

Patient's Rights and Citizen Empowerment

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The European platform for Patient's Rights and Citizen Empowerment tries to include citizens in the important process of decision-making. With its declaration of patient's rights, that was completed this year in Jerusalem, a first, important step was made, a quarterly and permanently actualised report supports their concerns.

Health systems in any country are highly regulated by law and thus build the political basis for the maintaining of health. The law wants to combine different perspectives of co-workers (medical professionals, patients, legal institutions), but one question remains: On which side does the law stand? Is it on the state's or on the one of the doctor, who executes these laws? Or are the consumers those, who define health care, grounding on their needs? The truth is somewhere in between: "We need balance between law and self-determination", says Fons Dekkers, lawyer and head of a Dutch foundation of consumer-oriented concerns. Proposals for improvement are: Approval and promotion of patient's rights and values. This should ensure that everyone involved is treated respectfully. Besides, the co-operation of doctor and patient is equally important as the co-existence of general regulations and specifically medical guidelines. The European development tends toward internationalisation, economical

interests and border-cross activities are equalised by international standards. The aim of this harmonisation process is an improvement of patient's protection policy, if the programme of one country is well established, others can take it over. The programme should also include Eastern European countries. At the same time as health services should be optimised, the consumer's rights have to be made transparent. The information of the citizen is central, a beginning could be the instalment of central offices for patient's complaints, which is already practised successfully in the Netherlands in order to prevent patient's lawsuits. Another advantage of such an institution is: give trust and make reluctant patients brave enough to complain.

"Modern" diseases like cancer, heart diseases or Aids are the ailments of our time, they demand individual action for prevention. The individual is responsible for his behaviour in this respect, or should the state prohibit dangerous products, or put high taxes on them? When is it allowed to make one's own decision and when should the decision be made for him?

Citizen Empowerment in Public Health

The state regulates threats that endanger other persons, but what, if one only exposes oneself to danger? Patients have expectations, and they have rights. For instance they have the right to neglect treatment and to take one's health in one's own hands. This individual autonomy on the one hand rises the personal risk and on the other one it is a contrast to the principles of Public Health. How far can the state go in encouraging the citizen's to prevent their health?

Wendy Mariner, Professor of Health Law, University of Boston, reported about a programme for breast cancer prevention in the USA. In a promotion campaign data was intentionally falsified, instead of the correct figures a much higher percentage of ill women was given. Can medicine lie to its clients? Is the wish of the individual what is to be respected or is Public Health more important?

One proposal was: there have to be financial means for comprising information, the patient has to

be aware the health risks and at the same time be responsible for his behaviour.

Another important question was, where the patient's data should be kept, in times of information technology the danger of data abuse is given, the forum could not find a conclusion, that was agreed by everyone.