



The Global Future of Inspire2Live

Consultation of scholar activists

“Sapere Aude” (dare to know)

I. Kant

Note 1: Shortly after Inspire2Live's (I2L) 2020 Annual Congress in January, a brief reflection was written about the future of I2L. It concluded with two recommendations: (1) Focus on widening our global representation and (2) pay more attention to agency, epidemiology and demography.

Note 2: “[One development] will ultimately prove critical to the success of any expansion of I2L: What important cancer-related functions/activities/programs/institutions are missing in countries and places that create a vacuum, that I2L could (help to) fill? There should be glaring shortfalls in the presence of various types of institutions that are holding back the improvement of patient care in one or another country. I2L could come in and help to create institutions that fulfil cancer-related functions, woefully absent in that country, doing so in a “home-grown” manner, i.e., not imposing neo-colonial mentality that says “here is what we’ve succeeded in the NL to do” but instead “how could you respond to the challenges that exist in your country, given the various identified shortfalls”.

Bob Weinberg

I2L convenes leading experts from a wide range of disciplines, we listen carefully to each scientist-leader; we integrate all of perspectives and potential solutions; we **educate**: the experts regarding the patient-perspective, other patients and their care partners, providers, health systems, regulators, policy makers and government officials, and the public at large.

Setting

On June 5th 2020, I2L organised a tele-consultation session. The objective of the session was to consult four leading scientists about the global future of I2L. I2L is committed to expanding its presence among patients and researchers all over the world.

June 26th the four science activists are asked to reflect in the first version of the report and also to respond to the planning of the global expansion so far. The reflection is summarised in the Appendix.

The COV-19 pandemic is the backdrop of this thoughtful and action-oriented exchange. **What should we (members of I2L) DO?**

Cancer patients are a demography that is hit particularly hard by the coronavirus. The wounds that are inflicted vary markedly in severity when we also take into account intersections with other factors, such as where you happen to be borne, live and grow up, your gender, your dietary habits, whether you smoke or not, your work, the colour of your skin, the country you live in, your postal code, your age, your habitat, your genes.

Information about the nature of the virus, its impact and the human response is reaching us in bursts: from Asian, African and European countries, Northern America, Southern America, Australia, New Zealand. The global perspective is practically forced upon us.

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Concurrent with confronting the impact of the coronavirus on oncology patients, we must also adapt I2L efforts to improve the availability and effectiveness of cancer therapies in competition with Covid-19-only patients, who by the nature of the pandemic have impacted and stressed countries healthcare systems to the extreme. In this environment, I2L must also strive to ensure that oncology patients can continue to have access to life saving care they require.

This is I2L's first move to come to purposeful action on a global scale. We seek the strengthening of **reciprocal** relationships with scholar activists and patient advocates from all continents.

Present: Scholar activists: Bob Weinberg (Boston, MIT), David Lane (Singapore, A*Star), Laura van 't Veer (San Francisco, UCSF), Jan Hoeijmakers (Rotterdam, ErasmusMC). Patient advocates: Peter Kapitein (Amsterdam, DNB), Ilona Schelle (Amsterdam, DNB) Jeff Waldron (Boston, Sherborn Consulting), Jan Gerrit Schuurman (Berlin, Max Planck Institute for Human Development).

Chair: Jan Gerrit Schuurman is the chair of the meeting.

Introduction

In 2011 the first I2L Annual Congress took place on the premisses of the Dutch Royal Academy of Arts and Sciences (in the historic Trippenhuus building) situated in Amsterdam. It was supported by the Central Bank of The Netherlands.

At the time, the first invited speaker was Bob Weinberg, who warned specifically his fellow-scientists of a Titanic disaster. His point was simple, if couched in dramatic language. Cancer is a very complex disease, nowhere are we close to crack its code (assuming it can be understood as a code to be cracked), cancer is a moving target and unless we manage to reduce the financial burden of the disease, we are bound to leave many people untreated, not cared for, neglected.

Alluding to Weinberg's dramatic outlook, in 2020 Cancer hits an iceberg called Corona. Not in a few unfortunate countries, not on one continent, but all over the world.

I2L wants to create many hubs similar to the I2L organisation, all over the world, that share our wish to make this world a better place.

Prominent achievements of I2L

Inspire2Live has grown since 2010 into a stable, warm, focused organisation.

In retrospect we can discern at least four ways in which the patient advocacy group made its mark.

Community development: I2L has become the action-centre of a group of dedicated patient advocates, medical researchers and doctors, scientist, ex-politicians, entrepreneurs and (ex)government and bank officials. This network is international. Each year a large fraction of the community meets at the annual congress in Amsterdam. The meetings are always a mix of science and patient experiences, emotion and reason, sadness about the loss of loved ones and vital energy, anger and remorse.

Science impact: I2L has a keen eye for scientific research, state of the art and on the edge treatments and new research techniques. Often the interest is intensely personal: we wish to help one particular patient—but always with the next step in mind: what is necessary to get this personal treatment/care to all patients? Sometimes its impact goes much further. This was the case with the use of organoids for cancer research. I2L successfully pushed organoids onto the bench of many cancer research labs: Cold Spring Harbour Lab, MSKCC, Sanger, to name just three. The Dutch lead researcher Hans Clevers was challenged by I2L to share his ideas, to speed up the transfer of his knowledge and competences. A

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more recent example is fasting. Jan Hoeijmakers uncovered the biological mechanisms that fasting engenders. Laura van 't Veer has adopted fasting as part of the UCSF breast cancer trials.

Political influence: I2L has lead several lobbying efforts. The Dutch parliament was successfully influenced to vote for DNA sequencing as the normal 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.

Institutional embedding: It is hard to say what developmental routes sister hubs will take. But let I2L be exemplary. Its life history is instructive. Leaving many details aside, I2L was created by and attracted cancer patients. It included the participation of scientists and doctors. We are an inclusive organisation, not concerned with just one cancer. I2L had the fortune to be supported by the Central Bank of The Netherlands, by the Royal Academy of Arts and Sciences, by Health Insurance companies, entrepreneurs and many individuals. But the support was always reciprocal. A vital governance structure emerged. Its governance structure and its membership structure is the backbone of an organisation that is ready to expand.

We do not know in advance to what extent achievements similar to ours will be relevant to other people and places. But we contend that by seeking reciprocal relationships with people like us from a variety of cultural backgrounds we can and will strengthen each other. In effect, it is our ambition to initiate a patient organisation that can act on the level of national institutions and government, EU, UN and WHO.

Paraphrasing Thomas Friedman in a recent op-ed in the New York Times: "Out of many, [acting as] we."

Consultation

The consultation was set up as follows. The chair coordinated the discussion. Peter, Ilona and Jeff listened and made notes. The discussants were informed about the aim of the meeting. Each took turns and a lively exchange followed. Discussion took place right after and in the weeks following the meeting.

The aim of I2L is to derive from the consultation information pertinent to what it wants to do. The summary will therefore focus on action sentences. Daring to know means daring to act. It also means daring to focus.

Bob Weinberg was our first interlocutor.

Bob addresses I2L by speaking to us directly, as "you". He wants us to be **cautious**. Do things step-by-step and not taking too big steps at once. He wants us to think of the **profile** of people and organisations that we would want to hook up with. We should ask ourselves what we think "they" can learn from us and what we can learn from "them".

David Lane responds to Bob. He does not suggest caution, but makes us aware of some critical differences between people and places. A good example he mentions is the financing of healthcare. Europe, the US and many Asian countries have completely different ways of financing healthcare. But he believes we should focus on that which other organisations such as CRUK or NIH have not done, or due to their focus on funding have failed to do. He wants us to talk to CRUK officials. What would they wish to do but has been neglected? David also encourages us to speak to people of his lab. I2L might be able to create the **infrastructure** for (inter)national cooperation and set up networks that may have political influence locally and globally.

Laura Van't Veer suggests that we should listen to Sue Desmond-Hellman, the former CEO of the Bill and Melinda Gates Foundation, who said: "We failed on races and cultures." In one word: focus on **equitability**. That is a strong imperative. We need to pick up on inequality. Covid-19 is hitting people of colour with extra force. Add to the prevalence of cancer the disastrous inequality and the impact of a pandemic on top. Laura does not leave it there and sees an opportunity for the hubs in this respect: focus on the right **organisation levels**: EU, UN(ENSCO), WHO.

Being the last in the series of consultations, Jan Hoeijmakers makes an effort to summarise the points made by Bob, David and Laura. He stresses that **I2L can do things that "we" (the scientists) cannot**

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do. Work with people and organisations with the right mindset and skills. Create strong voices. Find your strength there and explore it with the hubs you help to create. He is a promotor of the idea to let scholar activists and patient advocates work together. By way of example he reports his own research on **fasting**. Fasting is a relatively simple intervention but has huge impact on the benefit and harm done by many cancer treatments, in particular chemotherapy. The effect of fasting is now well understood and the biological mechanism of impact on treatment is universal. Hubs could benefit the spread of this kind of knowledge.

Discussion

The discussion took place, during the video conference and a week later in Amsterdam between Ilona, Peter and Jan Gerrit, of course respecting the rules of social distancing.

We heard words of caution and encouragement.

We are aware that the encounters with new people will broaden our outlook, but will also oblige us to seek focus. We want to be open to new venues, learn, further our focus: to broaden and enrich our community, searching for good science and practices, educate and confront politicians, influence decision making.

We see two levels of exchange and impact.

First, we want to meet our equals and just sit down with them and discuss what we share, what makes us different and binds us together, what our experiences are. This should be a blend of informal exchange and structured meetings with patient advocates, doctors and scientists. The annual congress is a perfect spot to convene and organise for example demand-driven crash courses. Over time video conferencing is an valuable way to further and deepen collaboration.

It will be crucial to strive for reciprocity. Reciprocity is the building block of the cooperation between hubs, between members and drives the interaction with others.

Second, we hope to create a powerful action-centre that is capable and respected. We do not mean "centre" as one location, but as the combined strength of a crowd or **swarm**: WE are the centre! We as a network of hubs should be willing and able to organise outreach: to individuals in need of support and to institutions at the level of the European Union, the United Nations (UNESCO in particular because of our focus on education), the World Health Organisation.

Conclusion

I2L is a warm organisation. We have found a metaphor to express what that means in particular. We do not wish to be driven by extremities of cold reason or hot emotion; we are as much driven by emotion as by reason. Sure, there is tension between the two, but no opposition.

This is our metaphor: **we serve cappuccino**, which is a blend of milk and coffee but is neither milk, nor coffee. Likewise, we will always aim at a delicate melange of emotion and reason. Neither too hot nor too cold, but always **warm**.

Steps

The following steps will be taken:

1. We will organise the follow-up meeting. Later occasional meetings with Bob, David, Laura and Jan Hoeijmakers may be called for, but also other scholar activists, depending on the subject matter, may be approached.
2. I2L will organise a team (of PA's) that will meet on a regular basis. In time the team will be extended. The team will split up in subgroups of 2/3 actors. Each actor group will take on the creation of a hub: in Asia, the Americas, Africa, the Middle East and Australia. The team will figure out practices to reach out, enhance exchange of experiences, share failures and successes.

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3. The February 2021 Annual Congress at the Royal Academy in Amsterdam will be the first occasion to meet in a fully open environment. If Corona allows it, we will meet face-to-face. Of course, this is a gathering of patients, scientists, doctors and others. We serve cappuccino!
4. In September 2021, we will convene again in group meeting with a loosely organised set of focused workshops. By then it should be clearer what topics come up and we want to share within and between the hubs. Again, it is important to stress that we see the workshops as a cementing of the reciprocal relationships between hubs. If so required we will organise crash courses, invite experts and kick start a critical development.

Jan Gerrit Schuurman will be the chair of the Inspire2Live hubs throughout.

Appendix I

Friday June 26th we meet again.

Present: Bob Weinberg (Boston, MIT), Jan Hoeijmakers (Rotterdam, ErasmusMC), Peter Kapitein (Amsterdam, DNB), Ilona Schelle (Amsterdam, DNB) Jeff Waldron (Boston, Sherborn Consulting), Jan Gerrit Schuurman (Berlin, Max Planck Institute for Human Development).

Absent: Laura van 't Veer, David Lane.

Chair: Jan Gerrit Schuurman

Update

Peter Kapitein provides an update of our global initiative.

- I2L has started Hub talks with Brazil. PA's Piarella and Maria are the representatives from I2L. We have so far contact with Carlos Mencks (SA) and Marcos Santos (PA).
- I2L has started Hub talks with Africa. Kwasi Boahene from PharmAccess is our contact.
- I2L is planning to start Hub talks with people from the Middle East—Saudi Arabia. Contact person is Brian Meyer.
- Talks are planned with Singapore.
- Talks are planned with New England (Boston) and California (San Francisco).

Because of Corona travel is severely restricted. Digital contact will be crucial.

Comments

1. Bob and Jan Warn against contacts with countries in the Middle East. The reason is primarily the following: Middle East countries are overall flush with money and the leaders and their ilk do not work. In other words, the native people are not used to act themselves, but rely on others to do the job for them. Strongly recommended not to take this venue.
2. As an alternative both Bob and Jan endorse Turkey.
3. Bob and Jan endorse Africa, in particular Kenia, Tanzania, Ghana and South Africa. Brazil (with Carlos Mencks, a scholar activist who we got to know through Jan) is a good place to start in Latin America.

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Four topics to discuss are brought in by the chair:

- Comments on draft earlier consultation session.
 - Reflection on topics for the next annual conference: agency, epidemiology and demography
 - What crash course would you want to give a group of patients—you get 2x2 hours?
 - Extreme agency: can patients be cancer hackers?
1. The report is considered correct and accords with the spirit of the June 5th consultation.
 2. Bob asserts that agency is an underestimated factor in cancer: he claims **that 60%-70% percent of the cancers are preventable through agency alone**. Those are staggering numbers. Jan endorses these numbers. Bob expresses his wish to bring the topic of epidemiology into focus, it is often ill understood. For example the relationship between incidence and mortality. He considers demography a consequence of epidemiology. Jan agrees with Bob's comment. Epidemiology is the instrument, demography is the output. Jan asserts that cancer is related to different societal circumstances. It is good to have a global perspective on this. Also in COVID19 there are many comparisons to be made across communities, countries and continents.
 3. Both Bob and Jan see crash courses as a tool for education. Bob would focus in his crash course on how cancer develops ontogenically (in the course of a lifespan), how it can be influenced through agency in the lifespan, and how this relates to cancer supposedly being an inevitable consequence of human nature and circumstance. Jan would focus on nutrition, and he would focus in particular on nutritional effects on onset and treatments, dietary restrictions and of course agency.
 4. The final point triggers controversy. The point is made by both Bob and Jan that despite the limitations of the oncologists and haematologists, huge restraint is mandatory with regards to letting patients become cancer hackers. We are pressed to be very clear what we mean by cancer hackers. **What does a hacker do exactly and within what jurisdiction does he or she act?**

When the meeting is closed, Jeff, Ilona, Peter and Jan Gerrit discuss some of the issues that were covered.

- Jeff suggests we contact Marian Neutra in Boston. Jeff will inquire, no commitments made yet.
- Peter and Ilona will further their contacts in Africa through Kwasi
- We agree Turkey is a good alternative to Saudi Arabia.
- Jan Gerrit and Peter will push hard to visit Singapore in 2020.

Appendix II

Recommendations I2L-Global

As Chair I take the liberty to formulate the following recommendations:

- Concentrate on **Agency and Epidemiology** in our 2021 Annual Congress. Reason is that (a) 60-70% of the cancers are unnecessary, (b) however the drivers of the majority of cancers (i.e. the drivers of the epidemiology of cancers) is hardly part of subsidised cancer research.

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- Create **Hubs** on all continents, based on **reciprocal relationships** with I2L-NL, and ultimately between all hubs. Consequently each Hub is surrounded by other Hubs, just like the nave is surrounded and held in place by the spokes in a wheel.
- Speed up learning through **crash courses**, to which patient advocates and scholar scientists contribute and are participants. Make the crash courses available on line.
- Select and post **lectures** in a way that makes the lessons to be learned transparent.
- Make I2L and **opinion leader** and a vehicle for **education**: for science, politics, community development and governance.

Regarding our opinion leadership, I propose we take a closer look at cancer as a disease of the **anthropocene**. It goes without saying that this involves educating ourselves.

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