

Patient's Empowerment and Behaviour Change: Complementary Approaches in EU Projects PALANTE and PEGASO

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Abstract. Patient empowerment is widely considered a key component of an effective Health-care system. Empowerment, by effective communication, information and education and thanks to innovative ICT solutions, enables patients to be more active players in their own health, improving the quality of patient/physician relationship and, as a consequence, helping the physician to be more effective as well. However, a patient cannot be properly empowered unless he wants to. He has to be an active part of the empowerment process. Hence, we can say that empowerment requires the patient to have the right attitude, which, often and for various reasons, is not the case. Proactive initiatives need to be undertaken to develop the correct attitude towards patient empowerment.

This paper provides an overview of key concepts in relation to *patient empowerment* and illustrates the approach of two EU-funded projects tackling empowerment from different perspectives. PALANTE project (<http://www.palante-project.eu>) has worked extensively on empowerment and many different way of fostering empowerment in different kind of patients. PEGASO Fit 4 Future project (www.pegasof4f.eu), on the other side, is working on the development of a Behaviour Change Platform, a system, which may be an effective complement of any empowerment effort.

The results of PALANTE have shown that empowerment can only be achieved by developing an attitude of better attention to lifestyle and self-monitoring and care. This can be developed through information and education and with the support of instruments that can foster behaviour change.

Keywords: Patient empowerment · Engagement · Chronic conditions · Prevention · Behaviour change · Healthcare · Motivation · Healthy lifestyle

1 Introduction

Starting from the experience and the results from two EU-funded projects – PALANTE and PEGASO Fit 4 Future - this paper provides an overview of key concepts with regards to patient empowerment.

Patient empowerment enables patients to take an active role in their own healthcare provision, which allows them to stay easily informed and ‘self-manage’ their own health services. In the context of an ageing population and increasing number of chronic patients, patient empowerment is a key tool to reduce healthcare costs and improve quality and efficiency of the health delivery process.

With this objective, PALANTE has sought (through a number of specific field trials in different countries) to empower patients so they are able to make informed decisions about their health, take an active role in their care and collaborate effectively with their healthcare team through the use of information and communication technologies. The project is now in its completion phase and the results are illustrated in this paper, however one of the key findings has been also that “empowerment” requires the right attitude and needs to be developed.

PEGASO Fit 4 Future is a project that addresses prevention and is oriented to the younger population. Objective of PEGASO is to develop the right attitude towards healthy lifestyles by fostering and supporting motivation for behaviour change.

It is the opinion of the authors that the work of the two projects is complementary and while patient empowerment today mostly focuses on individuals in need of care and it is particularly relevant for chronic patients (which is the focus of PALANTE), an early education in understanding “health” in wide sense and the development of awareness towards healthy behaviours (which is the focus of PEGASO) is fundamental in developing the “future” empowered patient.

The paper is organised in three main sections covering respectively:

- the concept of patient empowerment, illustrating the principles of successful patients empowerment and the main approaches;
- an overview of the PALANTE project and its main findings from the; and
- an overview of the project PEGASO Fit 4 Future, illustrating how awareness about health and motivation can be developed through an approach oriented to behaviour change.

Some conclusions and acknowledgments are then provided.

2 The Concept of Patient Empowerment

Any care process is built around a relationship between patient and doctor. Any doctor has a better chance of achieving maximum result by engaging in a productive relationship with a collaborative patient. The doctor has to be good at his job, of course, but the patient as well, needs to have the right attitude, knowledge and tools to provide his carers with appropriate information, feedback and event hints. Patient’s empowerment aims at creating the best possible conditions for that to happen.

The concept of patient empowerment is not new; it dates back to the 1960s when “social action and self-help ideologies have placed an emphasis on the rights and abilities of individuals and communities rather than deficits or needs” [1].

Over the decades the issue has attracted growing interest and, now, patient empowerment is considered a potential tool to reduce healthcare costs and improve efficiency of the health systems, reinforcing healthcare quality. Patient empowerment

has become an element of high priority in the EU health strategy, supported by national and regional health authorities.

“Chronic diseases are now the biggest cause of death and disability worldwide – including cardiovascular diseases (CVD), cancer, diabetes, obesity, and chronic respiratory diseases – account for an estimated 86% of deaths and 77% of the disease burden in the European Region, as measured by disability-adjusted life years (WHO 2009). This development has brought about a fundamental shift in health systems and healthcare, and as a consequence, in the roles and responsibilities of patients.

In line with this health transition the focus on patient responsibilities and their role in managing their health has grown substantially and is an increasing focus of health policy. With this, has come a shift towards care and treatment moving out of the hospitals and into the community and the home, leaving patients and family with a greater responsibility for their own health [2].

Even if the concept of patient's empowerment is widely known, it is difficult to find a commonly agreed definition of empowerment both in literature and among practitioners. A common element to many existing definitions of Patient Empowerment is that it is considered a means of improving health care effectiveness, increasing the efficacy of chronic conditions treatment as well as transforming the relationship between healthcare providers and patients.

During the early phase of the research conducted within the framework of the PALANTE project (EU funded project, ICT PSP 5th call 2011, grant n° 297260), after a thorough literature review, the following definition has been adopted.

“[Empowerment] is the situation where an individual is an active member of his/her own disease management team. Patient empowerment integrates multiple concepts that allow a patient to effectively self-manage his/her disease. In a context of aging population and increasing number of chronic patients, it is considered a key tool to reduce healthcare costs and to improve quality and efficiency of the health delivery process. ICT applications already help to empower patients (...)”.

In consideration of the definition given above, it becomes clear that empowerment involves several subjects and requires actions at different levels in the Healthcare Systems. Back in 1999, Edward Wagner, working with his team at the Mac Coll Institute for Healthcare Innovation [3], developed the Chronic Care Model (CCM) [4] with the goal of designing a framework where all subjects involved in the care of chronic patients were considered and areas of improvement could be easily identified.

The CCM provides a structure for organisation/practice change and encompasses six elements, or areas, for improvement, namely: Health Care Organisation, Community Resources, Self-Management Support, Delivery System Design, Decision Support, and Clinical Information Systems.

More recently, the World Health Organisation (WHO) has expanded the CCM framework, designing a model called Innovative Care for Chronic Conditions (ICCC). The new “framework, recognizes a broader policy environment that envelops patients and their families, health care organizations, and communities” [5].

Going deep into these models is out of the scope of this paper. What is relevant is that they both point out clearly how properly addressing the care of chronic patients requires a joint effort of different people in different contexts and organizations.

Orchestration of these efforts is impossible to achieve unless all players are committed and properly empowered.

The patient is, by definition, at the centre of care process and, in the next paragraphs, we will take a better look at patient's empowerment, trying to highlight the key success factors by having the patient as our focus point.

There are a few distinctive elements that can be considered as pre-conditions for effective empowerment policies and approaches [1]:

Engagement: the patient actively participates in accessing appropriate care, attending and preparing for appointments and using additional resources to maintain a high level of continued involvement in their care.

Knowledge: the patient understands his or her condition, is aware of treatment options but also has a basic understanding of their health care system including benefits, available resources and health care consumer rights.

Collaboration: there is a perceived partnership in care and the patient seeks to participate in shared decision-making about their care. He or she can practice assertive communication and active listening and has a reasonable level of trust in their health care provider and the system.

Commitment: the patient is committed to goals/expectations of his/her own treatment approach.

Tolerance of Uncertainty: the patient's ability to balance the probabilities and risks of treatment paths for instance through shared decision-making processes.

These five points may be considered as foundation stones. Any empowerment approach, to be effective, has to deal with them and, of course, there are many different ways for doing so.

2.1 Approaches to Empowerment

The old models of care, where physicians tell patients what to do and try to motivate them to change, are no longer adequate because patients must be active and informed participants in the health care processes.

There are several ways to put the patient at the heart of the process with an active role. The following paragraphs shortly describe the most common.

Education. It is difficult for patients to do what they don't understand, so the first step to improve patients to take on a more active role in their health care is to educate them. Start by communicating to patients that education is perhaps as important to their health as getting their prescriptions filled. They need to know all they can about their disease [6].

Information. Even an educated patient is helpless without proper information. Information gathering is not an easy task and being an active information seeker is helpful in shaping the right mind-set. The issue for the patient is, on one side, not to be misled by wrong or inaccurate information and, on the other side, not to be

overwhelmed by information overload. In the past, gathering information was not easy at all, nowadays, thanks to the Net, finding information is easy, what's difficult is finding the relevant one. Education provides good grounding for that, as it is harder misleading an educated patient than a not educated one. The role of the caregiver as a guide is of paramount relevance.

Motivation. Keeping motivation high is another key success factor. Motivation depends on many things. Inevitably, motivation has ups and downs but there are approaches and techniques that can help to keep it high. To keep going, clear and reachable goals are a must, and people need to have a good level of confidence about themselves and in the system. On the contrary, when motivation is low, people are likely to stop gathering information, keeping themselves properly documented about their health and they are likely to be less compliance with their set care path.

Communication. Proper communication is essential but often, looking at care processes and at the communication flow among the involved players, deficiencies can be spotted in several cases. Good communication requires all players to have the right information easily accessible otherwise the care process may be harmed or even compromised. Improving communication is not only a matter of providing players with the right tools, it also requires keen attention to the process, which sometimes calls for process reengineering, including the development of tools that better fit and are tailored to the process. When proper communication protocol and processes are not in place, even the best tools may turn out to be ineffective, at best.

In the following two sections the approaches followed by the two projects are illustrated.

3 PALANTE

PALANTE (PATients Leading and mANaging their healThcare through EHealth) is an eHealth implementation project with 21 partners aiming to reach 70,000 new users of electronically-fuelled health services. Users from most pilots have a chronic disease.

The main goal of PALANTE is to improve eHealth services that empower patients so that they make informed decisions about their health, take an active role in their care and collaborate effectively with their healthcare team of professionals through the use of information and communication technologies. The project has pursued its objectives through the implementation, scaling up and optimization of 9 pilot studies, of which 7 are new pilots – developed within PALANTE. Two pilots, in Denmark and France, were already running, however their experience was very important for the new pilots. All 9 pilots were evaluated according to a shared protocol.

The project has generated a rich pool of knowledge, experiences, lessons learned, validated approaches and innovation elements for the benefit of its direct and indirect beneficiaries, the members of the implementing consortium itself and a much broader audience. While, it became clear that it was challenging to make the overall PALANTE project more than the sum of the individual pilots; the results achieved are satisfactory

and allowed all project partners to learn more about the services provided and process of empowerment, going beyond the mere support of the implementation of the pilots.

While pilots are of heterogeneous nature, it has been possible to classify them according to three clusters:

Healthcare portal: it includes those Pilots that do not address to a specific pathology but enable the sharing of clinical documents and information between healthcare providers and patients. In some cases, pilots can incorporate booking appointment tools and services.

Chronic Disease Management: this cluster intends to group Pilots mainly focused on the care pathway that the healthcare professional establishes for the patient in a chronic condition, rather than his/her remote monitoring.

Telemedicine services: this cluster refers to remote monitoring systems usually adopted for patient affected by a specific pathology.

Some Pilots cannot be associated with just one of the three clusters. Indeed, some Pilots have characteristics that position themselves in an area between two clusters. All pilots focused on a set of services and not necessarily on all the services available to citizens. For instance, Lombardy focuses on the management of a care pathway and on sharing personal health information through a web portal (Fig. 1).

Within the PALANTE project, different services have been assessed against a wide population of users. The results are of great help for the design of new services as well as for re-designing eHealth strategies.

The research has been designed having in mind, as guiding principles, the following questions:

- Which role might eHealth play for patient empowerment?
- How should eHealth be designed to empower patient?
- Which other variables should be taken into account?

The evaluation work has been carried out using the PAM methodology. The Patient Activation Measure (PAM), licensed by Insignia health [7], is a methodology assessing an individual's knowledge, skill, and confidence for managing one's health and healthcare. Individuals who measure high on this assessment typically understand the

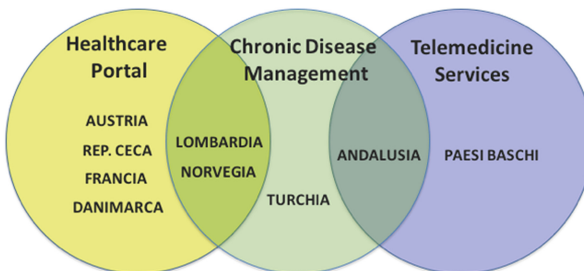


Fig. 1. PALANTE pilots by cluster

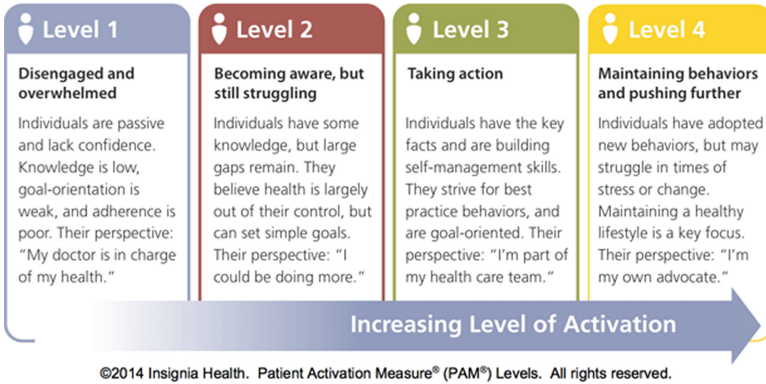


Fig. 2. PAM levels

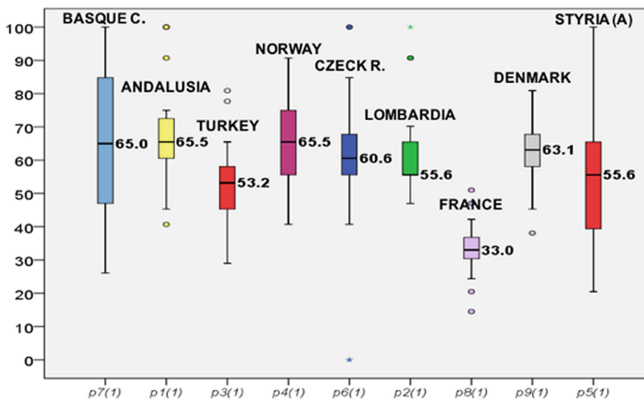


Fig. 3. PAM of PALANTE pilots

importance of taking a pro-active role in managing their health and have the skills and confidence to do so.

PAM was developed using qualitative methods, Rasch analysis, and classical test theory psychometric methods. Developed by Judith Hibbard and colleagues [8] at the University of Oregon, the resulting 13-item measure is a uni-dimensional, interval level, Guttman-like scale (Figs. 2 and 3).

Multiple studies show that PAM scores are predictive of most health behaviours, including:

- preventive behaviours (e.g. obtaining screenings and immunizations);
- healthy behaviours (e.g. healthy diet and regular exercise);
- self-management behaviours (e.g. monitoring and medication management);
- health information seeking. Higher activated individuals also have better health outcomes and lower rates of costly utilization, such as emergency department use and hospitalizations.

3.1 Relationship Between Empowerment and Attitude

Empowerment without the right attitude may be ineffective. Patients need to be proactive to take advantage of empowerment and often they do not have the right attitude. Empowerment is a good way to foster behaviour change, but alone, it may not be enough. Empowerment and Behaviour Change need to work together [9].

4 PEGASO Fit 4 Future

Another EU funded project in the area of empowerment is PEGASO – Fit 4 Future. PEGASO (Personalised Guidance Services for Optimising lifestyle in teen-agers through awareness, motivation and engagement) does not address patients as such; rather it targets healthy people (teen-agers in the case of this project and with a focus on prevention of obesity and lifestyle related diseases) with the objective of “educating” them towards adopting healthy lifestyles.

Patient empowerment is therefore a secondary objective. However by building awareness about healthy lifestyles from the early stages, we will develop also the right attitude towards health, i.e. a person that pays the right attention to health, leading to an informed “empowered” patient, in a positive loop with impact on prevention and better self-care management.

In practical terms PEGASO – Fit 4 Future will develop a Behaviour Change Platform, with an approach based on three level of intervention enabling teen-agers to become co-producers of their wellbeing:

- Generation of self-awareness (acknowledgement of risks associated to unhealthy behaviours);
- Enhancement and support for motivation to take care of health with a short/medium/long term perspective;
- Change of behaviour towards a healthy lifestyle.

4.1 Overview of Approach

The solution proposed by PEGASO comes from the convergence of the need to address the rapidly increasing prevalence of obesity among children and adolescents on one side and the rapid development of ICT, and in particular mobile technologies, on the other side.

The behaviour change solution proposed by PEGASO is based on a **mobile, social and networked gaming platform**, considered as a powerful tool to actively engage the younger population in activities that will stimulate healthier choices in their daily lives. From the technology point of view, cloud computing, and convergence towards mobile are the key enablers.

The PEGASO system framework offers three main functionalities to the users:

1. *Individual & Environmental Monitoring*, through a high level-monitoring platform including wearable sensors and mobile phone as well as multimedia diaries for the acquisition of physical, behavioural and emotional attitude of adolescent.
2. *Feedback System* provides feedback in terms of “health status” changes, required actions to undertake etc. This function will also propose personalized healthy modification of the lifestyle thus promoting active involvement in behaviour change.
3. *Social connectivity and engagement*, social network where users can share experiences with a community of peers concerning e.g. physical activity, food consumptions and everyday habits through different gaming strategies.

4.2 Elements of Behaviour Change

PEGASO considers four levels of engagement towards persuasion for user empowerment in healthcare: awareness of risks, motivation, affective learning and finally behaviour change.

Various types of expertise/knowledge and technologies feed these levels of engagement.

Develop Awareness: teenagers need to be aware of what they are doing; what is right and what is wrong for their healthy living. Some of them are unconsciously and automatically acting, and often under estimate or have no clear notion about information they receive. Monitoring lifestyle of teen's activity, collecting parameters and integrating their own data will enable self-awareness on their current situation. Through developing self-awareness and self-reflection, the user can frame the problem or the opportunity area to act upon or intervene.

Affective learning is the “highest” learning goal. The learner should trust in something that will happen in several years from now. The use of a constructivist learning model and special media like “social games” are appropriate to reach this goal.

Create Motivation: it is important to motivate teenagers to change their behaviour and sustain motivation in the long-term. The actors in the ecosystem are requested to offer “healthy” (or healthier) benefits and services satisfying their needs or desires. This is quite challenging, since motivation depends on many factors as well as emotions, psychological environment and personality. The system needs to provide constant different layouts of motivational activities where experts, technological frame monitoring and stakeholders services come into play.

Enable Behaviour Change: once teenagers have awareness and motivation, it is important to involve experts and use PEGASO to support the behaviour change process and reinforce existing virtuous behaviours. The turn from old unhealthy behaviours into new healthier ones has to be monitored through technology on a longer period.

In order to create prevention, it is important to change or stop old unhealthy habits and develop new healthier habits. In this respect, PEGASO takes a holistic approach

involving the teenager's environment and specifically the families, by means of an education process empowered by training that will be provided on location (schools) and on line. The expert team will give feedbacks to the users allowing them to change their behaviour on a long-term basis. The overall system takes advantage of gaming strategies to persuade users to change their behaviour.

5 Conclusions

Empowerment has positive impacts on the whole care process. On one side the patient brings a better contribution to the care process, on the other side, the patient/carer relationship becomes more effective as the empowered patient is more compliant to the care plan and provides the carer with more appropriate and accurate information.

Empowerment may achieve a lot, contributing to:

- Healthier Behaviours;
- Greater Satisfaction that comes from knowing what's going on;
- Better Decisions (well informed decisions are the best ones);
- Sustainable Services;
- Reduced costs.

Indeed the costs of healthcare are an issue in Europe and there is a stringent need to control the level of expenditure in this area, as the European population is growing older and the prevalence of chronic illnesses is increasing.

Key elements that contribute to controlling such costs are prevention on one hand (to avoid the insurgence of pathologies – in particular those related to lifestyle) and patient empowerment on the other hand (to increase the capability of individuals to self manage their health conditions, to reduce hospitalisation and to ensure a more active and healthy aging). In both areas the adoption of ehealth-based tools and procedures can strongly support development of a new culture of self-care where the individual is aware of health-risks and has self-management capabilities. The results of PALANTE have shown that empowerment can only be achieved by developing an attitude of better attention to lifestyle and self-monitoring and care. This can be developed through information and education and with the support of instruments that can foster behaviour change, such as the PEGASO platform.

PEGASO Fit 4 Future will be tested and piloted with a population of about 400 teen-agers in three European countries (Italy - Lombardy, Spain - Catalonia and United Kingdom – England and Scotland). Results of the pilots will be available in mid 2017.

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