



## Prospectus Inspire2Live-World Campus

### Global operational rules, founding and federation principles

#### Who we are

The World Campus is the global arm of Inspire2Live. It is led by patient advocates and scholar activists. It is joined by scientists, doctors, nurses and educators. Its roots lie in the biggest funding event ever to happen in The Netherlands, Alpe d'HuZes.

Unlike Alpe d'HuZes and its partner the Dutch Cancer Society, Inspire2Live is a global organisation; its seeds have blown over national borders and intercontinental boundaries. It has broadened its constituency to all parts of the world. Its roots lie in Latin America, North America, Asia, Australia, Africa, The Middle East and Europe.

The World Campus is the collective name for the network of representatives. Each representative is called a *hub*. Being a hub means being an active member of the World Campus.

The singular purpose of all hubs is to *improve control over cancer*. The World Campus is the closest link between scientists who study cancer, doctors, and nurses who treat and take care of people with cancer, educators and the patient.

The prospectus is not a descriptive text; it is a *declaration*, acting on behalf of Inspire2Live and whoever joins the World Campus. The two parties subscribe to a responsibility, to which they are firmly committed. The building block of this relationship is one of *reciprocity*.

We are committed to the coverage and stimulation of three areas of patient interests:

- Prevention (primary, secondary and tertiary).
- Performance (e.g rehabilitation, support for travel and lodging for patients, return to work, et cetera).
- Pain and care.

More pragmatically stated, we are committed to improving prevention and quality of life, but any urgent call from patients to invest in treatment will be taken seriously.

#### Why Inspire2Live?

When we write "we", from here we refer to the World Campus and whoever reciprocates with the World Campus.

Cancer knows no boundaries. Finding better practices for prevention, diagnosis, treatment, after care and support should never limit itself to region or country. By pooling the knowledge of patient advocates and collaborators (scientists, doctors, nurses, educators) from all over the world, through joint actions and speaking with one voice, we strive to improve the creation and access to better practices, diagnostics, treatments, after care and support.

The search for improvement is led by patient advocates, by scholar activists and is governed by a procedure central to scientific practice. We adopt peer review as the mechanism for self-correction. Importantly, we explicitly recognise (when necessary loud and clear) that patients have considerable understanding of the progression of their diseases or the side effects of treatments. Our conception of cancer is informed by cancer biology. Cancer is a disease generated through genetic susceptibility (e.g.,

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breast cancers in identical twins reveal genetic susceptibility, which may even represent half of the factors governing disease incidence); it is a disease rooted in the life histories of people; a third major factor besides genetic susceptibility and life history is bad luck. Bad luck means there are many random factors that play a major role, and we have no idea how to control them. But we can ameliorate the effects.

Cancer is many diseases, not one. It is life unhinged, so to speak. Cancer will not disappear in the foreseeable future, nor will the collective human effort to get cancer under control ever stop. It is our *raison d'être* to concentrate and speed up the best research, the learning and the adoption of new ways of working.

## The problems we confront

We step in where others cannot or lack the means to reach out beyond their social, professional or personal boundaries. We reach out at all levels: through community development, science, politics and governance. We reach out beyond boundaries: that is we wish to move beyond existing procedures, to search for, find and initiate new pathways. Naturally, we strive for the achievements to find their way to people who will benefit.

The problems we confront are mostly problems of cooperation and coordination.

We address these problems by connecting individuals and groups, building coalitions, acting as middle-man, speaking as one voice for many, educating, setting up meetings, lobbying, inspiring, organising exchanges between patient advocates, scientists, caretakers, technicians and a great deal more. Our self-defining event is the Annual Congress, which as rule happens on the premises of the Royal Academy of Arts and Sciences in Amsterdam.

We are acting locally and we are connected globally. It is crucial to avoid partisan involvement in any national or international conflict. This would undermine our mission to empower patients and to improve control over cancer. We adopt the first five of [the principles of the International Red Cross](#):

## Our achievements

Inspire2Live has grown since 2010 into a stable, warm, strategically autonomous organisation. Looking back, we can discern at least four ways in which the patient advocacy group has made its mark:

- **Community development:** Inspire2Live expanded from a European-North American-Dutch initiative to a World Campus, encompassing more than 20 nations all over the world, in Asia, Africa, Europe, North and Latin America, and the Middle East .
- **Science impact:** Inspire2Live has boosted the development of organoids for cancer research in institutions such as the Hubrecht Institute (Utrecht), Cold Spring Harbour Laboratories (New York) and Memorial Sloan Kettering Cancer Centre (also New York).
- **Political influence:** The Dutch parliament was successfully influenced to vote for DNA sequencing as the standard for metastasised cancer patients. At the EU level I2L was invited to host a session on the pricing of drugs. Currently I2L leads an international effort to escalate a trial against the Tobacco Industry. Inspire2Live brought the legal possibility of magisterial preparation to the awareness of the Dutch and European parliament and the academic hospitals.
- **Institution building and governance:** Inspire2Live is a legal entity, firmly supported by the Central Bank of The Netherlands, by the Dutch Royal Academy of Arts and Sciences, by Health Insurance companies, officials, entrepreneurs and many inspired individuals, patients, doctors, nurses and educators. The World Campus is establishing an alliance and working relationship with the World Health Organisation (IARC).

Please read more about our [Inspire2Live World Campus Vision](#)

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## How we operate

Inspire2Live respects evidence and empirical rigor. However we are a patient organisation, not a scientific endeavour. Importantly, as rule we adopt the peer review procedure as the most suitable means to judge the quality of our opinion documents (e.g., regarding vaccination and cancer), manifests (e.g., regarding pain management for pancreatic cancer patients), projects and initiatives. The World Campus is itself a peer reviewed initiative. The review is inclusive yet specific. The essence is independent commentary by equals, and a match between competence and the content to be reviewed.

Two aspects of the peer review stand out:

1. The peer review is fully **transparent**. Thus, reviewers are asked to do their work openly.
2. The peer review is **engaged**. Thus, reviewers are not only asked to comment but also to offer solutions or guidance.

## Self-correction

Science is self-correcting because scientists have a culture of mutual correction and use mechanisms to correct one other. Hence, we have adopted the mechanism of peer review to enable active and focused self-correction by an inclusive group of peers: along with scientists, we include relevant experts and patient advocates in the review. In the World Campus, roles, experiences and expertises can overlap.

## Reciprocity and peers review

We risk being accused of rallying, but let us attempt to position ourselves in the grander scheme of things. Reciprocity & peer review reflect one of the core values of democracy: fraternity and solidarity. Fraternity and solidarity imply a procedure for self-correction. The peer review is an inclusive procedure that furthers the improvement of quality.

Reviews are the rule, when:

- a major initiative is undertaken;
- an opinion document or manifest is being published;
- a project or collaboration is defined;
- a new principle of operation (such as the peer review) is installed.

Two comments:

1. We do not profess that Inspire2Live will be a reviewer of research reports of preclinical or clinical research. The peer review undertaken by the members of I2L should be specific, focused on a match between area of expertise and content domain. We are aware that it is rare that patient advocates have the scientific expertise to comment in a truly competent way on the details of research. In addition, we must be cautious to participate in peer review panels that function merely as window dressing: as a means to give the impression that the patients' opinion is being heard, but actually their presence on the peer review panels does not improve the quality of the review.
2. However, and to the contrary, we do believe that the procedure of science (peer review) and the opinion of scientists and experts from "outside" should be imported into our organisation, to guide and direct the internal functioning of Inspire2Live and the World Campus: hence our continuous effort to include scholar activists in the World Campus.

## Membership rights of the World Campus

Every member has the right to lobby for a peer review. What we say is that a peer review is required if an initiative is undertaken or individual is seeking publicity on behalf of the World Campus.

Peer review is focused on three categories:

- Publications, both internal (on the website) and external (articles, papers, educational materials).

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- Initiatives that have a lasting impact on the structure of Inspire2Live (e.g. the World Campus).
- Systematic collaboration with other organisations (e.g. the World Health Organisation).

### **Operational embedding**

The chair initiates or is requested to initiate a peer review. In case of major publications or initiatives, the chair will seek advice from Bob Weinberg, Laura van't Veer, David Lane, Jan Hoeijmakers and Olufunmilayo Olopade. Depending on the objective of the review, chair and advisers may select and approach specialised reviewers. Reviews should be concise, open and engaged. We expect the reviews to require 1 to max 5 participants.

### **How we expand**

Mid 2020 Inspire2Live has started creating the World Campus. Inspire2Live sets up hubs in all continents. It follows some rules ground rules regarding the selection of people who will act as hub representatives in new locations.

- Find Patient advocates who have been affiliated with Inspire2Live for a number of years.
- Find Patient advocates through a trusted third party (for example a scientist who is affiliated with Inspire2Live).

The nature of the relationship between hubs is reciprocal. Transactions are of course habitual, but the basis is one of trust and having a common objective: getting cancer under control.

Unlike units in a business, the hubs are loosely connected; there is no franchise-type relationship. This creates huge freedom and potential though it also poses a challenge regarding the maintenance and improvement of quality. Hence all who join Inspire2Live are, without exception, accepting and adopting, in spirit and in word, the principles formulated in the prospectus and the [Foundation Principles](#) and [Federation principles](#) of Inspire2Live.

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