



"The countless small deeds of the unknown people "

The Inspire2Live 2018 Annual congress

June 13th, 2017

'What matters are the countless small deeds of unknown people who laid the basis for the significant events in history. They are the ones who done it in the past and they have to do it in the future.'

(Noam Chomsky, American Philosopher).

Daily we see that healthcare is distracted from its essence: the patient. The change will come from the citizens and the patients: *'the countless small deeds of unknown people.'* Each and every one of the stakeholders is a citizen whose actions in the present will consequently reflect into our future. It is time that we not only look into ways on how to improve the practices in our own fields of health care, but also look into ways on how to influence it into a sustainable health fostering system that embraces universal access. Inspire2live departs from its traditional way of working where actions are taken up *after* the congress. By building momentum and engaging our multi-stakeholder, multi-generational and interdisciplinary partners into thinking and dreaming of ways in which we fundamentally shift from traditional frameworks and paradigms within cancer care into sustainable societies of health *before* the congress. As a way of going back to the beginning of 'Understanding Life' (also the name of the program of Inspire2Live to get cancer under control) and building upon life and health as a movement of the citizens and patients, we invite young academics with an experienced researcher to reflect on Inspire2live's assignment for the congress. They reflect and *combine their beginners mind with the experienced hands.*

There is a tendency in the public debate to point to 'our' responsibility to fulfill the goals regarding the approach to health and health care in our societies. This year we introduce an important term when discussing issues regarding our approach to health: *'agency'*. The need to switch this view is to depart from archaic, traditional ways of approaching health and health care in all of its dimensions from the initial stage of research and developing treatments to policy making and implementation. It is important to depart from a static responsibility to a more dynamic approach in which we; the citizens and patients have the possibility to exercise our right to be engaged in all these processes that have such great impact in our daily lives.

As patient advocates we know that data holds the key into shifting not only our health practices but also into bringing back a symmetric relationship in health care. This data-topic is thus at the base of the different stages and dimensions of health care. Having individuals taking agency over their data is a more accurate way to conceive this future in health care and which goes beyond any duty or responsibility outside of the individual and points to a more dynamic approach to a fair system in health care: *'The patient will see you now'*. Making the shift in this realization may create greater possibility into building societies of health. Inspire2live feels it is important to bring explicitness to this concept, as it is a movement what we are referring to when we speak of *"the countless small deeds of unknown people"*

never ever quit!

Getting cancer under control and inspire people to lead Happy and Healthy lives in Harmony with cancer! • www.inspire2live.org



The assignment for the beginners mind and the experienced hands.

We have learned over the years that the actions and observations of patients and citizens are crucial. Their data are crucial. How can these be put to value for themselves and health care at large? And how should we do that? And in what new way can citizen-driven data generation be joined with new forms of data-governance, research and responsible business? With this in mind, at the occasion of the Inspire2Live congress we ask *beginners minds and experienced hands*, to reflect on the empowerment of the countless small deeds for the sake of the health system. In the India, Switzerland, the UK and the Netherlands. We've formulated these 3 questions:

- What practices do you see/dream/hope within your field of expertise and within your geographical area, as key examples of engaging the public on data, that impulse a movement that will create a shift from the current focus of disease into health societies?
- What new combinations of citizen-driven data generation, data governance, research and responsible business are emerging or needed?
- What are steps that can be taken, and by who, that will make these practices applicable, in a way that citizens and patients remain in the driver's seat?

They reflect in the months preceding the congress and present their findings in the interactive sessions.

The result

The unknown people will influence the stakeholders in healthcare:

- The citizen is inspired to stay healthy.
- We are determined to make our self healthy.
- The scientist creates a broad spectre, works with tons of data with which he can do endless research. The scientist is aware of the impact his work has on the quality of life of us and our loved ones.
- The doctor is listening and acting for us. The doctor is aware that he can only do a small part of what is necessary. The doctor evolves from god to guide and is aware that 'The patient will see her now'.
- The industry will only allow herself to make profit with products that benefit us.
- The health insurance company is in conversation with us and negotiate for us for the best treatments and the lowest costs.
- The government acts preventive and knows what to do. The government has guts and supports us.

Wednesday, February 7, 2017

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

18.00 – 19.00 Drinks

Welcome speech by Inspire2Live Patient Advocate Linda Burger

19.00 – 21.30 Welcome dinner

never ever quit!



Thursday, February 8, 2017

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

08.45 - 09.15	Registration with coffee and tea	
09.15 - 9.30	Welcome by the Conference Chairs	Piarella Peralta (Inspire2Live) & Ilona Schelle (Inspire2Live)
9.30 – 10.00	The need for doing the right thing for the common people by the common people	Mary Baker (PA Brain diseases)
10.00 – 10.30	Reducing Incidents and the common people – what should government do for them?	Erik Gerritsen (Secretary General Dutch ministry of health)
10.30 – 11.00	This is how you change society	Young one & Annemieke Roobeek (Nyenrode University) TBC
11.00 – 11.30	Coffee, tea and networking	
11.30 – 12.00	Why is data of the healthy people so important	Stephen Friend (Sage & Apple)
12.00 – 12.45	Rapid Fire Participants Talks	
	What happened in my organization? How did we realized this change and why? In speed presentations <u>of maximum 3 minutes</u> young and inspirational participants talk about their way of refurbishing the organization they are part of.	
	Bas Caron (TU Eindhoven) TBC , Nikkie Aarts (ErasmusMC) TBC , Tinke Wesseling (Accenture), Seun Adebisi (American Cancer Society), Fintech representative, Erik Teunissen (Dutch Central Bank), Coen van Veenendaal (Inspire2Live), Marta Fernandez (Fundacion Josep Carreras) TBC , Barbara Moss (Colon Cancer UK), Susan Gabriëls TBC , Tim van Veenendaal (TU Eindhoven), Patrick van de Mosselaer (Doctena) TBC	
12.45 – 13.30	Lunch.	
13.30 – 16.30	Group A, B, C and D have their breakout session in the city centre of Amsterdam.	
	Moderators:	Guan Schellekens (DNB), Ian Banks (vice President ECC), + 2 Inspire2Live patient advocates

never ever quit!

Getting cancer under control and inspire people to lead Happy and Healthy lives in Harmony with cancer! • www.inspire2live.org



17.00 – 21.00 We all come together at **The Van Gogh Museum, Museumplein 6, Amsterdam.**

At the Van Gogh Museum 4 short report backs of the activities and actions to be taken.

After that drinks and walking dinner, networking and visit of the museum.

Friday, February 9 2017

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

08.15 - 08.45	Registration with coffee and tea	
08.45 - 09.00	Welcome by the Conference Chairs	Piarella Peralta & Ilona Schelle
9.00 – 9.30	Data is a gift. Deal with it that way	Khadija Ferryman (Data & Society Research Institute)
9.30 – 10.00	How unknown people take agency over their data? (Introduction to the beginners mind sessions)	Gaston Remmers (Inspire2Live)
10.00 – 10.20	Beginners mind & experienced hand Neetisolutions	Parag Mankeekar (Neetisolutions) + beginners minds TBC
10.20 – 10.40	Beginners mind & experienced hand ETH	Ernst Hafen (ETH Zürich) + beginners minds
10.40 - 11.15	Coffee, tea and networking	
11.15 – 11.35	Beginners mind & experienced hand Univ. Glasgow	James N'Dow (Univ. of Aberdeen) + beginners minds
11.35 – 11.55	Beginners mind & experienced hand ErasmusMC	Jan Hoeijmakers & Dik van Gent (ErasmusMC) + beginners minds
11.55 - 13.00	Lunch	
13.00 – 16.00	Group A, B, C at work.	
16.00 – 16.30	Presentations of the plan of actions by the groups	
16.30 – 17.00	Reflections on the past two days	Ilona Schelle & Peter Kapitein
17.00	End of the conference.	

never ever quit!

Getting cancer under control and inspire people to lead Happy and Healthy lives in Harmony with cancer! • www.inspire2live.org