Citizens' participation in healthcare: a productive opportunity or just a populist ethic idea?

Udział obywateli w opiece zdrowotnej: obiecująca szansa czy etycznie populistyczna idea?

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Szybki wzrost długości życia w Europie jest pozytywnym wskaźnikiem poprawy opieki zdrowotnej i rozwoju społeczno-gospodarczego, ale wzrost średniej długości życia pociąga za sobą wzrost kosztów. Dlatego rządy zmuszone są do racjonalizacji usług medycznych oraz wskazać nowe technologie. Jednakże, planowanie zdrowotne, jak planowanie opieki oraz kontroli wydatków, nie wymaga zaangażowania obywateli.

Celem artykułu jest próba odpowiedzi na pytanie: czy proces uczestnictwa (społecznego) może uczynić decyzje w obszarze opieki zdrowotnej bardziej efektywnymi i mniej kosztownymi?

Udział obywateli jest polityczną zasadą, powszechnie rozpoznawaną jako prawa obywatelskie i wielu badaczy jest przekonanych, że udział obywateli w podejmowaniu decyzji w obszarze opieki zdrowotnej przynosi korzyści.

Naszą opinią jest to, że udział obywateli w opiece zdrowotnej zawiera kilka cech odróżniających ją od klasycznych modeli uczestnictwa opracowanych dla oceny wpływu środowiska lub dla procesów planowania miejskiego.

Po przeanalizowaniu najbardziej dostępnych modeli partycypacji i po szybkim przebadaniu podstawowych doświadczeń partycypacyjnych w zakresie opieki zdrowotnej, nasz artykuł omawia podstawowe warunki dla uczestnictwa obywateli w opiece zdrowotnej oraz podkreśla wstępną hipotezę teoretyczną modelu, który próbuje sprostać dwóm celom: po pierwsze, przyczynić się do racjonalizacji usług medycznych z nadzieją na spadek kosztów, po drugie, przypisać do obywateli sprawiedliwą części odpowiedzialności wedle priorytetów. Twierdzimy, że proces partycypacji w opiece zdrowotnej potrzebuje ciągłego i całościowego zaangażowania obywateli oraz, że edukacja odgrywa tutaj fundamentalną rolę.

Słowa kluczowe: *partycypacja obywatelska, opieka zdrowotna, edukacja*

The rapid increase of life expectancy in Europe is a positive outcome related to improved health care and to socioeconomic progress. But increased life expectancy entails higher costs. Thus, governments are forced to rationalize health services and aim at new technologies. However, health planning, care programming and expenditure controls, generally do not include citizens' involvement.

This paper aims to address the following question: could participation processes help to make more effective decision in health care and contribute to produce less expensive outcomes?

Citizens' participation is a political principle universally recognized as a civil right, and many researchers have claimed that citizens' involvement in health decision-making could bring forth many advantages. Our opinion is that citizens' participation in health care presents some peculiarities when compared to the classic participatory models developed for environmental impact assessment or for urban planning processes.

Following an analysis on the most available participatory models and a rapid survey of the main participatory experiences in healthcare scope, our paper discusses the primary requirements for citizens' participation in healthcare and highlights a preliminary theoretical hypothesis of a model that attempts to meet a twofold objective: the first one, to contribute to rationalize healthcare services, hopefully saving costs; the second, to assign to citizens a fair share of responsibility in priorities definition. We concluded that healthcare participatory processes need a continuous and not fragmented involvement of citizens and, most of all, that education plays a fundamental role in it.

Key words: *citizen participation, healthcare services, education*

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> *We are challenged with a great responsibility, it seems to me,*
> *to educate for more enlightened human relations in fields*
> *not yet well correlated or accepted universally as essential.*
> Samuel R. Harrell, 1942 [1]

Socioeconomic sustainability of healthcare services

The rapid increase of life expectancy in Europe is a positive outcome related to improved healthcare and to socioeconomic progress. However, increased life expectancy entails higher costs for our health systems. Thus, in recent years, many European governments, in pursuance of saving money, have changed their strategy to regulate health services [2]. To achieve health care goals and, at the same time, improving economies, several functions were decentralized or re-centralized, moving from central to the regional levels, or others. Many efforts have been made to rationalize services or introducing new technologies involving change management actions. The greatest limits of these governmental actions can be indicated as follows [3]:

1. The success in implementation is influenced by the priority of choices;
2. The costs of strategies are important decision-making points;
3. The effects on local health systems are strictly connected to other policies that are set at the national, regional and global levels;
4. The health effects of specific policy changes are not necessarily direct and immediate but they could become evident only much later.

It is manifest that tackling the above challenges requires a capacity for matching actions to citizens' needs, obviously taking into account the budget availability. Nevertheless, health services are traditionally provided by public or private institutions where citizens assume the status of patients who passively use the offered services. The more widespread paradigm for health services does not provide that citizens/patients are involved in decisions concerning the healthcare system and its organization. Although there are many active committees of patients and volunteers, the same are not involved into the rationalize services and reduce costs. Moreover, healthcare planning, care programming and expenditure controls, generally do not contemplate citizens' involvement. Thus, a question arises: could participation processes aid to make, instead, more available decision in healthcare and produce more effective and cheaper outcomes? In other words, is citizens' involvement in the specific scope of healthcare an utopist idea derived by a populist perspective or, on the contrary, a productive opportunity for achieving appropriate services and cutting costs?

Citizens' participation in healthcare

Public participation is a political principle universally recognized as a civil right. In general, it is assumed that both transparency and public participation can promote democratic legitimacy by strengthening the connections between government services providers toward the public they serve. It is also observed that the benefits from public participation are numerous and it is not easy to categorize them. The principal assumption lays in the fact that if the public are involved in decision-making processes, their concerns may be met early in the planning process and it could result in saving time and money during the development phase.

Patients and citizens involvement in planning, delivery and evaluation of healthcare services of patients and citizens, was theorized for the first time by the World Health Organization during the conference of Alma Ata (6-12 September 1978) [4].

But, what does participation really mean for the specific healthcare scope? And how could participation contribute to improve the effectiveness and the economy of healthcare services?

There is a great confusion over this issue, mainly caused by the various ways in which participation is expressed. In fact, healthcare systems involve different kinds of interacting actors: administrators, medical professionals, technical/administrative employees and obviously patients and their families. Furthermore, it should be added that healthy citizens who interact with the healthcare system are paying for its cost through taxes.

Thus, participation assumes a huge range of forms [1/]. However, at the beginning of the 1990s, two main broad topics pertaining citizens' participation, also called lay participation, were identified by researchers and still continue to attract attention [5, 6, 7, 8, 9]:

- patient preferences could be incorporated into decision making that involves individual treatment choices;
- decisions about the allocation of healthcare services resources could be taken providing they are more suitable for the communities.

In Italy, the Health Ministry has recently published a report entitled „Developing tools to ensure active participation of patients, staff and all other entities that interact with the NHS" (July 2010) [10]. The report contains the results of an analysis, not limited to the Italian context, focused on different aspects of clinical governance and aimed at continuous improvement of health services through organizational changes, especially those which are achievable by the use of new knowledge and research-based approaches. The report claims that the current literature indicates patient satisfaction as the principal form of active

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[1/] Participatory processes are often linked to the concept of community; see the collections of writings in: Meredith Minkler, Nina Wallerstein (eds), Community-based participatory research for health, San Francisco, Budd hall, 2003 participation and questionnaires (usually based on Likert scales with 5 or 7 responses) as the principal participating tool.

Participative models in health decision-making

Sociological literature which deals with lay participation in healthcare is abundant and very different from the one of health professionals that face the same issue. Sociologists pose more complex questions than health professionals, since they explore a larger range of perceptions on the concept of being healthy. People's perceptions are influenced by gender, age, family responsibilities, cultural background, social status, personal understanding of illness, and so on. They do not always accept the role of a patient. This role acceptance can be common for short-term patients, but it turns out to be a problematic challenge in the case of long-term contacts with medical experts.

Citizen involvement in healthcare decision-making has been brought forth by several motivating issues:

- It produces benefits;
- It is a right;
- It opens to a positive communitarian lifestyle improving citizens' consciousness.
- It allows contributions by local knowledge.

Social, political and ethic suggestions encompassing the concept of participatory decision-making are quite evident. Advocates for active participation claim that, over the past 30 years, public participation not only has reached decisions that were productive to community interests and values, but has also helped resolve user's conflicts, to build trust, and to educate the public about the environment [11]. But literature can also present some critical positions that show the limit of many current claims on the participatory decision-making: participatory development hides a potential tyranny for decision making and control, and three particular sets of tyrannies were identified [12, 13]:

- Tyranny of participatory facilitators; they can override existing legitimate decision-making processes.
- Tyranny of the group; participatory decisions can reinforce the interest of a group already powerful.
- Tyranny of method; participatory methods can drive out those which have advantages that participation cannot provide.

Furthermore, participation requires an effort and is not easy to achieve. It has been observed that citizen's participation in healthcare requires an enhanced level of information that may be difficult to attain; moreover, involving citizens in health decision-making may actually lead to increased costs [7]. Social Psychology demonstrated how people's ideological believes can be manipulated and how individuals feelings and behaviors are influenced by leaders or by lobby groups. Participatory events often take place with the involvement of a facilitator, a consultant or an animator; their supervision changes things. In this respect, Cooke observed that the problem of participatory "intervention" – as social psychologists say when someone enters into an ongoing system of relationships – was largely ignored by the participatory development literature [12, p. 103]. Moreover, there is a risk of incurring in the Abilene paradox [2/], since a group of people can collectively decide on an action that is contrary to the preferences of any of the individuals in the group.

Pitfalls in participatory processes

Many problems arise with the practical application of participatory decision-making principles. An example can clarify this issue. The case concerns the important problem such as citizens' involvement. It is emblematic of a situation rather widespread, especially in countries, such as Italy, affected by political disaffection, though it cannot be generalized since there are many countries with a long experience in participative processes.

In the 2008, during the campaign for the mayoral election in the town of Udine, one of the candidates had included participatory balance in his political program. He was elected and assigned the achievement of participatory balance to the woman who propagandized it in his campaign. She was an activist of citizens' participation; enthusiastic of Giovanni Allegretti [3/] ideas, she had attended courses and worked in the team of an Urb-al project, coordinated by the Udine municipality and inspired by the Puerto Alegre participatory experience [4/]. She attempted to apply her progressive beliefs, helped by a group of supporters who contributed to her election in the city council. A little over a year ago, she remised by the city council and resigned from her position as mayor delegate to participatory balance. Her resignation was preceded by an acrimonious controversy widespread in local press. Since then the participatory balance has been tempo-

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[2/] The Abilene paradox was introduced by Jerry B. Harvey, an expert on management, and is related to the concept of groupthink. It tells that, in a very hot day, a family was comfortably playing dominoes, sitting on a porch, until the father-in-law suggests that they could go for dinner to Abilene, which is 50 miles far. They decide, by mutual agreement, to go. The journey is long, tiring and the lunch disgusting. Arrived back home, exhausted, they find that nobody wanted to go to Abilene but all they believed that the others wanted to go; so they have acquiesced (Jerry B. Harvey, 1988).

[3/] Giovanni Allegretti is an Italian architect, activist and theoretician of participatory balance, known and appreciated by alternative left movements. He works as senior researcher at the Center for Social Studies of the Faculty of Economics of the Coimbra University.

[4/] Urb-al is a EU program aimed to encourage experience exchange between local authorities of Europe and Latin America; the Urb-al project of Udine municipality started in 2005.

rarily suspended and the Udine municipality preferred to implement other targeted actions. However, a single attempt of participatory balance was made involving the citizens of the 2th district to express their opinions on the placement of three concrete slabs in the neighborhood park. The low participation of ordinary people and the assemblies mastered by some stakeholders, pointed out one of the most common limits of participatory practice [5/]. To overcome the low participation of private citizens, a crestfallen supporter of the Udine participatory balance proposed, polemically, to fine the non-participating citizens. In his opinion, in a democratic society, participation is not only a right but also a duty. This is not surprising, since the Italian constitution (dated December 1947) states that voting is a civic duty (art. 48), putting it at the same level as the sacred duty of defending Fatherland (art. 49)! And the activist had it right: a duty, without a punishment, is simply a moral obligation. Obviously, our activist did not consider one of the most important points of participation: in order for people to participate they must not be forced to do so, instead they ought to be persuaded and made aware that their actions can really produce some positive results. It is not casual if apathy is cited as the principal obstacle to recruiting people for participatory processes. Indeed, participation is a cultural habit; it is a right as well as an opportunity.

In this perspective, a twofold question arises: why should citizens participate and how can they do it effectively?

We believe that participation is not a problem-solving tool, but a problem-solving aid that could be useful under specific circumstances, and much of the outcome depends on how it is performed.

How can citizens be attracted and motivated to participate? How can we avoid the situation that politically organized groups occupy the space of ordinary citizens?

Pat Taylor (2005) [14] examines the contribution of lay perspectives to public health in light of the United Kingdom experience [6/]. Her aim is to answer the questions on why and how lay people can and should be involved in public health practice. Her analysis, according to the current literature, shows that most of the policy for the public involvement in healthcare concentrates on patients' involvement in health services, rather than on a wider attendance of public in healthcare scope. Like many researchers, Taylor considers the lay involvement in public healthcare important for understanding the people's needs and takes advantage from their experiences: the lay perspective could be seen as a form of public health expertise. However, the UK experience also shows that there is a different concern between medical and lay perspective on health. Thus, even though the lay opinion is considered very important by researchers, in reality, the biomedical model appears dominating and this circumstance limits the discourse on public health. To realize an effective lay contribution to public health development, Taylor considers four approaches:

1. The consumer approach,
2. The representative approach;
3. The interest group approach;
4. The networks approach.

In her opinion any one of the preceding approaches is interconnected with the others and, in using any one approach, it is important to understand what the other approaches might offer. We completely agree with this interconnected perspective, but we also believe that it is crucial that health participatory models should provide a continuous and not fragmented involvement of the public. Indeed, choices on healthcare are different from those practiced in environmental or urban purpose, since they concern organization and use of services, which are part of collections of long-term related and structured business processes, subject to evolutionary changes. In general, representative approaches present the higher degree of continuity, especially if they are promoted and performed by government institutions. Nevertheless, representative approaches might not be able to capture all the public needs and their feelings, and might be influenced by dominant models in services management and supply. Moreover, there were authors who have underlined the consultation fatigue, and the ways in which social service managers often use consultations simply to legitimate their own purposes [15].

The Oregon participatory experience

In healthcare, as well as in other scopes where the public participation is exercised, the greatest citizens' concern is on whether and how their work will be used. So, priorities choice is another very significant issue. Traditionally, priorities and assistive methods are unilaterally defined by medical and healthcare authorities. However, many studies show that patients

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[5/] In 2008, approximately 30 persons attended the three hours assembly of November 24th; among them 5 members of municipality, two presidents of sporting associations, a representative of a local committee and the husband of the delegate to the participatory balance. Their attendance dominated the assembly (<http://www.comune.udine.it/opencms/opencms/release/ComuneUdine/comune/bilancio_partecipativo/allegati/081121-verbaleincontro.pdf>, July 21th 2012). At the final voting on five alternatives participated 82 persons on 20.000 residents (November 29th 2008).

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and healthcare authorities have different notions of care and assistive services and these differences complicated the priority choices in the presence of spending cuts. On the issue of priorities, the case of the Oregon Health Authority is a very interesting example. It is a Commission instituted for helping people and communities to achieve optimum physical, mental and social well-being through partnerships, prevention and access to quality, affordable healthcare [7]. The Commission shall report to the Oregon Governor and Legislative Assembly a list of health services, the Prioritized List of Health Services, ranked by priority, from the most to the least important, representing the comparative benefits of each service to the entire population. Ranking is the result of measures made to best capture the impacts on both the individual's health and population health.

The Commission is made up by twelve members. There are five physicians, including one Doctor of Osteopathy, four consumer representatives, a public healthcare nurse, a social service worker and, since 2009, a dentist. The Commission maintains a Prioritized List by making changes in one of two ways:

1. The Biennial Review of the Prioritized List of Health Services, which is completed prior to each legislative session according to the Commission's established methodology.
2. Interim Modifications to the Prioritized List that consist of:
   a. Technical Changes due to errors, omissions, and changes in codes;
   b. Advancements in Medical Technology that necessitate changes to the list prior to the following biennial review.

The Commission's Prioritized List of Health Services is made up of condition-treatment pairs composed of diagnosis and treatment codes used to define the services being represented [8].

The Oregon prioritization methodology at first provides the definition of a rank-ordered list of nine broad categories of health care. This is the basic framework for the Prioritized List. Next, the methodology requires that each condition-treatment pair is assigned to one of the health care categories. Once the assignation has been performed, a list of criteria is used to sort out the line items within the categories. The criteria exposed in the report 2011 on Prioritization of Health Services for 2012-13 are [9]:

- Impact on Healthy Life Years;
- Impact on Suffering;
- Population Effects;
- Vulnerability of Population Affected;
- Tertiary Prevention;
- Effectiveness;
- Need for Medical Services;
- Net Cost.

Since not every service in a category is more important than other services in a lower level category, a weight is applied. Each category is multiplied by the total criteria score for each condition-treatment pair achieving an appropriate adjustment for most cases. The total score is then calculated for each line of condition-treatment pair using the following formula:

$$\begin{array}{l} \text{Category} \\ \text{Weight} \end{array} \times \begin{array}{l} \text{Impact on Healthy Life Years +} \\ \text{Impact on Suffering + Population} \\ \text{Effects Need for + Vulnerable of} \\ \text{Population Affected + Tertiary} \\ \text{Prevention (categories \& 7 only)} \end{array} \times \text{Effectiveness} \times \text{Service}$$

A participatory hypothesis to improve healthcare decision making

Methods developed for realizing the public participation have been more or less experimented within healthcare scope. However, the preference in this field is for non-deliberative (or consultative) rather than for deliberative methods. Non-deliberative methods are easier to implement, less expensive and less exposed to criticism. On the other hand, deliberative methods require participants' deep domain knowledge, skilled facilitators, places for assemblies, staff for meeting organization, and so on.

In general, the most positive results referred to the citizens' participation in healthcare are:

- New effective communication means for patients;
- Greater accessibility to services;
- Simplification of procedures for services provision;
- Better organization of services;
- Greater accessibility for disabled people.

Our participatory hypothesis takes into account two types of experiences: Oregon priorities list and citizens panels, in particular Planning Cells, a method for participatory deliberation developed by Peter C. Dienel in 1972 [10].

Our model provides a variable number of citizens' cells that we call Trained Cells and which are used for continuous consultative tasks (Fig. 1). In fact, before

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[7] On Oregon Prioritized List see the governmental site: <http://www.oregon.gov/oha/healthplan/pages/priorlist/main.aspx>, retrieved: October 22, 2012.

[8] The conditions on the list are represented by the coding nomenclature of the International Classification of Diseases, Ninth Revision, Clinical Modification (ICD-9-CM).

[9] See Prioritization of Health Services for 2012-13, (2011), (<http://cms.oregon.egov.com/oha/OHPR/HSC/docs/r/2011br.pdf>, retrieved: July 28, 2012)

[10] Since its first application in the German town of Schwelm, the Planning Cell was applied many times and for a very large number of cases. Initially the model was used for purposes ranging from urban planning to drafting regulations for information technologies (Dienel and Garbe, 1985; Dienel, 1986). The method was further modified by the same Dienel and by Renn (Dienel, 1978; Renn et al , 1985) and inspired the Renn's participatory models of the Three-step procedure (Renn at al., 1993) and the Cooperative Discourse (Renn, 1999).

their involvement in participatory processes, the components of cells are trained with targeted knowledge and about the rules of participating. Training and new technologies play a central role in our model. Another crucial aspect is the involvement of people participating in cells for a long period of time, i.e. a year. In fact, decision-making processes in healthcare, encompassing choices on priorities or other planning activities, modalities to access services, amounts one must pay for them, etc., require a large amount of time. Moreover, there is a substantial difference among the healthcare choices and those made in environment scope or those concerning the implementation of infrastructures having a strong impact on the territory, such as highways, power line, railway yards, airports, etc. The last ones are conclusive choices: the decision can take long and be hard, but it is taken on something which has a beginning and an end. Depending on factors such as the age of the population, the economic situation, the effects of prevention, etc., the choices in healthcare are not final. They are influenced by numerous socio-economic variables and have to be reformulated in relation to the current context. Wherefore, if any one wants to open to the participation of citizens in healthcare decision-making, he/she needs a constant, not a sporadic, involvement. This is what Oregon's experience teaches about the participatory process for the selection of priorities ruled at institutional level.

If anyone wants to involve citizens in decisions and evaluations of healthcare, an additional strategic element is their personal training. A primary concern should be the knowledge of the healthcare system as a whole, next the domain information necessary to formulate the required advices or assessments. Equally necessary should be the understanding of the rules by which the participatory process will be performed, and the tools given for it.

However, for an effective participatory process in healthcare a third element ought to be added to training and continuity: citizens' welfare benefit. This is not easy to achieve, so specific strategies must be implemented to motivate citizens to participate, and some incentives can help, such a reduction of cost for healthcare services, a discount for the purchase of computers, and so on. Finally, since the model provides that, after being trained, the components of a cell communicate via Web, using web community tools, they must possess a computer. This means that owing a computer is a prerequisite for entering into the participatory process, and the authority ought to provide computers with the Internet connection to the participants devoid during their participation to the cell activities. An alternative that would work as an incentive should be a discount or reimbursement for purchasing a computer with the Internet connection.

Our method is based on a variable number of cells, each of them made up of approximately twenty five people from various backgrounds. There is no limit to the number of cells, considering that more cells produce more representative results. The components of cells are recruited with a random selection by a list of persons who were asked to participate, filling a form with their data. Filters may be applied for making selections more effective, e.g. for avoiding the influx of persons belonging to organized groups. Indeed, the objective of our method is to capture the opinions of common citizens and allow them to express their point of view.

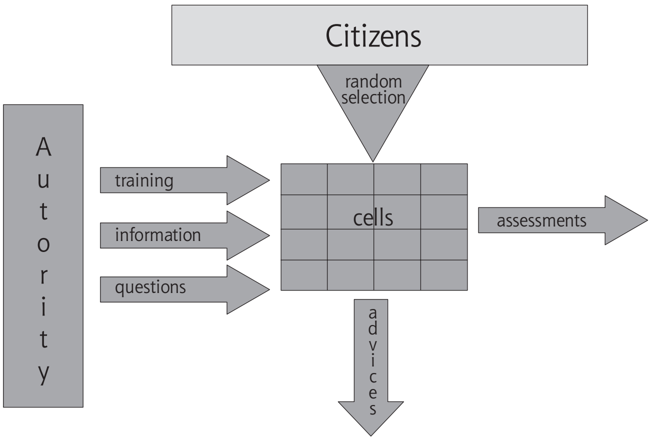

Fig. 1. Trained Cells scheme

After selection, the cell components are trained by suitable classes and all of them must acquire the basic knowledge needed for the participatory process (Fig. 2). They are taught about the healthcare system, and the use of the Web community tools provided for the participatory process and the rules to be observed during this process. The cell components work together using the web community tools, attended by two moderators, who have a very crucial role. They establish when the cell must come up with the results, verify the right development of the participatory process, provide additional information, and resolve all practical problems related to the use of the web community tools.

The main community tools are:

- chat area;
- forum-like room for the discussion of the issues related to the questions given by the authority;
- instruments of assessment (we hypothesized on the resort to suitable multi-criteria methods like Electre methods, effective and easy to use) [11];
- document repository;

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[11] ELECTRE is a family of multi-criteria decision analysis methods that was developed in the mid-1960s and proposed by Bernard Roy and his colleagues at SEMA, a French consultancy company (Roy, 1985; Munier, 2011). The acronym ELECTRE stands for: ELimination Et Choix Traduisant la REalité (ELimination and Choice Expressing REality).

- groupware programs for collaborative document writing, etc.;
- e-learning units;
- external links to other knowledge sources.

The main strengths of the method are:

- The random selection of the citizens, because it increases the acceptance of the results since they are representative of the relevant population;
- The opening of results, since there are no pre-defined solutions.

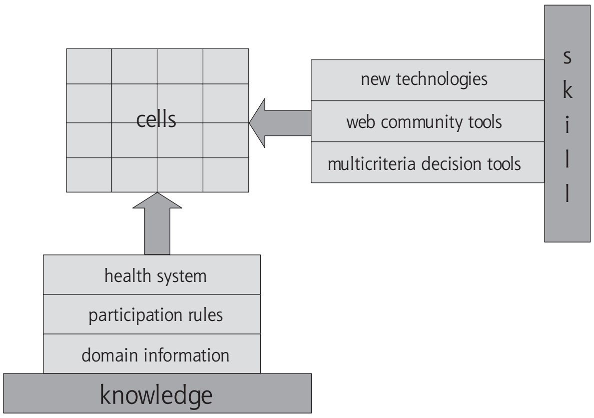

Fig. 2. Basic understanding needs

Our method shows the same weaknesses as in Planning Cells: citizens are not responsible for implementing the final decision; hence they may choose solutions that are not financially or physically feasible. In this perspective, crucial is the role of moderators who can apply appropriate constrains. Compared to Planning Cell, our method, with the exploiting of new technologies, avoids the costs to cover personnel travel costs, accommodation, food, and other expenses.

In addition, the benefits deriving from training must be considered. The knowledge of healthcare system by citizens is very important for their awareness of the services offered and the right way to address them. The understanding of using the community web tools allows for the improvement of citizens' background on new technologies, increasingly widespread in their lives.

The challenge of education

In the participatory hypothesis depicted above, training plays a primary role. For this reason, we deem important to report some observations about education in health scope. These are in fact related to the issues which should manage the process of preparing the Trained Cells components.

One of the final observations contained in the Italia Health Ministry report "The involvement of citizens in in health care choices" (2005), is that training programs must be provided for patients and citizens aimed at knowledge acquisition, self-esteem, awareness of service rules (p. 47).

This goal is hard to achieve. Indeed, a program to educate the public to participate and profit from participatory processes involves different generations of citizens: young, adult, elderly, and these categories are very broad. However, the specific domain represents only one reason while participatory processes cannot be left to the initiative of unskilled people. Thus, the staff of a hospital or of a healthcare service which is involved with participatory actions needs a multidisciplinary know-how, tools such as questionnaires, polls, interviews, fora, data analyses, etc. Furthermore, it cannot be ignored that significant penetration of high speed internet access and the advent of the social web is changing the dynamics of communicating.

Our participatory hypothesis suggests a way of educating citizens to interact with healthcare system and to acquire a higher level of responsibility on health issues.

Communication is a fundamental aspect of public participation and highly influences its outcomes. Sometimes a participatory process is started without the healthcare staff trained about the dynamic of interaction between citizens and patients. Regarding the barriers which affect citizens' participation in healthcare, it has been observed that education should be put on the requirements of participatory processes, since the public needs to be educated to participate [15-25]. However, the public may need relevant information and support, but education should be seen as a two-way process, involving either the public, i.e. to learn the domain jargon, or facilitators who have to manage participatory process. Since the public contribution to health is impossible without an interaction with health professionals, it also needs their involvement. Professionals should be educated, too, in accepting the challenge to their traditional power and habits; an education program should be thought to promote an effective cultural change.

Conclusions

Age-related deteriorations of health greatly impinge upon the healthcare and welfare systems. The necessity to keep the elderly in good health condition requires assistance, medication and organized services. Many costs are often offloaded to families, involving them directly in the elderly assistance, especially if affected by degenerative diseases, such as the various forms of dementia, Alzheimer, vascular dementia, dementia with Lewy bodies, Parkinson, etc. The problem is faced by searching solutions for maintaining activity and independence of the elderly, thus improving the quality of life at older age. Distinguished scientists claim participation can help to reduce the elderly impact. Nevertheless, participation cannot always be put in place everywhere and there are different types of participating in health scope.

We tried to show that participation is not a universal panaceum for problem solving, but rather an aid and an opportunity for it. We have underlined the fact that it is not easy to capture citizens' concerns and manage their suggestions; to do so, investments are needed for training, facilitators and ruling reliable participatory procedures by authorities.

However, in our opinion, participatory processes in healthcare would be useful, but only if they are guided and accomplished through suitable training actions. The citizens' education is in fact the added value to their involvement in healthcare and, in a lifelong learning perspective, participation ceases to be a populist utopia. Nevertheless, it is necessary to experiment on the ways the citizens should participate and find solutions and models suitable to the actual context. New technologies could be exploited to reduce costs and provide feasible participatory approaches. Our paper is intended as a contribution to this purpose.

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