the members. Alternative access is also possible by transforming an ECCS_Document to transcend device boundaries. Fig. 5 depicts the same document presented through a mobile device equipped with Android (http://www.android.com/) operating system. Here, users navigate within a document by selecting sections of the document and then elements. When an element is selected users can utilize the available widgets to place their tags for the selected element, evaluate the content using the rating widget, view the comments of other users or add their comments.

V. DISCUSSION

The distinctive characteristic of the approach presented earlier is that it fosters a computer-mediated practice for clinical guideline development. This practice inherits engineering and social properties required to facilitate guideline development through cycles of ‘conception – elaboration – negotiation – reconstruction’. Throughout these cycles guidelines become first class objects with designated structure, properties and affordances which make visible the evolution of the guideline and the associated rationale. A distinct quality attribute of the process is plasticity which is manifested not only in the structure of the document but also in the way it is manifested, accessed and negotiated amongst social worlds.

The approach sketched above has been tested and verified in laboratory settings with a large variety of existing guidelines from different sources. These informal tests, with sample data and users, revealed valuable insights to what peers actually do when developing clinical practice guidelines. Detailed analysis of these tasks led to the refinement of the social widgets and the definition of new ones, such as the questionnaire / assessment widget, to facilitate different purposes. For instance, it turned out that different people recruit different repertoire of resources to provide input. As an example, patients and their representatives frequently rely on story telling to reflect upon experiences. Health researchers strive for scientific rigor, robustness of recommendations and frequently resort to heavy argumentation (which justifies the need for the designated widget). Another key outcome is that guidelines need to be related to knowledge which is emerging, through for instance, cancer research trials. It turns out that our approach is flexible enough to facilitate encoding of cancer research trials in a manner similar to clinical guidelines. In fact, we have carried out a number of experiments in this direction and have introduced sample data from cancer research trials registered in http://clinicaltrials.gov/. Nevertheless, to fully appropriate the benefits of such knowledge, it is important to develop additional boundary spanning widgets to facilitate intelligible links across clinical guidelines and cancer research trials data sets. This is an issue currently being investigated.

In terms of large scale validation the approach described in this paper is being used in a remote setting in Italy to help cancer patients to find information about nutritional care, clinical trials and guidelines as well as get their questions answered through interaction with others cancer patients and experts. At the time of writing this paper, the case study is fully detailed and designed in terms of procedures, target groups, questionnaires, etc., and it has been submitted for approval by the ethical committee.

Figure 5: The Android version
VI. SUMMARY AND CONCLUSION

The work presented in this paper aims to make two distinct contributions to the relevant literature. The first is general and amounts to an engineering approach for designing systems for cross-organizational communities. Here, the concept of transformable boundary artifacts is revisited in an effort to further validate and enrich recent experiences [3]. The second contribution is domain specific and re-frames the development of clinical practice guidelines through the lens of cross-organizational, multi-party collaboration. To this end, the paper demonstrates how guideline development can be facilitated by a dedicated guideline management information system which appreciates and supports the boundary spanning nature of guideline development process. Although initial experiences with the method and the tool are very promising, large scale experiments are the means to test the concepts and assess utility. This is currently being attained through an Italian case study in the context of the EuroCancerComs project. The results of this case study are expected to provide valuable input on the design of the system, the sufficiency of the transformable boundary artifacts scheme to cope with related domains such as cancer research trials as well as on the intrinsic properties of cross-organizational collaboration.

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