



How to add value to research?

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The most persistent and urgent question in life; what do you do for other people?—Martin Luther King

Hundreds of billions each year are spent worldwide on research for improving the quality of life (QoL) for patients with cancer. Part of the research is never implemented or it is implemented too late. We are justified in asking whether this research has added value or not: firstly, because we are dealing with the lives of patients that can be saved or prolonged with better QoL and secondly, because it is unethical not to implement what has been proven as better for patients. Moreover, we are dealing with tax-payers' money and from an economic perspective, it is wrong not to implement what has been studied and proven better for patients.

In this document, I present two ways in which we can improve and add value to research for the benefit of patients and therefore for society. Firstly, we have to concentrate our research on what will benefit patients. Secondly, we have to put into practice what we already know that is of greatest benefit for patients. Of course, there are more ways in which we can do this, but let's start with these because the impact of implementing this is huge.

Well; how do you do that?

Improve the benefit for the patient

After visiting a patient with pancreatic cancer with professor David Tuveson, researcher at Cold Spring Harbor Laboratories on Long Island, he asked me what the most important thing is a patient with pancreatic cancer has to deal with (besides the fact that they all die in 12 to 18 months): 'Pain Peter. If we can take away the pain, we give them six to twelve months more with a good QoL. Nobody is doing research on pain!'

David Tuveson learned this from his patients themselves.

As a researcher, he speaks to patients directly and in this way, he learns where his research should be directed. You can't simply think of added value research in healthcare while sitting in your own office or laboratory on your own. You have to communicate and work with patients and listen to them about their needs and complaints. While listening, discuss what needs to be done with them. Patients are not stupid. They know what they are talking about. They are the experienced ones.

When you talk to them about their needs, you can decide, together with them, about what should be done and what should be done first. Working in this way, your work will have greater value and impact for patients and society. There is no doubt this will also improve your satisfaction in work.

When spending tax-payer's money this is the way to go forward. Policy makers should know this and work out the procedures in order to spend funds in this way: talk with patients, work with patients and decide with patients. It's not 'Go get a patient' after working out your proposal. It is essential to start, from the beginning, with the ones you are serving. It adds value to good research. It adds value to society and most importantly: it adds value to the patient's QoL.

Policy makers and regulators should therefore make this a condition for giving grants to researchers. Actually, grants should only be given to researchers and patient advocates for their cooperation. Regulators should be aware that researchers continue working with the patient advocates; they don't stop after getting their grant. It's 'our grant', not yours or mine.

We don't execute what we already know

We learned from Nobel laureate Daniel Kahneman and his friend Amos Tversky (who died before he could receive the

Nobel Prize together with Kahneman) that people fight harder to prevent loss than to win (1). This is an important barrier to recognise when implementing new techniques and treatments in healthcare. When science has proven that treatment B is better than treatment A, nothing will change by itself. People don't want to change; they talk lengthily about it but only adapt when there is an urgency. We have to bring urgency into healthcare. It sounds weird but today there is no urgency in healthcare.

It's simply not true that we implement a new treatment when it is discovered to be better than an existing one. A powerful example is radical mastectomy for women with breast cancer. After proving that lumpectomy had the same result as radical mastectomy (that mutilated women), it took Bernie Fischer (who proved this after a study with more than 10,000 women) and the director of the NCI, Vincent DeVita, more than 6 years to change the procedure (2). Think of the number of mutilated women that could have been prevented. What happened? Why didn't we act immediately and do our best for these women?

When change is needed these 5 elements have to be in place.

Why are we doing it? Is there a need?

Quite easy, patients can let you know what their needs are. It is always related to their QoL. Therefore, we need to communicate and work with patients. The absence of working with patients is the reason we do not know why we do things in healthcare.

Is it possible? Is there evidence that B is better than A. Can we achieve this?

Of course, we have to be certain that the new developed treatment is really better than the existing one. That's the role of science. When science does a good job, then we can be certain. The next question is whether we can achieve this. Can we look at this from a technical viewpoint? Is it legally possible? If not, can we change the regulations? Et cetera. Finally, we have to make a decision: a yes or a no to the question, 'Is it possible?' Here there is also an important argument to be made about the lack of patient interest in implementing better treatments. Right now, any benchmarks for new treatment implementation are weighed against overall survival (OS), progression free survival (PFS). Not whether a patient sees a benefit in QoL. In the example of pancreatic cancer and pain there would still be a hurdle to take if OS and PFS do not significantly differ from what

Folfinirox brings to patients.

Do we know where the resistance comes from?

Deliberate resistance and unconscious resistance

As stated before: people don't want to change unless there is an urgency. Only then do they adapt. For this reason, there will be resistance against change. Most of the resistance will be known and visible: people lose their jobs: the flow of money that can be earned changes: when specialization is required, there will be employees who find the new way of working boring because they dislike specialization, et cetera. There are many reasons for sticking to the way of working we have been used to for many years.

There will also be resistance from people who do not realize that they, themselves are resistant. Think of researchers who were educated to work in a certain way and simply don't see that work can be done in a different way. You have to seek out these people because, in most cases, they will adapt to the new way of working when they are shown that things can be done in a different way. These are intelligent, kind people who want to help and to do good. This type of resistance is very tricky because it is hard to spot. By bringing all this out into the open and discussing these matters publicly, you might find them. If not, you will find them during execution. This is not too late for them, but the sooner you know who they are, the easier it will be to change the way of working.

Do we have coalition between those who are willing?

This is often an easy one. It is easy to do but nevertheless, it can be a lot of work. You will find a lot of people who are in favour of the new way of working because they like innovation (at least that's what they say) and of course, these are the ones who have done the research on the new way of working. They want to see the results of their work. Also, regulators will quite often be in favour. The building of the coalition of the willing is a lot of work but doable. Please be aware that change comes from the outside. Thus, if you have the coalition of the willing, you still need forces that can help to change the way people work. Patient advocates can be these forces of change. Inspire2Live is, as we speak, in conversation with physicians and researchers of the Sarcoma Discovery Network we are setting up. They are all willing and see it is wrong not to share the data needed for research. Still no one knows how to start and pull the change through all the way! This role is for patient advocates who can help and state; 'This is my data. Stop

talking about the abuse of data. Use it!

Do we know who pulls the strings?

Most of these people are known. They are the ones in charge: the head of the department, the politician(s), the minister(s), ‘the big influencer’, the specialist. But sometimes the specialist is not known. Then it’s more difficult. When we have defined the ones who pull the strings, we have to convince them or have them work for our cause. This can be done via lobbying. This is difficult but may not take too much time, especially when you know how to lobby.

To conclude

‘Healthcare is like dogfood business. It’s a blunt statement but true. A dog doesn’t buy his own food and doesn’t pay for it. Patients ‘don’t choose their own treatments either and most of the time they don’t pay for it (3).

We learn about patients’ needs from patients themselves; therefore, they need to be part of the coalition of the willing and science has to deliver the evidence. When there is resistance (and there always will be), we can easily overcome the unconscious resistance by bringing the patient into the equation and when confronted with the need of patients we can work on the deliberate resistance by convincing the obstruction with arguments and facts. There is urgency for the patient and their needs; therefore, the patient should play their part in this. They should be one of the people pulling the strings and making, in cooperation with the stakeholders, the real decisions. They should not only be consulted.

Organizing science and healthcare this way will give greater benefits for patients. We would most certainly implement what we already know far better, faster and we would spend tax-payers’ money the way it should be spent.

In 1996 in the Netherlands a very well-known physician and scientist, Professor dr. Joep Lange, together with some of his best friends and colleagues, discovered the

combination therapy for HIV/AIDS. He brought this combination therapy to the Dutch Minister of Health, Dr. Els Borst and said to her: ‘Dear Els, we know how to treat HIV/AIDS patients now but because of your department (your civil servants) I am not allowed to treat them in this way, so these 6 patients whom I have brought to you, will be dead in 3 months. The minister and my dear fellow patient advocate stated: ‘Dear Joep, we are not going to let them die. You are going to treat them and I’ll take care of my department with the regulators.’ She later explained the reason why she did this: ‘When science says: this is how it is. And the doctor says: this is how I can treat my patients. And the patients say: this is how we want to be treated. Who am I not to facilitate this?’ We love her for this. She saved many lives in the Netherlands. It’s our duty to follow her example.

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Footnote

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