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# The payer determines, but it is not the patient

In healthcare patients are not consumers with the economic power they have in other markets, but the arguments for patient involvement are compelling.



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“Healthcare is like dog food business”. Here we hear an American explaining that in healthcare, just like in buying dog food, the consumer is not the one who determines what is on the menu, nor the one who pays. Patients are not consumers in the sense of a normal market. There consumers decide what products they buy and they determine the price through supply and demand. Dogs have to eat what their masters buy.

In many cases patients have little or no say in what treatments with medicines they get. Citizens are the ones that pay, through government taxes and health-care insurance premiums. A citizen differs fundamentally from a patient. I hear many people say: “Eventually we all become patients”. That is true, but the moment you decide something determines your thinking and decision. As a healthy citizen people think differently about a treatment than when they are patients. For me as a cancer patient it is important to be there when my first grandchild is born. When your life comes towards an end, three months can make the difference. For a citizen who thinks economically living three months longer and paying €100,000 for that is a curious and very expensive decision. Economists work with a ‘quality adjusted life year’ (QALY). For patients, a QALY may be a big offence. The value of a life must not be expressed in euros. However, this is the consequence of a health-care system that starts from a market without paying consumers (patients). Then the payer determines and this is not the patient.

Why are there so many discussions about the prices of medicines? In the last few years they have been vehement, because for the first time we see that patients do not have access to medicines because of their price. And this happens without patients realising it. In the discussions and problems we come across it is important to realise that patients are not involved in the process of decision making when a medicine is ready to be used. Nor in the question of what medicine has to be developed. Nor in designing the trial to test it. Nor in determining the group on which it has to be tested. Nor

in the question for which tumour it has to be used. Nor in the decision on whether it will be reimbursed. They are all moments when the patient is very important and is not involved, while the larger part of the research is realised through the use of the vital data of the patient him or herself. Instead of patients getting a reward for this in the form of accessible medicines those medicines are getting less accessible.

“IF THE PATIENT IS VERY IMPORTANT AND IS NOT ASKED TO PARTICIPATE, ISN'T IT ABOUT TIME TO CHANGE THIS?”

It is also essential in treatments that patients’ data are registered and made available for research by universities and industry. This has to be implemented or continued. Patients want this. They are our data and it is not justified that politicians and lawyers fill this in differently. In this way, they block the solution for us and we die. This is not their intention, but definitely a consequence of their action. Patients and patient organisations should apply themselves on this much more and make data available for research. In this case too the patient has to determine and not, like in the dog food business, the payer.

Until a short time ago the quality of most cancer medicines was low (exceptions are blood cancers and testicular cancer). A life extension of three months was quite an achievement. As mentioned before, in individual cases this may be longer and meaningful. Primarily, however, patients want treatments that lengthen their lives till they are 87, and what is more important they want a product that improves the quality of life seriously. These are two conditions for patients to find a medicine with added value.

After years of being neglected immunotherapy seems to lead to a breakthrough. The results for, amongst others, metastasised melanomas are spectacular. If seven years ago 100% of the cases were deadly, now 65% is cured! Hodgkin’s disease moves into the direction of a 100% cure. We patients want this to be tackled

with priority and together with governments we want to play an important role. Let us prevent an excellent treatment like CAR-T (where modified white blood cells are returned to the patient and are used to fight the tumour) from being taken hostage by the industry, after which it will be priced at €475,000. With a powerful government this is not necessary at all and we can treat everyone. Let the government focus on publicly financed trials, for then it has power and can promote competition. Innovative industry can be directed towards earlier discoveries: it can earn enough money with that. Most industries earn money with real breakthroughs and are innovative. More innovative than the medicine industry, which has shown few spectacular developments in the last few decades.

Also note that with one exception medicines have all been developed with government money. Medicines are developed via universities and biotechs and bought by the industry, e.g. successful Pembrolizumab, which was developed with Dutch money by Organon and was bought and patented by Merck. And now we have to pay a very high price for it. Patents are fateful

for innovation. When are we going to realise this? When you are allowed to market a product without competition for years, you lose your interest in innovation, because money can be earned more easily by means of sales and marketing. And an industry that does not innovate developing medicines leads to patients that die when they don't have to.

If with all those questions that have to be answered, before a medicine is marketed and reimbursed, the patient is very important and is not asked to participate, isn't it about time to change this? We are not stupid and it is our data. We know much about making medicines, setting up trials, including patients, registering medicines and the accompanying reimbursement. When we are involved in the decision-making, this does not lead to inferior products that are costly. For we do not want these. It is so simple: we want lives that are long and of good quality. And good medicines are crucial for this. And if we do it well, we change the 'dog food business' into a normal market with outspoken consumers that choose what is important for them. And why wouldn't we do it well? ■

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