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# The need and speed of cooperation instead of competition in research

Questions that need to be answered taking into account benefits for the patient.

Academic rivalry is not in the patient's interest, and as long as patients are not involved in healthcare and healthcare research on an equal basis there will be no solutions for the questions that need answering.



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Léó Szilárd wrote in 1948 *The Mark Gable Foundation* (Szilárd 1961). When asked by a wealthy entrepreneur who believes science has progressed too quickly how to slow down this progress, he says:

*...Set up a foundation with an annual endowment of thirty million dollars. Research workers in need of funds could apply for grants... Have ten committees, each composed of twelve scientists... Take the most active scientists out of the laboratory and make them members of these committees. ...First of all, the best scientists would be removed from their laboratories and kept busy on committees passing on applications for funds. Secondly the scientific workers in need of funds would concentrate on problems which were considered promising and were pretty certain to lead to publishable results. ...By going after the obvious, pretty soon science would dry out.*

The story is funny and says a lot about science and especially the way it's done. The question is of course: 'If it's popular is it also relevant for patients?' and: 'Is cooperation the way to speed up the process or is competition to be preferred?' From my perspective, the second question has to be answered taking into account benefits for the patient.

## How does science work?

Research is done for several reasons but ignorance is an important driver. Since we realised we are ignorant and curious and that we should keep learning, we discovered a lot.

(Doing) research is fun to do. Researchers are excited about solving a problem and society may indirectly benefit from it.

Because we need to know something for a particular reason. Think of designing and building a bridge that saves hours of travel but has not been constructed due to technical restrictions. Or we need the knowledge for making better treatments for patients. This is user-inspired basic and applied research.

Research and the attention of researchers is predominantly guided by hype and the possible impact it may have. Of course, not always, but scientists do the science their teachers and senior researchers do. In every biomedical field at any time there are leads and topics that are believed to yield more and better results.

In a remarkable investigation Professor Aled Edwards from Toronto University showed that most molecular biology scientists work on the same genes (Edwards 2017). There are 20,000 genes and they're only working on a small percentage of them. This is not unique to Canada, but a serious worldwide problem. How can we expect to solve the cancer problem (or many other problems) if we only do research on a limited number of genes and topics? How can we expect to solve these problems when we only grant proposals that do research on these limited topics? How can we expect solutions from the same people that were not able to solve the problem in the past because they only look at these limited topics and the solution is probably somewhere else?

By doing the same things again and again we will fail in the same way.

The biggest problem we are facing in healthcare, in my opinion, is the medical-industrial complex (Kapitein 2016). Before we can begin productive research we have to be aware of this complex (we don't have to solve it, we have to pass the hurdle while being aware).

### **The medical-industrial complex**

General Eisenhower went public with the expression 'military-industrial complex' in 1962. It refers to the interweaving of the military forces with government and industry. Through politicians (who depend on industry for their election and jobs after politics) the different parts of the army are influenced by the industry and manoeuvred to the product of the supplier. Whether this product is actually the best is not the most important issue. It must be sold and a lot of means are justified.

“ IF YOU'RE NOT  
AT THE TABLE YOU'RE ON  
THE MENU ”

This complex works the same in healthcare. The medical-industrial complex consists of all stakeholders: government, research institutions, hospitals, industry (pharmaceutical and medical equipment suppliers), insurance companies, and last but not least patient organisations. The lobbies are strong and often focused on revenue, profit (money) and survival. This in itself is not surprising, and when given good thought does not have to be bad either, as long as there is honesty and transparency about their interest, and the right stakeholders are at the table for discussion and decision. I think we've got a problem with the visitors at the table. All stakeholders are present except patients? If you're not at the table you're on the menu.

As long as patients are not involved in healthcare and research on an equal basis there will be no solutions for the questions that need to be answered. It will be hard to raise the right questions at all. Research will be done by researchers without any prior consideration for what questions patients have. How can we expect the outcome to benefit them? Treatments will be designed with quality standards that are not defined in collaboration with patients. Most trials have 'overall survival' as an endpoint. Why

can't researchers and clinicians think of 'quality of life' as an endpoint? If overall survival is not improved by a new treatment but the quality of life is, patients want this new treatment.

How can we take care that treatments will benefit patients and bring them a longer life with good quality instead of a marginal life expectancy often burdened with very intense side effects at high costs? I think that it's now time to work on the question 'Speed through cooperation or competition?'

### **The patient is the problem and the solution**

If better research, better treatments, a longer life with good quality don't come naturally from healthcare professionals that have been active for a long time, it should come from patients. How?

In my opinion three groups have to work together to define questions and give answers: patients, clinicians and researchers. The patient has a problem, an unmet clinical need and a need for care. The patient wants to get her/his cancer under control and wants to live with a good quality of life. The available solution most of the time is a treatment for cure or for life extension. Clinicians know (or should know) the available treatments, the side effects and the impact on quality of life. Well prepared and informed by the doctor, the patient starts a treatment and after a while it becomes clear if the solution works or not. If there is no available treatment for a cure or life extension the patient and the doctor will ask the researcher for a solution that works. This is the assignment for research, how it should work and often does. Doing their job researchers find solutions that translate into new treatments. Hopefully fast, but most of the time this takes years.

One of the reasons for delay is, among others, the aforementioned medical-industrial complex. For several reasons this complex works against patients. One of them is money and this we quite easily understand. But also because of change. Change is difficult because people do not like change. This is a common rule but applies even more to old organisations, and healthcare is an organisation that's existed for more than 2000 years. We seriously have to deal with this.

I like to emphasise that this 'working against patients' is not because of bad intention. I am convinced that there is no stakeholder in healthcare with bad intentions, but 'the way we work' makes us do things that we actually do not want to do. We want to help, but 'the way we work' prevents us sometimes

from helping. An example: How is it possible that a good doctor tells her patient that she can't give her a specific drug because we do not know yet what the long-term side effects are? And this patient responds: "But doctor you just told me that I'm dead in 3 months. I'm happy with long-term effects." This is a real-life example. Nobody wants this, still it's happening.

When patients collaborate with clinicians and researchers, the relevant questions will be asked and answered and the right decisions made. Right because it's about the life and death of the patients. When well-informed, the patient makes the right decision. A good example is pancreatic cancer. No results so far and also no results on the quality-of-life part. Cold Spring Harbor Laboratories researcher David Tuveson worked with patients and asked them about the most important symptom that influenced their quality of life: "Pain, Dr. Tuveson, pain". Based on these discussions and working with patients Tuveson decided to work on this: "If we can take away the pain we give them 6 to 12 months more with a good quality of life".

By working in cooperation with patients we will be able to improve the research agenda and research the subjects that benefit patients and society. The good news is it can be implemented tomorrow and in some situations, we're already working in this way. We now have to amplify it, and it has been done before in the 1980s and 1990s by the AIDS movement. They sat at the right table together with government, industry and scientists to decide (after a long and activist struggle of course) (France 2016).

### **Cooperation is the way to speed up the process**

Looking at the way science works several things are remarkable. Most of the time there is the drive to compete and win. Researchers almost all want to safeguard the results of their own scientific work. Not sharing it until it's published. Go for number one and number one is you.

Why is there a need to compete? Why is there a need for academic rivalry? It is not in the patient's interest. Not sharing means that other scientists are prevented from helping you in an earlier stage of your work to improve it. Not sharing means that you are not able to reinforce the work of another scientist and speed up his or her work. Not sharing means you or other scientists might work in a wrong direction, wasting energy, time and money. Not sharing means patients have to wait for their treatments longer and they might die because of this.

What if the allied forces had been competitive forces in 1944? We in the Netherlands would probably speak German instead of Dutch. During World War II there was great danger as the Nazis were developing a nuclear bomb. Thousands of scientists and engineers out of different countries gathered in Los Alamos with one assignment: make sure that we (The Allies) realised the nuclear bomb before them (The Nazis). The knowledge and experience of The Allies was brought together and they were asked (and sometimes mandated) to cooperate with each other and compete with the enemy. There was a strong external force, and an urgency, to cooperate and compete.

We humans have a strong external force and urgency as well: cancer kills millions of people each year. Why don't we do the same and work together, share everything we know and compensate what the other lacks in order to compete with the enemy? Don't consider other scientists or companies as your enemy. Please consider cancer as your enemy and reinforce each other. We have lots of proof this way of working speeds up the process.

### **The data problem**

Working together deals with many issues but the sharing of data is one of the most important aspects. We know that some research results cannot be reproduced. Being critical of one's own data is hard to do. Being critical of someone else's data is easier. The data used, however, is not the property of the researcher but the property of the patient. The patient has given their consent for the use of this data, but the patient is not connected with the setting up of the consent. Why is that? At least it should not be this way. If the patient is connected to this process most of the problem will fade away.

When the data is not the property of the researcher, they always have to request consent to use the data. If it's my data (as a patient) I can give it to everyone I want when I'm well informed. Patients want to give access to the data to researchers almost all the time. Just because they know it will improve their quality of life or the quality of life of others. Most of the time patients don't talk about privacy. They know that the fail-safes for the good use of data are thorough. The research that will be done is controlled by institutional research boards. A researcher will think twice before using the data in an inappropriate way.

Privacy is mostly an issue for people who want to protect their own work and prevent others from using the data. If patients want to share their data

with scientists, they will (have to) share the data with other scientists. Patients will simply demand this. It will lead to a critical approach and appropriate use of data.

### The right incentive and rewards

Researchers' behaviour is a logical and natural response to the incentive and reward system they work in. In academia, to survive and advance one's career one has to play the game. Predominantly, research and researchers are evaluated still on the basis of publications with a strong emphasis on high-impact factor journals. Over the past 30 years this system has developed in an autonomous way, and all actors in the system have adapted to it in order to optimise their cause. Agenda setting of biomedical research is guided by this system, which selects research that has high short-term output and that is appropriate for publications, getting the next grants, etc. High-risk, long-term research which does not yield high-impact papers is avoided. Sharing data and specimens as in Open Science with colleagues is not rewarded and weakens the position towards international competitors.

It has been argued that to improve agenda setting to enhance clinical and societal impact, to accelerate use and reuse of data a fundamental change in the incentive and reward system in academia is required. This affects all actors in the knowledge production process: funders, deans, learned societies, administrators and publishers. Fortunately, increasingly this awareness is growing and will lead to better policies in the near future in Europe and elsewhere (Miedema 2018; Moher et al. 2018; Science in Transition 2015).

### Finally.

What would happen if patients were involved in defining the research questions and agenda? What

would happen if patients were in the driver's seat when it comes to their data and use of their data? What would happen if patients were to demand this and otherwise stop participation in clinical trials? We believe that the system will change in a more effective way and will benefit patients and therefore citizens and society.

The question is not what is to be preferred, 'cooperation or competition'. The question is when to use what? It's our strong belief that when fighting with the enemy 'cancer' it should be competition. We have to beat cancer by all means. And when determining the right way to do the right thing it should be cooperation. By combining the best expertise and knowledge for the best reason thinkable we enforce ourselves and are more capable of fighting and defeating the enemy. It is what history teaches us. So, we had better listen. It's not about You, it's about Us! ■

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### KEY POINTS



- ✓ The biggest problem in healthcare is the medical-industrial complex
- ✓ A fundamental change in the incentive and reward system in academia is required
- ✓ Cooperation is necessary to forward the research agenda for the benefit of patients



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