



## Background and vision of Inspire2Live

*In memory of those who died too young of cancer and to inspire those who are fighting it.*

In the fight against cancer, both patients and their loved ones feel a huge sense of helplessness. Cancer is everywhere. Fighting it seems pointless. One in three people develop cancer. Everyone involved has first hand experience of how dramatically their lives are affected and how destructive it can be.

Inspire2Live was created with the aim to empower people to convert the sense of powerlessness, caused by cancer, into one of strength. We strive to achieve this by motivating as many people as possible to constantly challenge and expand their boundaries. Our dream is for cancer to evolve from a deadly disease into a chronic illness - a disease that people die *with* and not die *of*. We want to support cancer patients so that they have the opportunity to lead a happy and healthy life in harmony with cancer.

Additionally, everybody can experience an ultimate feeling of happiness, by giving the best you can for others. Everyone who has taken part in Inspire2Live events knows what that feeling is and what it means. It is the drive that realizes our dreams.

*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 motto is “Never, ever quit!” We refuse to accept any limitations in what we can and will achieve.

## Mission statement

*To facilitate and inspire people to lead Happy and Healthy lives in Harmony with cancer.*

## Background and vision of ‘Understanding Life!’

‘Understanding Life!’ is a patient initiative by Inspire2Live, with support of The Royal Academy of Arts and Sciences (KNAW) and The Central Bank of the Netherlands (DNB). The objective is to get cancer under control within the next 10 years, while ensuring good quality of life for the majority of cancer patients. We are convinced that by joining forces and combining the talents of brilliant and dedicated individuals we will eventually win the struggle for life and prevent millions of unnecessary deaths every year. ‘Understanding Life!’ is committed to delivering exceptional results, and lasting research and treatment infrastructures to patients within 10 years time.

The program was kicked off with a conference in Amsterdam (12-14 January 2011), during which the world’s leading cancer experts prioritized a number of bottlenecks that need to be resolved to get cancer under control. A number of key questions around this goal were identified:

- How can we generate relevant knowledge faster?

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- How do we translate this knowledge faster into improvements in cancer care?

Based on these key questions, five topics have been identified as primary objectives to facilitate the goal to make cancer a chronic disease, rather than a deadly one:

1. Improvement of disease and drug response models;
2. Improvement of clinical practice;
3. Improvement of storage, retrieval and exchange of disease-related patient data;
4. Reducing the incidence of cancer;
5. Execution of plans for changes and improvements.

Research and development is translational in character. The program focuses on organizing human capital, providing incentives to work together, creating and maintaining infrastructures that support translational medicine within and between laboratories and clinics, and connecting communication infrastructures that support information exchange among the cooperating centers. The program also focuses on mobilizing the interest of the patient and strongly improving a patient-centric approach. Obviously, it is in the interest of the patient that cancer therapy becomes more personalized. Cancer must be taken personally. People grow up and have learned to avoid infectious diseases as much as possible, by day-to-day habits, means and intuition. This should also be the case for cancer. Inspire2live will not setup projects by itself. There are worldwide a variety of potential very good scientists and institutes that can realize the best projects in the interest of patients. However every now and then Inspire2live can take the initiative to setup small pilots for very innovative projects with the best of the best to minimize the risk and maximize the benefits for the patients. If these innovative pilots work we will urge for realizing the bigger projects in the more conventional institutes.

## Program infrastructure

The program will be implemented by setting up a network of the best cancer centers, academic institutes and laboratories all through collaboration with patient advocates. The center of gravity will remain in Europe, as European research infrastructures are more abundant and the roots of the initiative lie in Europe.

We will establish a mechanism that identifies in cooperation between patients, researchers and clinicians the best innovative programs from the best specialists and scientists from excellent centers to tackle the above-mentioned primary objectives. We will not have calls for proposals because we do not believe in calls for proposals. It's a waste of time and energy that can be better used to build programs that work best for patients.

We will only by ourselves start funding the so-called multiple, small and innovative programs of approximately € 0,5 to 1.0 million each.

## Discovery networks (objectives 1-5)

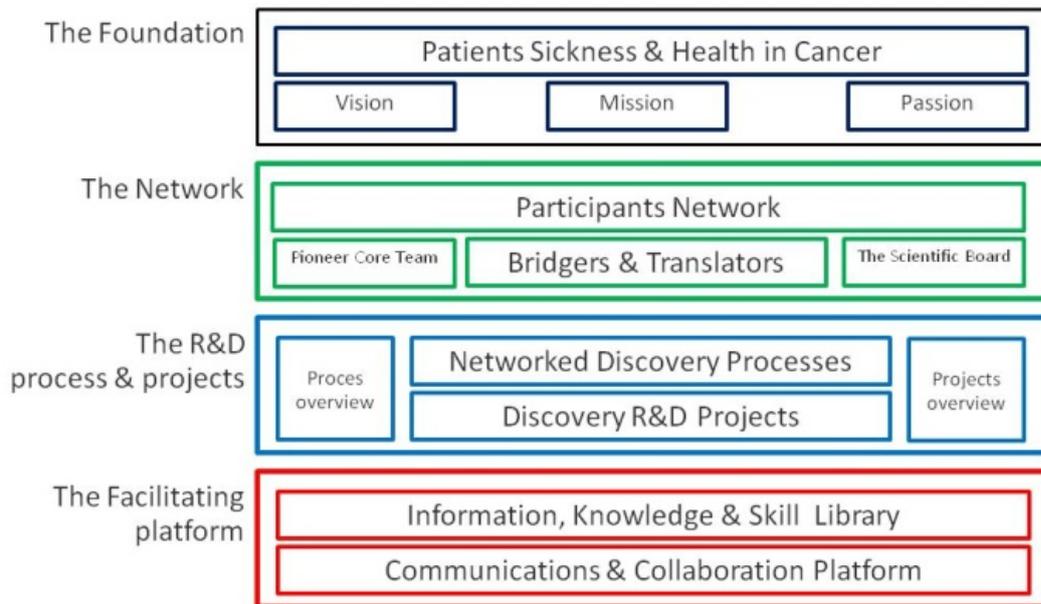
A number of top scientists, clinicians and patients in various Discovery Networks have joined forces in the Discovery Engine they defined, to significantly increase the speed of disease modeling, drug screening and treatment discovery. These Discovery Networks are formed around specific themes such as Targeted Medicine,

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Intervention Oncology, and Immunology. Our Boards (executive and supervisory) advises on the themes eligible for setting up new Discovery Networks:

- The foundation organization working from a patient orientation and passion, with a compelling mission and a clearly built vision.
- A participation and translation team stimulating projects in the participants network.
- A managed cancer R&D process and projects portfolio.
- Information, knowledge and skill library build upon a communications & collaboration platform.

**Figure 1. Overview of the program infrastructure.**



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## Outline and updates of the primary objectives

### 1) Improvement of disease and drug response models

This objective can be summarized under the theme of systems biology of cancer. Systems biologists are individuals trained in physics, computer sciences, applied mathematics and other quantitative disciplines, who apply their skills to new challenges in the field of medical biology. Systems biologists are needed to explore the genetic/environmental factors that are involved in cancer treatment and control. The goal of this theme is to take full advantage of novel technologies, analysis of data, and the ability to assess clear conclusions from the complex and large genomic, structural, and clinical databases that are available. By collecting and analyzing data across experimental and clinical settings we expect to learn how individual genetic profiles can lead to different treatment responses and the development of preventive approaches.

All projects within this objective must have a realistic chance to deliver substantive improvements in clinical disease management, and will be highly translational in character with frequent communication between lab and clinic.

Projects will include (but are not limited to):

- Development of state of the art animal models for treatment of human cancer, including “omics” analysis of tumors to develop biomarkers that can predict drug sensitivity or resistance.
- The use of “omics” technologies on in vitro cell line models to identify drug sensitivity or resistance mechanisms and development of interventions to eliminate or reduce resistance with existing drugs.

### 2) Improvement of clinical practice

A central goal will be to expedite and optimize the selection of patients that are likely to benefit from cancer drugs. While we expect that the majority of the drugs evaluated in this program will be the new generation of targeted therapies, we will not exclude the identification of predictive biomarkers of response to the more conventional (chemo) therapies. This objective will also focus on changing the mindset of both clinicians and researchers. It will aim to set up a network of clinical research sites, where a new generation of clinical researchers will be trained.

Projects within this objective will be hypothesis and biomarker driven. The use of adaptive trial designs will be used where appropriate, e.g. for the rapid validation of new biomarkers. Finally, projects should aim to educate a new generation of clinical researchers oriented towards translational research.

Projects will include (but are not limited to):

- The development and actual implementation of infrastructures to enable innovative omics-based diagnostics in clinical trials. These technologies include genome sequencing, imaging, and the development of these techniques into a ‘toolbox’ for the clinician to improve treatment.
- Innovative (neo-adjuvant) “adaptive” clinical trials that use candidate biomarkers of drug response. The aim of these projects will be to rapidly validate or reject candidate biomarkers of drug response. Biomarkers that graduate from these projects will be tested further in phase 3 studies.

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### **3) Improvement of storage, retrieval and exchange of disease-related patient data**

Biobanks should function as an open source work environment for researchers and clinicians. We will not try to reinvent the wheel and will seek collaboration with large international bio banking and data sharing consortia. Biobanking will serve as a major infrastructure to drive translational research, connecting researchers, clinicians and patients. Biobanking includes storing data and the sharing of data and knowledge with all stakeholders. Training of a new breed of bio-informaticians will also be a major goal of this program.

We aim to get patients involved in speeding the cancer R&D process “from the bench to the bed and back again” and to get them to work with us to close the gaps within that same project chain. They are the patients, they are the beneficiaries and they should demand a sooner and better outcome of cancer R&D.

This objective focuses on an interconnected network of open source biobank to support projects with state of the art stratification of patients. The projects within this objective should enable open sharing and mining of data. Additionally, patients should be encouraged to participate in the process of sharing their data, and initiatives should consider topics such as patient consent and incentives to participate.

Projects will include (but are not limited to):

- The integration of the biobank material consisting of biological specimen collected under program 2 in existing international bio banking initiatives.
- The development of an open access database of data sets in the public domain having a variety of omics data, where possible linked to disease outcome.
- International exchange between key cancer centers of trainees in data mining of large omics data sets.
- Coordination of clinical and genomics data platforms used in industry and for clinical care.

### **4) Reducing the incidence of cancer**

The incidence of cancer is biologically anchored, but is also a function of societal facets such as lifestyle, aging, persistence of unhealthy habits such as smoking, et cetera. Cancer is also a societal problem that requires a systemic outlook.

This objective requires a bottom up approach, with a focus on the experience, activities and values of actual people to increase personal control over the disease in its more chronic forms, and fostering a problem-solving attitude. Considerations for lowering the costs of treatment and prevention programs that reduce onset and incidence of cancer are important. This is similar to the tiered costing models used in vaccination programs in low-income regions, where vaccines are provided at a cost that is affordable depending on the income of each country.

Projects will include (but are not limited to):

- Health education
- Low-cost approaches with wide reach
- Fostering the mentality of the trial

We will promote projects in which we work on growing health literacy among youngsters, so they will make more informed and better judgments and decisions about their health life style and practices

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## **5) Execution of plans for changes and improvements**

The expression 'execute what we already know' was used by David Lane to give voice to his discomfort about the fact that we treat or withhold treatment, while the information is or can be available to come to better decisions regarding a treatment. This objective is deliberately activist in nature. Very importantly, this part of the program can (but need not) take place with no budget. All that it may require is keen knowledge on what can be done better anyway, and to activate the will of the people to get it done.

This objective focuses on identifying the knowledge gaps, determining how this knowledge will benefit the patient, and setting up permanent trials in which the gap between new insights regarding treatments and application of the knowledge is increasingly shortened.

Projects will include (but are not limited to):

- Improving the patient-doctor interaction, with an eye on applying the most up-to-date treatment information.
- Breaking open protocols, which are known to lead to sub-optimal treatments.
- Justifying the cases in which more personalized treatment benefit the patient, even when this means a breach of accepted standards.
- Empowering the doctor and the patient to act with more confidence based on heuristics and relevant information at the time of planning and executing a treatment.

## **Governance**

For the governance of all activities of Inspire2Live we refer to the website:

<http://inspire2live.org/about-inspire2live/board-members/>

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