

# Use of virtual communities for the welfare of groups with particular needs

**Iraklis Varlamis**

Athens Univ. of Economics and  
Business, Dept. of Informatics  
[varlamis@aueb.gr](mailto:varlamis@aueb.gr)

**Ioannis Apostolakis**

National School of Public Health,  
Panteion University  
[apost@panteion.gr](mailto:apost@panteion.gr)

## Abstract

The growth of scientific, technological and technical knowledge created the need for fast and precise communication of information and effective training of physicians, nurses and patients. Our aim is to support groups with particular needs by employing methods used by “communities of practice” and “learning communities” of the internet. The idea is to build bring together patients, their families, doctors and nurses into self-supportive communities, where doctors will disseminate their scientific knowledge, nurses will provide practical advices and family members will exchange empirical knowledge. The approach exploits internet merits and extends group-therapy in two axis: a) universal (distant) membership, b) asynchronous consults and support. We describe the structure, roles and services of self-supportive “web communities of patients”.

**Keywords:** Communities of practice in healthcare, learning communities, framework, group therapy.

## Introduction

Several categories of patients need special and continuous care, especially patients with uncured diseases. Such patients, apart from medical treatment have need of psychological support all the time. In the same time, they prefer to stay at home and to receive care from their own people instead of been treated by nurses and doctors in a hospital. It is also important for patients to discuss their issues with other patients and receive useful advices and support.

In the process of psychological and medical support of patients with special needs we distinguish three different types of participants: care providers, care givers and patients: **Care providers** are healthcare professionals, doctors and nurses, who treat and support patients as part of their work. The group is extended with researchers and scientists that convey knowledge on the disease. **Care givers** are those people who help a patient as friends or family of the patient. The group is extended with people who help voluntarily or otherwise deal with the specific disease. **Patients** are the “receivers” of the support. Care providers should be constantly informed on the scientific and industrial advances, on new products, treatments and devices. Researchers and scientist should disseminate their findings and guide industry and practitioners in favour of patients. Care givers should exchange information and useful hints concerning patient caring and support. Patients’ needs vary over time, in the course of their disease experience: they want information in the first phase, when they learn about their disease and the treatment alternatives; later, they are more interested in compassion and request for emotional support.

The notion behind this article is that group work is better than any individual attempt. In order to build a successful community that combines the efforts of care givers, care providers and patients for the welfare of the latter we should stand on a well defined framework, which comprises of architectures, structures and rules. Then we should build and deploy services that will facilitate co-operation and communication of participants. The basis for the community we discuss in this paper is a combination

of learning communities and communities of practice. Upon this basis, we define the types of our community members, and explain the requirements, the privileges and gains of each role.

The following section (section 2) presents an overview of the communities that will serve as a basis and illustrates the merits of the community approach. Section 3, summarizes on the roles defined in the community, lists the services that promote interaction between community members and details on the structure of the community. Section 4, discusses in detail several implementation and operation issues. Finally, section 5 concludes with the expected outcomes for care providers, care givers and mainly for patients.

## **The communities approach**

When people seek for medical advice they visit doctors and arrange check-ups in hospitals. However, when they seek for medical information they tend to contact experts, or people they trust and in many cases they consult books or the internet. Often they want to share their problems and findings with other patients. To the main core of patients a much larger 'zone of influence', comprising their friends, family members, co-workers and neighbors should be added. It is made clear that Healthcare is a highly social activity that should be carried in common and not individually.

The role of communities is crucial towards this direction. Since the aim of healthcare communities is both educational (or informative) and supportive we distinguish two community types that could be of use in this case: The communities of practice and the learning communities. With the advent of internet, both community types have been renovated, enhanced with new types of services and increases in participation. Both community types have their virtual counterpart which exposes permanence in time and world-wide coverage in space.

In order to better understand the structure of the virtual healthcare community we need a synopsis of the two types of communities it encompasses.

### ***Communities of practice***

The term Community of Practice (CoP) was invented by Lave and Wenger (1991), to describe groups of people with common interests, who mainly wanted to share practical knowledge and learn but were not restricted to this. Examples included butchers, tailors etc that joined groups in order to learn the "secrets of work" from the old-timers. However, people that needed social and psychological support, such as non-drinking alcoholics, created communities of practice, in order to help other people with advices and discussion. More recently, the notion of a CoP has been expanded (Wenger & Synder, 2000) to cover modern organizational structures. In these cases CoPs provide the learning channels between and outside an organization. The model allows knowledge to be circulated among all interrelated CoPs and increases benefit for organizations and individuals. The CoPs have been used to facilitate virtual team working, share organizational knowledge and accelerate adoption of novelties and complexities in the business environment (Kimble & Li, 2005).

The electronic networks of practice (ENOPs) extend CoPs, in the fact that members can virtually participate in the community activities and that members do not necessarily belong to the same organization. The coordination is performed by third parties such as professional associations and the communication is supported by as newsletters or Web sites (Brown & Duguid, 2000).

### ***Learning communities***

Virtual learning communities are recent additions to the educational landscape. The aim of such communities is to collaboratively improve knowledge in the field of

expertise of the community. In the case of open learning communities everyone is allowed to participate and either offer or consume the collective knowledge. As a result, the members of a virtual learning community vary from the non-experienced learner to the subject matter expert inside and outside of the community.

The core activity of virtual learning communities is writing. People exchange messages with a shared goal of building understanding produce an information base which is available to future members of the community (Harasim, 2002). Learning is no longer a transmission of knowledge from a teacher to a student, but a process of knowledge construction in which each participant contributes and benefits from the ideas shared by the group. Useful knowledge sources comprise: questionnaires addressed to patients and their families, personal reflections and confessions of patients, discussion forum logs, virtual interviews of doctors and experts etc.

Another aim of learning communities is to replace Internet as an information source for patients (Eysenbach, 2003). A common scenario wants patients to spend hours in collecting information from the internet before visiting their doctors (Ferguson, 2002. Such information can be misleading and confusing and is better to be filtered before visiting the doctor). Such filtering can be performed inside a learning community (Moon 2005).

### ***Merits of the virtual community approach***

The heart of a virtual community is usually a Web-based portal that members use to access the full range of knowledge resources, maintain member-to-member networking groups, share professional practice solutions, and conduct association business. The purpose of establishing a virtual community for healthcare issues is to advance patient support and promote unity and member interconnectedness (Gabbay et al, 2003).

A database of member profiles allows members to locate other members with similar interests, useful job titles and expertise, and neighbouring geographic location and create their own networks. A virtual community build over a web-based portal, allows distant and continuous membership (Leimeister et al 2004), thus increasing the probability of a member to find online other members of her network, to locate information of interest or communicate with members outside of her network. Apart from the online and synchronous communication, a world-wide community, offers to patients capabilities for asynchronous consultation and support. Members can join whichever communities they choose, or just visit a community to pick up information of interest at the moment.

The ability to build virtual groups of patients is very useful in special cases of treatment such as group therapy and is valuable for doctors. The ability to maintain history of all actions in the community is very useful for doctors and researchers, who have direct access to their patients profile and history of discussions, to the survey results performed in the community, to the information provided by other experts etc. They can also interact with colleagues in various communities by posting a question, sharing an observation, or sharing a document, data, or images.

The issues that must be considered in a community for healthcare relate to the amount and quality of information offered in the community. The flood of information can be confusing both to patients and doctors and as a consequence, information must be filtered and organized. Since anyone is able to publish information and since it is not always easy to see the origin of the information, users could be making decisions on the basis of a source that might not be quality assured. A certification authority is necessary to guarantee the expertise level of every user, control the quality of the published information and build trust among the community members. Even when the information is of high quality, users are not capable to make their own judgments and need support from the experts. Other issues relate to the expertise of all members in handling virtual discussions or providing diagnosis remotely.

These issues should be considered in the design phase in order to increase members participation and improve the quality of the community services.

## The structure of the community

The different roles and the tasks carried by each one of them are displayed in Figure 1. In the same figure the two valuable community sources; the Knowledge and Profile base offer multilevel access to members according to their role. Members are able to collaborate and search for information after registration.

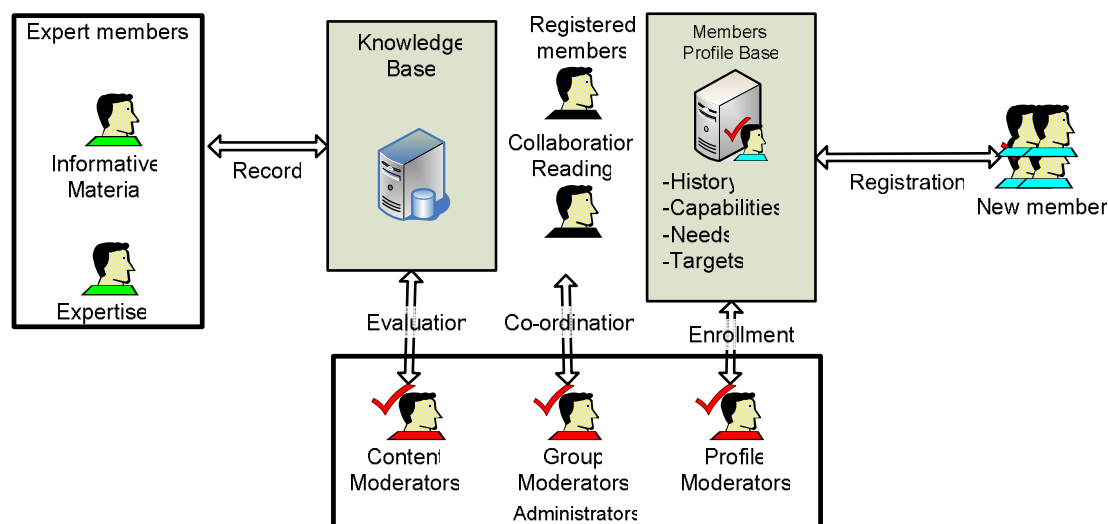


Figure 1. The roles and tasks of the community

### Roles

A vital step in the design of a community is the definition of its borders. This includes the gathering of the initial members, the definition of potential members' profiles and the identification of roles. The nucleus of a community for healthcare support comprises the doctors and scientists who share their knowledge and offer support. The community can be expanded to include patients who need special care and their care givers. People who are simply interested but are not related to the problem treated by the community can be left outside of the community borders, or have limited access to the community services. Patients with long lasting diseases, addicts, and people with mental disorders are among those who can be benefited from a virtual community of healthcare support. Patients participate in discussing groups and share their needs and problems with other patients and doctors.

The most important role in this community refers to the coordination of discussion groups and is handled by the **group moderators**. Another role which contributes to the building of trust inside the community is the administration of user profiles. The **profile moderators** check members' credentials and guarantee the truthfulness of their profile. They protect community from fraud and guide new members to the appropriate discussion and support groups according to their profiles. They guarantee the patients identity, distinguish care givers from professionals and in the same time protect patients' privacy by assigning them a virtual identity. In order to guarantee the quality of information provided to the community members, we establish an additional moderator role: the **content moderator** is responsible for reviewing and filtering all published material and act as a liaison between information providers (experts, doctors, scientists, etc) and information consumers (patients).

## Services

The services provided to the members of a community of support to patients must be carefully designed in order to be as useful to patients as possible. Extra care should be taken to guarantee accessibility of content and services and to avoid member exclusion.

The most widely used service is the distribution of **informative content** (i.e. medical documents, surveys, medical advices, news etc.). Content should be easily located and retrieved from patients. This subsumes that content should be available in various formats, so that it can be accessible to people with disabilities (deaf, blind etc). In order to facilitate new users, content can be forwarded to patients via e-mail to mailing lists. For frequent users, content can also be published in a web portal. It should be organized into meaningful categories and a search service should allow retrieval of the appropriate information.

Interaction between community members is increased with online and offline discussions (Rada, 2005). **Discussions** can be asynchronous (by posting questions and answers) or synchronous (in a discussion **forum** or in private chat-rooms). The aim of discussions is bi-fold: to support patients and their families and to allow experts to exchange knowledge. Debates are more meaningful, when their topics are predefined and organized. The discussions in the community forums should be moderated by expert users that filter information when requested, facilitate members or consult members about the forum rules. The presence of professionals (doctors, nurses etc) in a forum adds to its value and increases participation.

Additional services allow members to provide information about themselves to the community and build their profile. The part of the **user profile**, which is provided by the user herself, is her static profile and remains unchanged. Both patient and doctors should be able to update their member profile so that the community knows their current interest or expertise. Another part of the profile, which evolves all the time, is the dynamic profile which encompasses all actions of a member inside the community. In order to increase member interaction with the community and exploit the expertise of members we could assign moderator roles to frequent members and request their feedback concerning the community operations.

Finally, in an autonomous community members should be able to make their own, **self-supportive groups** inside the community. Members of a group should be able to set-up or attend chat sessions on topics of interest, to participate in point-in-time surveys or straw polls on a topic to allow communities to gather consensus and determine community activity, to start new communities related to specific problems and steer the content according to their collective needs..

## Operating issues

The principle behind a successful community is definitely not “build it and they will come”. As any other community of practice it should be member centered and member driven. Members should be supported at all times and should have all the tools that facilitate their stay in the community.

According to Wenger (Wenger 1998) participation in a COP can be: full from inside, peripheral or full from the outside of the community. The community designers must define the level of access to content and services for each type of participant. Administrators need the appropriate solutions to manage users, to check their credentials and protect their privacy. In the same time, they should think of activities that will increase participation (i.e. open forums) and motivations and rewards for active members.

Content moderators need systems for the collection and evaluation of knowledge and should offer search mechanisms to the amassed knowledge. Group moderators need

monitoring tools in order to proactively coordinate groups, and would be pleased to have collaborative platforms to support their groups.

An important issue for the designers of a community is the building of trust among members. This requires from the administrators to be aware of the complete profile of a member, whilst all other members have partial access. The protection of members' anonymity is crucial in a community of support and can be attained through the virtual identity of members. Virtual identity is always bind to the same user and stands for the static profile, thus allowing doctors to keep a history of their patients, while at the same time, preserves personal data of patients.

## Conclusions

This paper introduced the idea of a self-supportive virtual community of patients. The community will gather doctors, nurses and volunteers around patients and will provide the tools for requesting and providing medical information, advices and psychological support. The use of community services will load the community database with valuable information concerning user feedback, patient needs, treatment suggestions, patient profiles and medical record history. Parts of the stockpiled information can be analyzed: by the community administrators who want to improve services, by scientists who perform medical research, by future patients who seek for a quick advice from a fellow-sufferer. The knowledge produced inside the community will be continuously filtered and managed in order to maintain quality.

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