



# Inspire2Live

## *Patient Advocacy*

Vision Document

Version 1.2

December 26, 2016

**never ever quit!**

Getting cancer under control and inspire people to lead Happy and Healthy lives in Harmony with cancer! • [www.inspire2live.org](http://www.inspire2live.org)

# Inspire2Live

## *Vision*



In the fight against cancer, both patients and their loved ones feel a huge sense of helplessness. Cancer is everywhere, and fighting it seems pointless. One in three people develops cancer. All those involved have first-hand experience of how dramatically their lives are affected and how destructive the illness can be.

***Our motto is “Never, ever quit!”***

Inspire2Live is created with the aim of empowering people to transform their sense of powerlessness caused by cancer. This transformation is achieved by motivating as many people as possible to constantly challenge and expand their boundaries. We refuse to accept any limitations to what we can and will achieve.

***Inspire2Live is founded on the absolute belief that you can attain the greatest possible satisfaction if you put your heart and soul into helping others.***

### **Our mission:**

- Getting cancer under control and inspire people to lead happy and healthy lives in harmony with cancer.
- We aim to connect patients, clinicians and researchers. We always operate independently

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# Inspire2Live – Patient Advocacy

## *Mission*



The mission of patient advocates is based on the mission of Inspire2Live:

***Achieving the best possible cancer care and the best possible access to cancer care.***

With worldwide approximately 10 million people dying of cancer every year, it is unacceptable that we are not able to offer and access the best possible care. We know that it can be achieved, without need for extra money. What we need is re-allocation of money, more knowledge about social innovation and the courage to adopt it.

**We strongly believe in realising this by means of:**

- *Better doctors*
- *Better patients (citizens)*
- *Better decisions.*

If patients and doctors are better informed, they will make better decisions.

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# Inspire2Live – Patient Advocacy

*The group*



Inspire2Live's patient advocates consists of:

- ***Cancer patients***

The type of cancer doesn't matter to us

- ***Cancer survivors***

Everyone living with cancer, both patients and survivors

- ***Loved ones of cancer patients and cancer survivors***

This includes people living with cancer patients, cancer survivors, relatives of people who have died of cancer, in short people who are highly motivated because of their relation to cancer and who want to develop initiatives that add to our mission.

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# Inspire2Live – Patient Advocacy

*The best (access to) cancer care*



*'Whatever houses I may visit, I will come for the benefit of the sick'*

When we talk about the best cancer care and the access to this best cancer care we take the Hippocratic oath, mentioned above, as our starting point. Our policy and our actions are based on the principle of fairness. It is simply not fair that these differences exist. Awareness creates the necessity to act. Inaction kills.

Differences in quality between and within hospitals should not be tolerated. No laws need to be changed to put an end to this. Therefore, we believe that the following situations should change:

- *At present, patients do not have the right to expect the best possible treatment. They only have the right to expect some form of treatment.*
- *The quality of treatment varies enormously between hospitals.*
- *The quality of treatment varies enormously between countries.*

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# Inspire2Live – Patient Advocacy

## *Areas of communication (“what?”)*



### **Reducing Incidence / Prevention**

- *Making sure that the awareness and importance of a healthy lifestyle will be better understood by citizens.*
- *Improving a healthy lifestyle by promoting nonsmoking, healthy food, less alcohol, more exercise and a healthy weight, by using evidence based information.*
- *Creating a movement in society.*

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# Inspire2Live – Patient Advocacy

## *Areas of communication (“what?”)*



### **Innovation of the Clinical Practice**

- *Scientific knowledge has to be brought faster from laboratory to the patient.*
- *Informing patients that they have their own responsibility in participating in (fundamental) research. We will help doctors to communicate this issue well to their patients.*
- *Changing the publication culture and reward structure of scientific research.*
- *Patients have the right to (access to) the best treatments.*
- *Patient Advocates must be part of the Scientific Councils and decide on the research agenda.*
- *Improving the good use of blood, tissue and other relevant samples/data for research.*
- *Making it possible to find the right drugs and make them available.*
- *Taking care of Early Access to Drugs.*
- *Breaking down barriers when it comes to making new drugs available.*

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# Inspire2Live – Patient Advocacy

## *Areas of communication (“what?”)*



### **Quality of Care**

- *Arranging that all patients have the right and access to the best care.*
- *Promoting that patients will be treated in centers of excellence by the best doctors.*
- *Insisting on “making the right decisions” in hospitals. Patient Advocates must be part of the decision making authorities in healthcare.*
- *We organize that patients are part of their own treatment team.*
- *Patients have their own responsibility for their recovery and health, during and after their treatments.*
- *Not just patients will be made more literate. Also doctors have a long way to go. We provide.*

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# Inspire2Live – Patient Advocacy

## *Areas of communication (“what?”)*



### **Quality of Life**

- *Providing a focus on living with a good quality of life (which can be with cancer) and not on the cancer.*
- *You are not a cancer patient. You are Linda, mother of a child.*
- *You are not a widow. You are Ineke, not a widow of a diseased husband.*
- *You are not a man with limitations. You are Maurice, friend of Peter*

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# Inspire2Live – Patient Advocacy

## *Areas of communication (“How?”)*



### **International Cooperation**

- *Optimizing research and stimulate international cooperation in research. Only the best research helps patients.*
- *Taking care of knowledge sharing between patients from different countries.*
- *Bringing patients, clinicians and researchers together to speed up the process of getting cancer under control.*
- *Combine the emotional power of the patient advocates and their arguments and facts.*
- *Providing innovation of all cancer care as fast as possible.*
- *Breaking down the silos in research and healthcare.*

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# Inspire2Live – Patient Advocacy

## *Areas of communication (“How?”)*



### **The role of Patient Advocates:**

- Involved in the decision making process of cancer care and access to cancer care.
- Involved in the decision making process of the cancer research agenda.
- It's about the awareness of what to work on for the Patient Advocates.
- It's about education of the patients and their doctors.
- It's about being the voice of the patient.
- It's about being the connection between patients, clinicians and researchers.

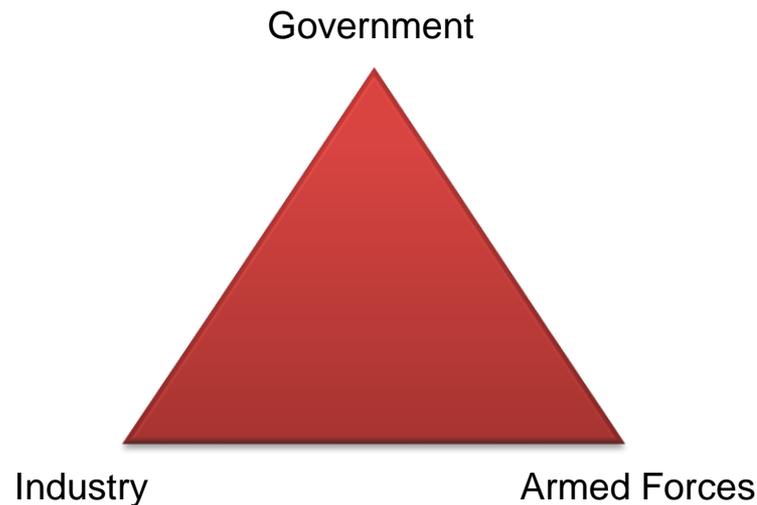
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# Inspire2Live – Patient Advocacy



## *Military industrial complex*

In 1961 president Eisenhower made us aware of *the military industrial complex*. It is a concept commonly used to refer to political and monetary relationships between legislators, national armed forces and the military industrial base that supports them.



Please be aware of the fact that Eisenhower was a former general who warned us that the way The Military Industrial Complex works does not mean that its main aim is the safety of the people. There is no malicious intent, but it is just the way it works.

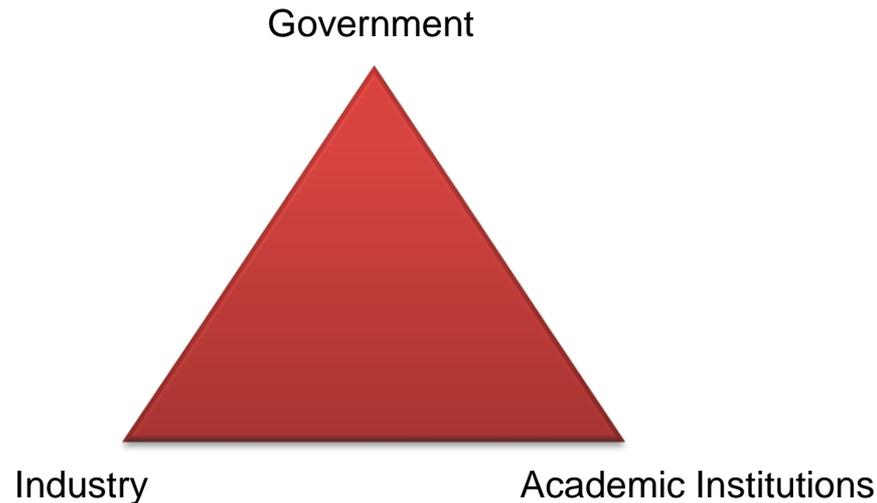
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# Inspire2Live – Patient Advocacy



## *Medical industrial complex*

In the concern about the care of cancer patients and their loved ones we also have to be aware of a similar complex. Stephen Friend, a former doctor, researcher, and head of oncology at Merck (so he should know), talks about *The Medical Industrial Complex*.



There is no malicious intent from one of these groups but we believe that patients can improve the way this triangle works by putting themselves first and in the middle. In this way patients and their loved ones will benefit first and most. As it should be.

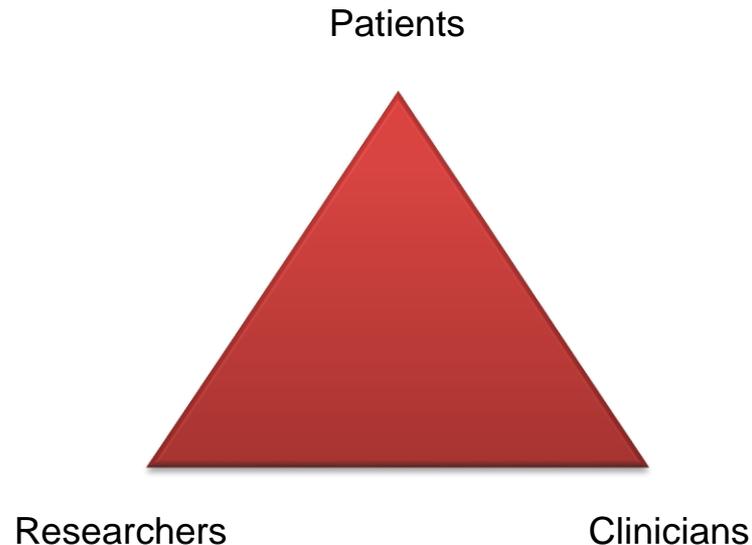
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# Inspire2Live – Patient Advocacy

## *Primary cooperation*



We have a strong faith in cooperation between:



Cooperation starts with these three groups and will get cancer under control. In fact it is the only way to get it under control before 2021. Patients have rights and duties and should always be willing to cooperate with clinicians and researchers, and they also should vent their discontent.

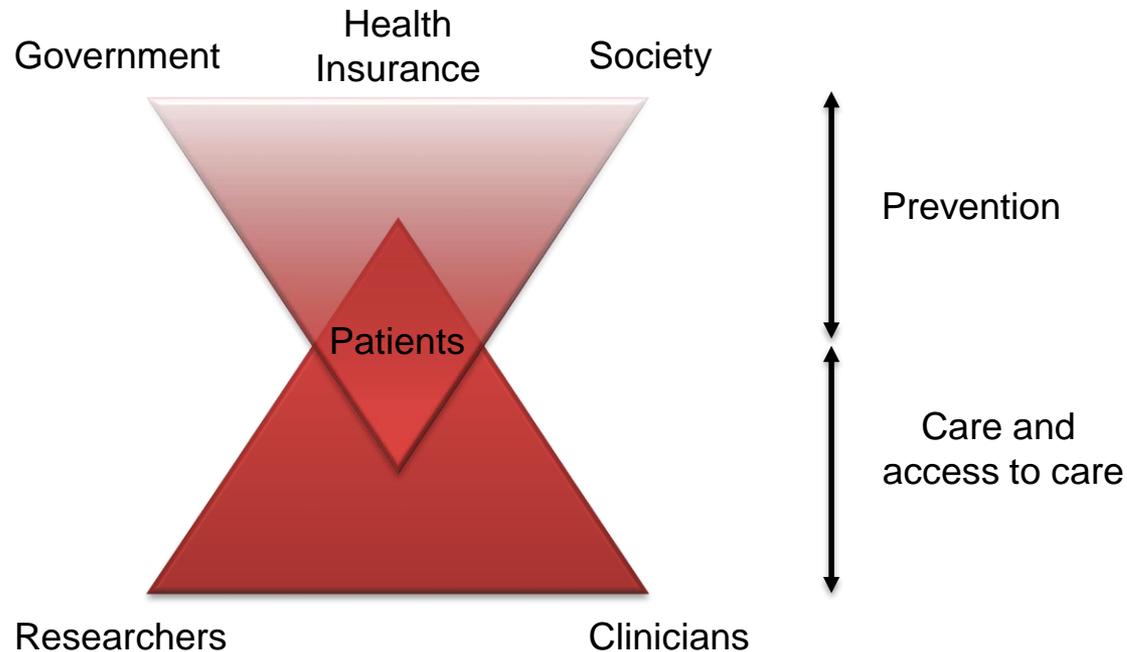
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# Inspire2Live – Patient Advocacy

## *Societal cooperation*



As said, we have a strong faith in cooperation:



PA's act as the bridge between the medical profession and society. To achieve better care and access to care, patients, clinicians and researchers must work together. Prevention demands cooperation with and between society and government.

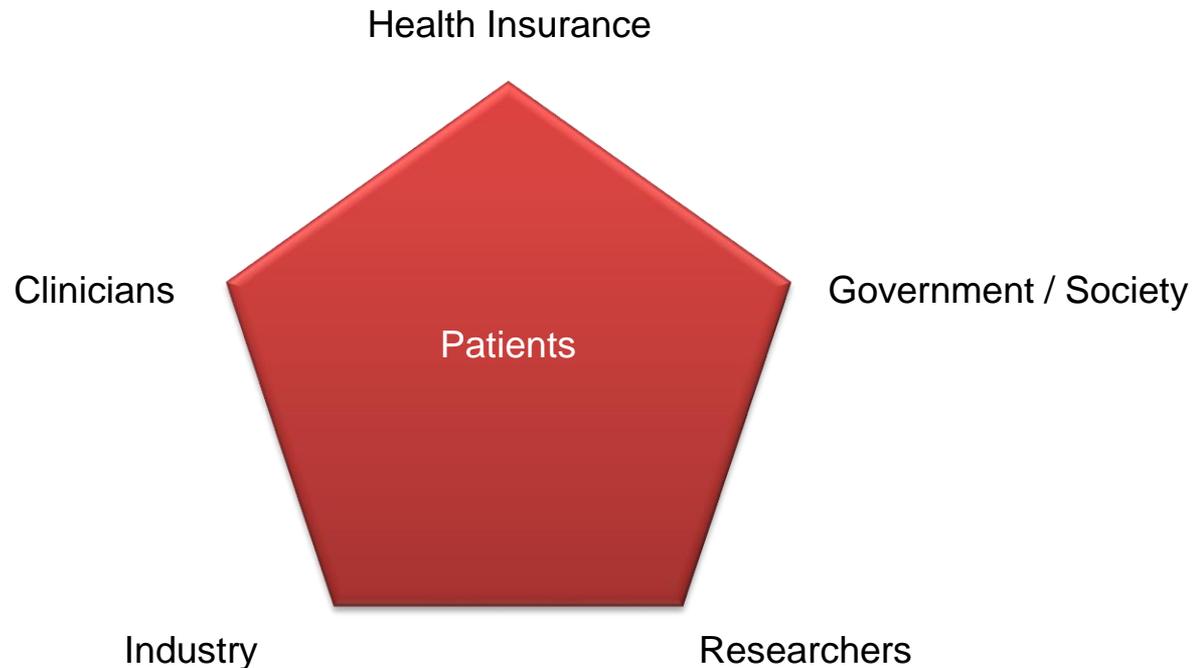
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# Inspire2Live – Patient Advocacy



## *Ultimate cooperation*

After clarification of the way the Medical Industrial Complex works and the way cooperation between patients, researchers, clinicians, industry and society/government influences the way we work the ultimate cooperation can get cancer under control: Real Cooperation. The *Pentagram* instead of the *Pentagon*!



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