



The whole business case from the patients view

Annual Congress 2017
(February 1, 2 & 3)
Amsterdam - NDSM Wharf

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Working group: 'A new Business model in health care.

Minutes:

New business models have to be open, based on sharing, patents are not allowed and have to create a movement.

Vision: Live longer, with a better quality of life

Value proposition: Preventive coaching and qualitative oriented interventions

Stakeholders: The whole health ecosystem

Key activities: Lobby for legislation, creating awareness, training, financial incentives, tools for empowerment, network building, community involvement

Key resources: 1% revenues of tobacco industry (The Iceland model), subsidies from government

Key resistances: From the tobacco, food & alcohol industry and there will be scepticism from some citizens

Actions to be taken:

- Start a lobby for The Iceland model where tobacco industry revenue from government goes for several percent to prevention.

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Working group: ‘How to get to a science agenda that’s relevant for patients?’

Minutes:

- Science advances one funeral at a time (Max Planck).
- Science is at the moment multifaceted and mulilayered.
- Discussions about: Who is the patient? What is involvement? What is and who is determining (stakeholders) the Science agenda? Who can influence that?
- There is a lot of redundant research and industry is redundant as well and we can prove both.
- 60% of the ideas in science are wrong.
- 95% of the drugs that are developed fail in phase 2/3.
- The system works as a license to poison. We do trials with patients with molecules that are known (by industry) not to work.

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Action to be taken:

- Create public private partnerships
- Negative outcome in research needs to be published as well through an electronic lab book.
- Open access to science – open science cloud. This can be realized through the funding agencies (NHS, KWF, L'ARC)
- Regulatory affairs (EMA) works too tight. Patient advocates should not accept this and go into discussions with the EMA. That has never done before in a proper way and based on equality.
- Patient advocates should Influence data protection transparency regulation (**Initiative in progress**)
- Educating patient advocates (**Initiative in progress**)
- Influencing the national agenda 2020-2027 now by patient advocates
- Help to decrease bureaucracy

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Working group: 'Business models for food, lifestyle & prostate cancer (or any other disease)'

With increasing levels of evidence, more business models become possible; vice versa, working business models generate funds to facilitate research. Hence, the challenge is to develop both simultaneously, building services linked to real time monitoring of results. This demands an inquisitive attitude of both researchers, clinicians, insurers, entrepreneurs and patients / citizens at the same time.

**Business
Models**

**Levels of
evidence**

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Minutes:

- If an Asian moves to the Western world adopting a Western lifestyle, his chances of developing prostate cancer are the same as for someone who lived all his life in a Western country: 4 times higher! This provides a big scope for food and lifestyle approaches to prevent PCa with potentially enormous savings.
- Different target groups demand different approaches
 - Public health education can build on existing knowledge base; urgency driven patients facing a threat want to explore less well researched applications of food to health
 - Do not only talk about 'how to inspire citizens to adopt healthier lifestyles', but also invest in changing the habits and structures that impede clinicians to include food in their counseling / research
- 'Active Surveillance' in PCa was considered ridiculous 10 yrs ago, now it is widely accepted, due to patient pressure → food is in the same position today. So start implementing food in health, even when evidence is not conclusive. And keep record!
- Components of new businessmodels are available and need to be knit together: food producers, food distributors, dieticians, personalised diet, research to track results.
- Do we do it within polyclinic situation, or outside it, but empowered by polyclinic advice?

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Actions to be taken:

- Pilot project with ErasmusMC, Inspire2Live, Platform Patients and Food, and horticulturalists planned for 2017 in province of Flevoland (Almere) (**Initiative in progress**)
- Dick Jan Abbringh (Purpose) & Gaston Remmers (Inspire2Live) will meet to explore co-creative development of new economically viable approaches to food and Pca (**Initiative in progress**)
- Include food and lifestyle in the debate on concentration on Prostate Cancer care

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+ Cancer & Work

Creating awareness is the first key step

Employee

- Create a Cancer & Work community
 - knowledge sharing between companies
 - Cancer & Work ambassadors

- Create webinars & Youtube movies in the workplace

Employer

- New knowledge base for employers & employees / improve & market better those that exist (e.g. www.kankerarbeid.nl)

- Round Table for employers

- Build & present the business case for employers

- Write & publish in HR magazines

We will build a communications plan to increase awareness around
Cancer & Work (*Timo and Peter are taking the lead*)

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Working group: 'Is there a benefit from screening?'

Minutes:

- All screening programs do harm. Some also do good (sir Muir Gray).
- Solving a problem simply means representing it so as to make the solution simple (Herbert Simon).
- Government implements and citizens take part in a screening or not
- Education:
 - Role of emotions
 - Risk literacy
 - For governmental officials
 - For medical specialists
 - For citizens both children at school and grown ups
 - Ways to do it, interactive homepages, spoken information (youtube)
- More effective screening through;
 - Profiles. Genetics, personalized, lifestyle
 - Perhaps reconsider techniques that screen. Too many false pos/neg

Actions to be taken:

- Reconsider breast cancer screening and prostate cancer screening in cooperation with government (**Initiative in progress**)

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Panel discussion: 'How to realize affordable drugs?'

- Science: Global differential pricing is helpful but not the solution.
- Government: It's high on the agenda and we want to speed up the process.
- Industry: We do not sell the product. We sell the knowledge: clinical trials, research and so on. We want the prices flexible and representing the value for patients and society, access to the right patients and sustainable.
- Clinician: I had to wait for 18 months for a drug for my patient because it was in a trial. My patients with pancreatic cancer can't wait that long. Now they both are dead.
- Patients: Costs are not an issue for patients. Citizens want to pay the costs for health care. The costs are less than 6%).
- Health insurance: The value of hope is important. Patients should not have to defend themselves for the high prices if they use them.

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Audience:

Most research is done with public money.

Government: Yes it is possible to discuss this with us. We do not want to pay twice for the same knowledge / drug development. We're open for new models.

Audience: 60% of the costs are because of regulations.

Government: we have to reduce regulations but we don't think it will lower the prices.

Actions to be taken:

Inspire2Live works together with Cinderella therapeutics and is in discussion with all the stakeholders. (**Initiative in progress**)

The proposal is on three levels:

1. A maximum price set by ema for the whole of Europe.
2. Public funded trials (also called 'The Tesla model'. No patents at all.
3. Make intense use of generics and repositioning of drugs.

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Working group: 'Personal Data Economy – My Data Our Health'

Minutes:

- Two issues are singled out as crucial for the Personal Data Economy to work: **trust** and a **not-for-profit governance structure**.
- Based on those two premises, a big diversity of for-profit service providers may access the data, and a great number of innovative, Big and Small Data research and care possibilities might emerge.
- Several relevant projects, initiatives and business present at the Congres: My Small Step, www.patientendossier.nl, Mijn Data Onze Gezondheid, breast cancer app (OWise), EMA-app for microbiome condition etc
- The MiDATA proposal (www.midata.coop) as developed by Ernst Hafen and colleagues is a very inspiring and promising example of how the two premises might be tackled in one go.
- Bearing this in mind, the working session explored more in detail some of the emergent possibilities.

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Emergent possibilities:

- A wide variety of applications (apps) and ICT-service platforms become possible and existing ones would be strengthened when citizen and patient based data governance is secured:
 - Within and outside care and research institutions
 - Between research and care institutions
 - Between medical and paramedical institutions
 - Between individuals / institutions and business
- Several of these applications, services and initiatives were already present at the Congress
- Pressure from outside the care system is needed to create a breakthrough.
 - Most promising is pressure generated bottom-up (citizens and patients); hence, the recently created Dutch My Data Our Health Foundation (Stichting Mijn Data Onze Gezondheid), actively supported by Inspire2Live, is spot on. For information: g.remmers@habitus.nu
 - Another type of outside pressure is legislation, obliging care and research institutions to deposit collected data in the digital vault of their patients. Possible drawback: there is a need to make explicit the benefit of this system of data governance for researchers and clinicians of this system, if not, legislation will only inspire professional to manipulate data donations in order to avoid penalties. The reference for the power of legislation is the centralized pension access point: citizens can log in with their unique code to access, one single website, an overview of their pension accumulated at different pension funds. (www.mijnpensioenoverzicht.nl)
- The governance model will also facilitate citizen science. The creation of a database where citizens / patients can upload, in a semi-structured way, their findings, would be very useful.

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Actions to be taken:

- The Dutch Foundation Mijn Data Onze Gezondheid (empowered by Inspire2Live) will proceed to explore possible implementation of the MiDATA proposal in The Netherlands (**Initiative in progress**)
- Multiple bilateral appointments made
- To move forward, the attendants of the working session proposed to organize regular follow-up meetings, with iterating and rapid implementation and learning cycles.

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