



"The whole business case from the patients view"

The Inspire2Live 2017 Annual congress

February 1st, 2017

Purpose of the congress

In creating breakthroughs that matter for patients, we have to think out of the box. This involves linking unexpected stakeholders and issues, putting problems upside down, be unreasonably positive, increasing fuzziness to become receptive to new insights, and sensing into wisdom instead of into knowledge. It seems that many promising new avenues are blocked by quite narrowly-framed economic feasibility. This 2017 Annual wants to develop a new view on the cancer health economy and will find solutions to overcome these obstacles posed by thinking in economic feasibility of new treatments and where quite a few elements are not taken into consideration. Partly they should be taken into consideration because it are hard economic benefits (for example, we forget the costs associated with side effects that are caused by a new treatment) and partly because the quality of life benefits are not included. What to think, for example, of reduced hospital stays and faster recovery? This has economic benefits, but also great benefits of quality of life. The omission of these elements leads to perverse outcomes and a sub-optimization of the cancer care. Promising new roads will be blocked. Naturally this leads us towards an inspiring program in which examples from other domains are presented in order to achieve this renewal in health care.

The NDSM-wharf as a metaphor

Twenty years ago, the NDSM wharf was a derelict industrial area, home of Amsterdam shipmaking enterprises. It had lost its function and economic logic. It became increasingly abandoned, a kind of no-go area within a district of the city of Amsterdam that in itself also was a no-go area; Amsterdam-Noord. Compared to cultural, social and economic hotspot Amsterdam south of the river Y, the NDSM-wharf was a completely forgotten and irrelevant place. Artists discovered these fragile and lawless areas. Slowly, an informal process of revitalization emerged. Cultural festivals were organized. And over the years, the NDSM-wharf (and with it Amsterdam-Noord) began to be rediscovered. Municipality recognized the incumbent potential and invested a bit in 'place-making' by attracting a mix of entrepreneurs, artists and the like and the postponement of regulations to the use of the area. The reputation of the area grew, and at present it is more of a magnet for creative and innovative start-ups than a burden to the city. It represents economic value in itself.

Cancer is what the NDSM-wharf once was: a problem and a burden. Patients are what the NDSM-wharf once was: irrelevant. The story of NDSM shows us that by giving room to creative out-of-the-box thinking and practice, both cancer and patients can be converted into sources of innovation and inspiration.

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Wednesday, February 1, 2017

Location: 'Restaurant Brooklyn', NDSM Wharf, NDSM-Plein 30, 1033 WB, Amsterdam
If you take the Ferry take the one to NDSM Werf.

18.00 – 19.00 Drinks

Welcome speech by Inspire2Live Patient Advocate Ilona Schelle

19.00 – 21.30 Welcome dinner

Thursday, February 2, 2017

Location: 'Under Current', NDSM Wharf, Papaverweg 265, 1032 KE Amsterdam
If you take the Ferry take the one to NDSM Werf.

Timeslots are including Q&A.

09.00 - 09.30 Registration with coffee and tea

09.30 - 9.45 Welcome by the Conference Chairs Piarella Peralta (Inspire2Live) &
Carin Uyl-De Groot (Erasmus University)

9.45 – 10.00 NDSM Wharf: part of Healthy City Amsterdam Diederik Samsom (Dutch politician)

10.00 - 10.30 How to create new business models in health care? Eriijn Sie (Ashoka)

10.30 - 11.00 Break.

11.00 - 11.30 How to get to a science agenda that's relevant for patients? Aled Edwards (University of Toronto)

11.30 – 12.00 To prevent is more cost effective than to cure: challenges in the case of prostate cancer Chris Bangma (Erasmus MC) &
Gaston Remmers (Inspire2Live)

12.00 – 12.30 Cancer and work - how to foster these assets Bert Kersten (Nyenrode University)

12.30 – 13.30 Lunch.

Group A A new business model in health care Simone Pourier (Ashoka) &
Jan Vesseur (Inspire2Live)

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Group B	How to get to a science agenda that's relevant for patients	Aled Edwards, Mark Lawler (Queens University Belfast), Jolanda van Rooijen (Inspire2Live)
Group C	To prevent is more cost-effective than to cure: challenges in the case of prostate cancer	Chris Bangma, Barbara Moss (inspire2Live) & Gaston Remmers
Group D	Cancer and work - how to foster these assets?	Bert Kersten, Jorien Dijk (WuWei4Life) Sabine Wernars (Inspire2Live) & Saskia Koopmans (Inspire2Live)
16.30 – 17.30	Presentations of the plan of actions by the groups	
17.30	Walk to restaurant ' Bistro Noord ', NDSM Wharf, Amsterdam, 1033 RG, Mt. Ondinaweg 32	
17:45	Drinks.	
18.30 – 21.30	Dinner	
	Starting with a dinner speech on Disruption in health care by Jelle Barentsz, University Medical Centre of Nijmegen, one of the Dancing Doctors	
	During dinner we will have a performance of the Sága kwartet. 4 Master students from the Tilburg Conservatory	

Friday, February 3 2017

Location: 'Under Current', NDSM Wharf, Papaverweg 265, 1032 KE Amsterdam
If you take the Ferry take the one to NDSM Werf.

Timeslots are including Q&A.

08.15 - 08.45	Registration with coffee and tea	
08.45 - 09.00	Welcome by the Conference Chairs	Piarella Peralta & Carin Uyl-De Groot
09.00 – 09.30	How much data do you want to share?	Peter Kapitein (Inspire2Live)
09.30 - 10.00	Is there a benefit of screening?	Wolfgang Gaissmaier (Konstanz University)

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10.00 – 11.00 How to realize 'Affordable drugs' (panel discussion) Chair and introduction by Lou Garrison (University of Washington, Seattle)

The price of drugs does not reflect the costs. Pharmaceutical companies seem to ask what they want. What are the barriers to bring the price of drugs to an affordable level? Inspire2Live thinks that the biggest barrier in the discussion about drugs prices is the Medical Industrial Complex that simply doesn't want to lower the prices of drugs because it means big money for some stakeholders. A lively and good panel discussion brings the answers.

In the panel Marcel van Raaij (Ministry of health), Huig Schipper (Inspire2Live), Susan Noyon (Achmea), Ad Antonissen (Astra Zeneca), Casper van Eijck (Erasmus MC)

11.00 – 11.30 Break

11.30 – 12.00 Personal Data Economy – a cooperative approach Ernst Hafen, ETH – Zürich

12.00 - 12.30 Your data – my health Marion Koopman, Greenhouse

12.30 - 13.00 Lunch

13.00 – 16.00 Personal Data Economy – 3 working sessions

Medical research is based on personal data. In the end, all of these data belong to the individual; individuals consent to their use in research through informed consent procedures. Yet, the exchange of data between institutions is difficult, double or triple use of the data is difficult through the need of repetitive informed consent, etc. The result is that research is slowed down and becomes more costly, and that citizens don't feel the power their data represent. Can we think of organizational models that re-empower citizens and patients, and that speed up research? What is their governance, what is their business case?

Group A The economics of screening Wolfgang Gaissmaier & Bert van Herk (Inspire2Live)

Group B, C & D Personal Data Economy – moving the Dutch case(s) forward (Dutch Foundation *My Data Our Health*, and several cases: Mysmallstep, Rotterdam Health Café, Diabetes..)

Ernst Hafen, Gaston Remmers (I2L), Ronald Hamaker (Inspire2Live) & Coen van Veenendaal (Inspire2Live)

16.00 – 16.30 Presentations of the plan of actions by the groups

16.30 – 17.00 Reflections on the past two days A patient, a researcher and a clinician

17.00 End of the conference.

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