

Tuberculosis **the quest for a better approach**

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As a patient advocate from Inspire2Live, the Dutch and international organization of patient advocates that aims to get cancer under control, it's not a weird question to write an article about tuberculosis. It is particular not weird because I was asked about how to come to a better approach of setting up research for a better treatment of tuberculosis. To be honest, I know almost nothing about tuberculosis. I know a lot about cancer and about how to organize settings, workshops and brainstorm sessions for realizing new approaches to deal with it. I'm convinced it works for other diseases as well. We call our approach 'The Discovery Network' (DN). Let's see how this



The Quest for Better Approach

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For the man with a hammer the whole world looks like a nail. When you never deal with other people, opinions, businesses and approaches, you will be convinced of yourself and find out that you can do the same thing over and over again and that you are always right. However, people around you see no chance and even worse, no progress at all. Arguments like 'change needs time' are needed to justify your way of working. When dealing with diseases this is not the right thing. In healthcare, we have a strong responsibility, we need change and progress.

People don't want to change. They talk about it a lot and adapt. But they only adapt when there is an urgency. And that's what lacking in the decision-making process in healthcare: there is no urgency. We say there is and that the patient is important, but we do not act upon it. The approach that Inspire2Live chose for improvement in treatments and change the way science works is to combine emotions with arguments. The emotions come from our fellow patient advocates; they are sick and dying. This brings the urgency we need: better hurry because we're dying. With emotions alone we do not get where we want to be. We need arguments: science, knowledge and facts. Patient advocates need to know what they talk about when working with the stakeholders in the Medical Industrial Complex: patient organizations, doctors, scientists, industry, government and health insurance.

When working on change and improvements we have to keep 4 maxims in mind. Let me explain (Reference 1).

Bring a range of people together

Invite someone who does not understand your field of expertise, but who is smart. Ask her to ask questions that you have never thought about before and look for the answer. You will be amazed by your lack of knowledge in your own field. You'll be amazed how much you take for granted, but what (for an outsider) is not self-evident. 'I don't know who discovered the water but it certainly wasn't the fish'. And always elicit someone's opinion: 'I want your opinion, even if I do not like it.' We are looking for the truth and for that everything has to be on the table.

Look for the real cause

'Johnny fits into the trouser. The trouser fits into the bag. Therefore, Johnny fits into the bag.' This is the logical fallacy of assuming the conclusion. This statement is clearly nonsense, but in practice there is often evidence that could hardly, if at all, be called evidence. I am referring to the fumbling with data that supports scientific articles and that in a number of cases simply is neither verifiable nor repeatable. Continue and ask penetrating questions (with the various people and their diverse backgrounds) as far as irritation point and the pain threshold, and beyond. Only once we know the real cause is a solution really possible.

Upscale Quickly

Think big, start small and upscale quickly. You don't solve cancer by thinking small. Cancer is a global problem and that requires great ideas, grand theories and sweeping approaches. This piece of knowledge comes from France, that insight from an American. And look what an essential contribution India is making on this point.

Be independent

We are never independent, because we always act because of something or someone. The only permissible dependency that stakeholders have in healthcare is dependence on the patient. In this, we must be vigilant. If we see otherwise, then it is our duty to correct it. All those involved in the Medical-Industrial Complex must ask themselves seriously whether this is the only permissible dependency, or whether there is another dependency at play. Everyone is obliged to answer this question in good faith and to weigh up that answer in the discussions they have with the other parties concerned about the patient's problems: 'Am I serving you or someone else?'

The four maxims help in determining the right route to reach a solution. And the nice thing is that they are placed in a certain order in which the various points influence and reinforce each other in their application. You bring together different people with different opinions, who jointly search for the real solution and find it. What they find must then be brought to all patients as quickly as possible. This solution can only be found and implemented if there are no interests at play other than those of the patient.

The DN concept

The DN creates an open environment for those who are in this structure to pursue a common goal and to better reach that common goal. Patients are an integral part of this open environment. The DN will facilitate at least three levels of cooperation in the area of research and treatment.

- Better sharing of better observations
- Better utilization of better treatments
- Better organization of better networks

To function as a full-blown information science, with connected brains, the DN must incorporate all levels of cooperation. An inherent problem in this kind of system is that the DN must enable the need for both openness to novelty and closure when disciplined research and/or treatment regimens are required.

Without better sets of high quality observations of groups and individual patients, better treatments will not be discovered and utilized. In fact, without capturing better quality data of treatment effects and sharing them, we will not be able to distinguish good from bad, better from worse or better from really better. At some point, strict regimens of diagnostics, treatment and observation of treatment effects are necessary to make progress at.

At the end of the day, treatments are central. Introducing better treatments also means adapting existing regimens and replacing existing regimen with better regimen at the level of well-defined groups and in given cases, at the level of the individual patient.

But we also need better networks (research groups, cooperating institutes, teams of clinicians and lab researchers, et cetera). We need to change the way we work within and between groups of researchers, physicians, engaged patient and all relevant others. Here data sharing and the fluent creation of problems focused networks of researchers, clinicians and engaged patients is crucial.

What is needed is a kind of hub connecting the relevant people and professionals, and this is the instrumental reason for creating the DN. The DN is about the discovery of better treatments: for groups and for individual patients. This needs better organization!

The functions of the DN

What is the DN? The basics are simple. The implementation and the use will be a lot harder to specify. In fact, actual use is a discovery process in itself. We enter the world of information science, because apart from the actual brains of people and the hardware, everything else should become exchangeable as information!

1. The first element: The basic idea is that we create a network, which supports the combination of ideas. This means: connecting brains and sharing all information that the brains need to reach the goal.
2. The second element relates to better observations. High quality characterizations will be needed. New imaging regimens, new imaging techniques, better reports and access to repositories will be necessary.
3. We need a map of all possibilities of treatments.
4. We need exchange with and connection to networks of scientists and clinicians. The networks include the people who operate the facilities to design animal models, screen drugs and set up trials.
5. Observations, treatments and networks must be matched. This is qua interfacing and technically the most challenging part. Human intervention will be required to get the details right. Only users from the proper networks will have the knowledge to make the right decisions.
6. Results must be studied in populations of patients and must also feed back into the DN.

Brokerage and closure

Improvement ultimately means discovery, invention, development and implementation. Quality new observations,, treatments and networks will have to be added to or replace the old sets of observations, treatments and networks. Brokerage and closure is about this dynamic process of improvement. The DN is an improvement system; ever open to falsifications, replacement of entrenched practices and better ways of working. To improve the system of discovery and speed up implementation for patients, we have to expand on the boundaries of observations, treatments and networks.

The DN connects brains and leaves to the brains what the brains are good at. It lets the network do what the network is good at. If the DN is based on any trick, this is its basic trick. It is not an Artificially Intelligent system. The Intelligence is in the interaction between brains of real people. If the people stop thinking and stop interacting, it will not make any difference at all. And this brings us to the human factor. The most important factor of all!

The central position of the human factor

The patient of the 21st century makes the importance of the patient perspective very clear (Reference 3). At the core, it is the patient who must benefit and who is smothered, because of regulations, the reputation of pharma, bad information, deliberate misrepresentation of research results (for example, reporting relative improvements in percentages instead of real improvements in terms of absolute numbers), et cetera. The human factor is the rate-limiting step. If we succeed to engage patients, funders, physicians and researchers, we make progress.

References

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