



Inspire2Live

*Walk (run) the extra mile for
patients*

Minutes Annual Congres Februari 11 & 12 2016

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Getting cancer under control and inspire people to lead Happy and Healthy lives in Harmony with cancer! • www.inspire2live.org

Science - 1

Collect all data and make it accessible for everyone.

Serendipity: finding something good without looking for it.

The patients of tomorrow depend on the science of today.

Thanks to data we can now predict in a much better way.

Organizations should invest in long term, risky, fundamental, 'big picture', curiosity driven research to find a next breakthrough.

Research should be done multi-disciplinary.

We should go for both: Fundamental & Applied research.

See the individual experience as the beginning of science.

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Science - 2

Merge these two data types;

- Exact data: 100% proven to be right
- Unstructured data: Give it all to me, I will find the missing value.

Barriers:

- Privacy regulations.
- NDA of organizations or other legal issues.
- Patients are the owner of their data.
- Wrong use of the data.
- Amount of publications is key measure of 'research impact' and fundament of reward structure.
- Throughput time of research results.

Use big data to shorten the time for research, and look for the golden question to help a lot of patients/people.

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Medical

The power of the patient should be in every little aspect of cancer.

Speed up the process of drug approval:

- Start in the medical school and change the concept of the doctor to communicate.
- Patient must be educated and empowered.
- Create a working group with all the stakeholders (patient driven organizations, doctors, Insurance companies, pharmaceutical companies, technical physicians and politicians.
- Patient oriented and driven organization.
- Work first then speak.
- Patients perspective of risk is different.
- Reduce long lasting RCT's.
- Phase 2 drugs availability for all patients.

Patient have the right to be informed about all (available) treatments.

Personalize the treatment for the patient.

Define methodologies that go beyond RCT's, to define relevant endpoints, and leave room for the unknown.

Jelle Barentsz; make the doctors activistic. Make them dance!

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Government - 1

Focus on how to get patients at the decision making table.

Fast track access to drugs should be realized.

The pricing is a matter of patients.

There could be different levels of "government": European commission/ European Union, Ministry of Health, European Medicines Agency/Dutch regulatory authority, Ministry of Education/Medical schools, ethical review boards, etc.

Events: 4 current and upcoming events could be the focus for action:

- Final 5 months of the Dutch presidency of the European Commission. In June there are meetings of government and industry. Patient advocates should be present.
- Dutch Ministry of Health, January 2016 recent letter of health strategy could be reinforced and affirmed by I2L.
- Dutch Elections first quarter 2017.
- Dutch Ministry of Health will have meetings with Pharma and Insurance companies in June 2016 for pricing/coverage negotiations.

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Government - 2

Process:

- Needs a neutral initiator (such as Inspire2Live).
- Engage press/media whenever needed to raise awareness in population.
- Organize 21 Dutch cancer patient organizations plus the overarching cancer organization.
- Meet with minister and government officials.
- Filter through spotlighted topics to find 2-3 points for a common agenda.

Possible topics:

- Securing patient seat at the table of decision-making.
- Promoting biomarkers to reduce overtreatment and clinical research implicating those who do not benefit.
- Breaking down the silos of regulatory bodies; they are usually hard to contend with.
- Improving data information quality and real world data.
- Improving access to new medicines and fast tracking of drug approvals.
- Ensuring affordable pricing of innovative pharmaceuticals (no cure, no pay policies).
- Our group emphasized using a proactive and positive approach towards breaking through government silos ("Make love, not war, use flowers, not violent weapons.").
- Patient advocates should act as 'one voice' when addressing anyone.

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Data

The content of an informed consent form must be much more SMART than before, because for a lot of people it is hard to understand.

Important is in the information to patients and citizens what the benefits and risks are when they donate their data. There is a balance between the benefits and the risks which has to be clear when you donate your data. And be aware that there is a legal and ethical aspect in regards to donating data.

All the patients in the session had less problems with giving their data for research purposes than the rest of the group. They see or suppose that there are more benefits than risks. We collect data, not to protect them, but to use them. Therefore; if someone has done bad things with data: punish him or her.

If the doctor has the data at his fingertips too he is going to dance for the patient.

The patients have the right to know what will happen with their data and they must be informed about the results of the research with their data. The reimbursement must be clear.

Put conditions of patients into the trial. For example: 'If you don't give open access (to data) we don't step into your trial.

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Health Insurance

Free choice of doctors by selective contracting. Should health insurance companies do this? | This is all about trust and reputation.

How do we define the Quality of Care?

CZ is very much interested in a pilot for Olaparib. Give it to patients after phase 1 and 2 and don't wait for phase 3 trial.

For the fair pricing of drugs, Cinderella and Inspire2Live organize a congress on April 15th.

See also the words written about a possible 'My best lung cancer treatment' in the chapter about the industry breakout session.

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Industry/medical equipment

Bring comprehensive molecular diagnostics/profiling such as the NEO technology to all the patients. It is possible and desirable. It allows therapeutically relevant mutations, copy number alterations and translocations to be determined on a single sample. This is already possible on tissue (paraffin blocks) as well as with a liquid Biopsy (2 blood tubes only.)

The latter has the huge advantage for the patient that no invasive biopsy with all the associated risks has to be taken. Patients should demand for it!

The benefit most prominently is seen (for example) in lung cancer patients that need a re-biopsy to gain critically important molecular diagnostics to determine further treatment options. Lukas Heukamp from NewOncology, together with Madelon Johannesma from CZ (the Dutch health insurance company) suggested that this might be an attractive project to follow up either as part of 'My best lung cancer treatment' or as a stand alone program. It is agreed between CZ and NewOncology that they will write a rationale on short term and that they will discuss possible cooperation centers.

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Final remarks

Choose 2 or maybe 3 topics and focus. Work on these topics in detail and combine it with emotion. And then go for it. Use good public relations.

Doctors: 'We can do our best but you can always do it better. You are the patient. Use us to do the work. You can do the plea.

It's important to make small steps.

But make them fast.

It's not Walk the extra mile for patients.

It's Run the extra mile for patients.

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