



Our health, our care!

Healthcare is there because of us, the patients. Because there are patients, people have jobs, profits are made and losses incurred, and the healthcare sector can thrive. Ask anyone, and they'll tell you the same. And then I reply: that's all very nice, but do you really feel that's true? And do you act like it's true too? My questions are sure to draw some puzzled looks. Fortunately, more and more often the answer is "yes!" The healthcare sector is made up of committed people with their heart in the right place: with the patients.

And yet... last week I read a blog on a health care site about some twenty healthcare managers getting together to discuss how things could be done differently, how healthcare services could be improved. Not a single patient was asked to take part in this meeting, let alone decide on anything. Countless conferences and seminars are organised at which patients and treatments are discussed – but patients are never asked to take part in them or hold a talk. Millions and millions are spent on cancer research every year, without patients being asked what should actually be researched or to decide which studies should be funded.

Hold on, Peter, that's not true! We do ask for patients' opinions. All hospitals have a patient council. Most conferences start with a patient's personal account. Scientific councils too consult with patients. Well, that's good then! But... what if patients don't agree with a decision made about them? Wouldn't it be better if they are not only consulted, but also can agree on the outcome? Or even better, if they are the ones actually making the decision? In my opinion, patients should have a say in deciding which subjects should be researched. And I don't mean just indicating what they think is interesting and important, after which the esteemed gentlemen (yes, they're still mostly men) retreat to deliberate on their decision, no, I mean truly deciding on what should be researched. Then it is up to the researchers to deliver some top-notch results. Everyone to their trade.

In an ideal situation, I see patients, doctors and scientists getting around the table to discuss the research agenda or agree on decisions for improving healthcare services. I see patients not only opening conferences, but also expressing their views on the conference theme. The commonly heard argument that patients aren't capable of doing this just doesn't hold water. Nowadays we have professional patient advocates who have received excellent training, are well informed and well spoken, and are capable of entering into dialogue on an equal footing with

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science are actually driven by patients is bizarre and beautiful at the same time. Patients have been sidelined for far too long, but that's about to change. Soon. After all, it's our health, our care!

Peter Kapitein, Patient Advocate

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