

Viewpoint

Emerging complexity and possible new approaches from a patients' perspective

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Although finding new strategies for developing new drugs is not, of course, the duty of patients, patients' representatives have important responsibilities, such as:

- ensure that all efforts to find new treatments are made;
- collaborate in studying for the removal of unnecessary constraints to research;
- collaborate in defining rules for trials;
- ensure cooperation in the passage of information on demand for health;
- collaborate with researchers to define which drug is good for the patient.

Another important task of patients and their representatives is to monitor, assess and report, in the appropriate place, whether the treatment needs have appropriate responses in terms of efficacy, safety, appropriateness, availability, cost and quality of life.

Any therapeutic intervention must be placed in a curing process that involves the patient as a person, with his/her wishes and needs.

Over the past fifteen years the number of new

drugs has decreased, the cost and development time of new drugs have increased, the prevalence of many diseases has not changed.

No one denies the value of research by drug companies, but some questions must be "supported" by the activities of associations of patients in fields like, for instance, the call for public funding for research and the call for prevention campaigns.

What has been described as "personalized therapy", the result of the availability of innovative molecular techniques, has not yet found adequate practical consequences, but right now we think about how to define the protocols for testing of these drugs: to do this, the cooperation of patients' associations is essential.

The answer to one of the essential questions, *i.e.* the definition of rules in case of unexpected pharmacological discoveries that open new and different fields of application, can hardly be suggested by patients. However, patients' associations can provide an important contribution, and should not be perceived as a mere controller, but as active actors of the process.