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Responsible research innovation – heard of that before?



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Inspire2Live has been created to empower people to convert the sense of powerlessness, caused by cancer, into one of strength. Inspire2Live is founded on the absolute belief that one can attain the greatest possible satisfaction by putting their heart and soul into helping others. Its motto is "Never, ever quit!".

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A reminder about who is at the centre of the complex healthcare hierarchy and industry – the patient.

In May I was present at the excellent congress "Responsible Research and Innovation in the Health Industry", organised among others by the EU Economic and Social Committee. I had the honour of speaking about my ideas on innovation and the obstacles that are connected with it. Of course this included how these can be prevented or how we can take care that there will be solutions for the problems this new development in healthcare research is confronted with.

The chairwoman kept asking how we can do this correctly and what is needed for to go forward. It was right that she kept revisiting this: in the various presentations, namely, the word 'patient' didn't occur often.

It did in the powerful and very concerned talk of Trish Grove of British Medical Journal (BMJ). I had noticed before that BMJ takes its patients seriously. There are editorial panels with patients and patient peer reviewers (in which I am allowed to participate myself). As one of the first and, as far as I know, as one of the few, BMJ has discovered that healthcare has to focus on the patient. As no other person, Trish managed to demonstrate this: "If about us, not without us" was a powerful one-liner of hers (Grove 2017). And that is how it is.

Dear stakeholders of the Medical Industrial Complex, you are here because of us, with which I say that without patients there are no revenue and profit. Please understand this in a different way than seeing us as working stock. Working stock? Yes, indeed. I had that strong feeling during the congress. We are working stock and necessary for revenue and profit. This is a very strong feeling during the talks and discussions. You also notice that nobody realises this. There is no evil intention. It is simply like that.

A short while ago there was an investigation in the Netherlands into who earns most money out of healthcare (Gupta Strategists 2017). What was the outcome? Banks earn the most out of healthcare. After that, it is the suppliers of medical equipment, then the pharmaceutical industry and then the doctors. It turned out that nurses earn the least out of healthcare. I don't think this is strange, for the further the distance from the patient, the higher the amount of money you can ask for your work. After all, behind your desk you are not confronted with the patients' suffering and needs so quickly. Bankers only see investors of the industry or hospitals and squeeze hard. There is no patient to hear complaining. This is For personal and private use only. Reproduction must be permitted by the copyright holder. Email to copyright@mindbyte.eu.

different for nurses. They work with patients every day and they see the suffering of the patients caused by the Medical Industrial Complex and they are continually trying to alleviate this suffering. What is the procedure with Responsible Research Innovation (RRI)? It's not much different. One of the speakers said that he has had the discussions for about 17 years now and that he in fact hasn't seen any change. Imagine 17 years and no change in the way in which research contributes to healthcare.

Meanwhile there have been hundreds or thousands of congresses about many healthcare subjects and we have concluded that much is going well, but also much is not going well. This has to be done differently and better. To my question to the panel if RRI isn't simply the same as Corporate Social Responsibility the answer was: As a matter of fact, it is. It is a little embellished and the buzzwords are somewhat different, but in fact there is not much new under the sun. However, what makes it so attractive are the hundreds of millions that are available in Europe to be divided among the same organisations that have not made the situation much better for the patient in the last 17 years. We adapt the presentations of the last few years a little, change the terminology and perhaps choose a new face within the organisations for better sales, but we are chasing the money again.

And the patient? He is not asked anything. When ever ything is signed and sealed, the question if the patients and/or the advisory board have been consulted is of course ticked off. Yes? Check mark. After this, submit the request for money.

How long will we say to ourselves that we are doing it for the patients? When will we become honest and simply say that the patient is working stock and that the more patients there are the better it is for our business? Be conscious of this and realise that this is how we work. Do not call this 'The System'. You cannot call the system. It is how we work. 'We'! And that brings responsibility.

Since we work like this, we can also work in a different way. We have a responsibility for the outcome of our work. Not only for the little piece we do ourselves, but also for the chain and the result. It may not be like that legally, but it certainly is morally. It was German- American political theorist Hannah Ahrendt who did a lot of work in this field and who indicated that responsibility arises in the contact with people and that we are responsible for what we do and its result (2003). If it is right, everyone is a specialist in his own field and oversees the whole. If we oversee the whole, we see that things do not go well. Then we adjust this and we ask the person for whom we are there how to handle and solve this.

Then, and only then, we can tackle the alienation (of which we are a part ourselves) that has been seen in the past decades. Alienation from the essence for which we are here. In healthcare this is always the patient. Trish Groves understood that perfectly.

## **Key Points**

- The patient is at the centre of healthcare
- · How can healthcare research innovate for solutions?
- · Banking sector profits most from healthcare
- Responsible Research Innovation needs results
- · Alienation in healthcare needs to be dealt with

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