

Our health, our care!

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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 doctors and researchers.

We have already demonstrated this at our own conferences since 2011. The good news is that government and industry have already embraced this development. Inspire2Live's patient advocates are well-known faces at government institutions and services and in the business world and many initiatives have been set up in close collaboration with these sectors. For example, one of us is working together with a pharmaceutical company in developing a cure against pancreatic cancer. And don't worry, she's not getting paid for it.

An example of an international or even global patient initiative is our concept called "The Discovery Network". In this network Inspire2Live brings together different stakeholders like patient advocates, clinicians, researchers and funders of countries around the world on important topics concerning cancer. In October 2011 we organized a Discovery Network about Targeted Therapies. During this session in Cambridge UK at Christ College, the concept of using tumour stemcells for drug screening (a discovery by the Dutch scientist Hans Clevers) was discussed and after that implemented soon for colon cancer, prostate cancer and pancreatic cancer. Other types of cancer will follow in

due time. This Discovery Network, initiated by patients, now makes it possible to test on real human stemcells with different combinations of drugs instead of testing in mice or with cell lines. We now can enormously speed up the process of drug testing. Recently the work on pancreatic cancer was published in Cell and Inspire2Live was given the credits for bringing together this group of people. We are now working on a Discovery Network for Intervention Oncology and will soon start with one for Immunology.

Over the past few decades much has been achieved in the fight against cancer—but not on all fronts. There's still a lot of work to be done. Progress in the fields of pancreatic cancer, brain tumours, lung cancer and many other oncological conditions is still minimal or even non-existent. It is time to step up the pace. Acceleration only comes about by external forces and change does not come from within.

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The fact that improvements in healthcare and science are actually driven by patients is bizarre and beautiful at the same time. Always realize that not only change comes from patients also collaboration has to be set up by patient advocates. Just because then they can decide upon the research agenda and let researchers study what's of real importance for patients and not just fun to do research on. The patient's perspective is different from the researchers perspective and always puts the patient in the first place.

Patients have been sidelined for far too long, but that's about to change. Soon, After all, it's our health, our care!

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