



Patients as researchers: accelerating innovation in food and health beyond the evidence based paradigm

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Commons Assembly: bridging divides

SAGE post Paris Assembly

September 19th 2015, Stanford University

This presentation

- 1. Who am I - the urge for reducing incidence**
- 2. The end of Public Health, the end of statistical certainty**
- 3. Food as an example: short video**
- 4. The collaborative triangle of Personalised Food**
- 5. Patient Movement on Food**
- 6. Stepping stones**
- 7. Patient Experimentation**
- 8. Food Coalitions - Prostate cancer**

Prevention & Reducing Incidence...

- are largely the area of **Public Health**: common, consensuated, generalizable knowledge in the area of food(safety), air pollution, etc
- based on statistical truths based on large numbers of research: “evidence based”.
- Formula based: “when this, (nearly) always that happens”
- Works well to a certain level

Let's consider Food

- Tremendous public debate on food and health
- Almost invariably wrapped up in inextricable wars on **claims**, leading to more in-depth research, trying to identify hard causal relations
- The question: **Is Food a Medicine?**
Yes and No
- Yes, it certainly adds to your health
- No, works completely different, as a multiple drug targeting multiple goals, 'covering' the body in a fine mist of substances
- **So why research food as if it is medicine?**
- Plus: Public Health says: "Eat more vegetables and fresh food". But it is not enough as a message; product quality should rise too... -> paradox: more stress, better food

What do we eat: caterpillars or butterflies?



How can we make sure we eat food that certainly adds to our health? That I eat food for My Health?

→ Project on Personalised Food

Appraisal 'Business Potential of Personalised Food'(2014)

amsterdam economic board



Centre of Expertise
Greenports

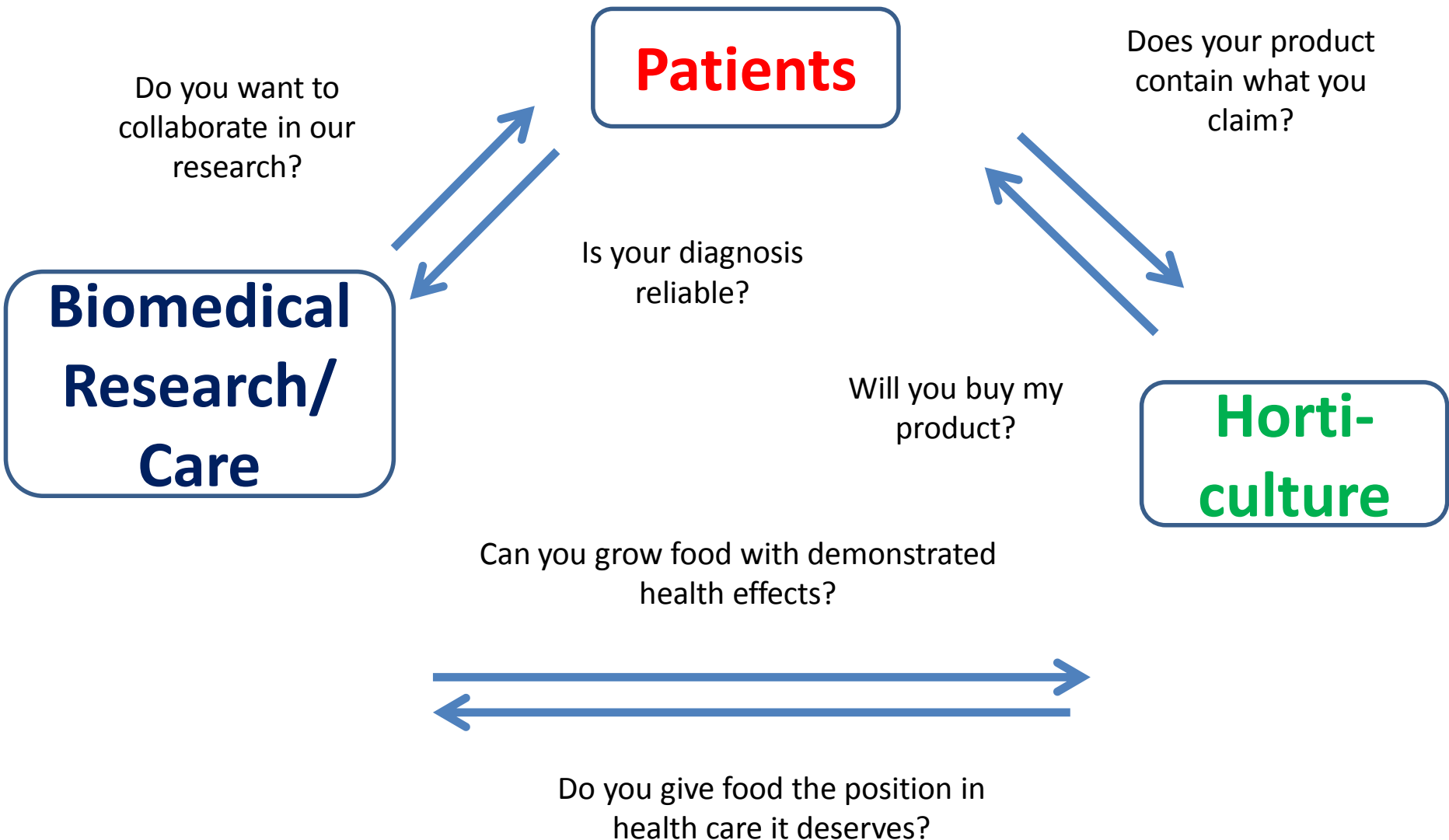
Born out of three sources:

1. Patients urgency and call for “Food that works for ME”
2. Crisis in horticultural sector: urgency to innovate beyond dominant global market orientation
3. Biomedical findings – better individual diagnostics available through metabolic map

The challenges of Personalised Food in a Nutshell

- <https://www.youtube.com/watch?v=Vt3PS5NW96g>

Multistakeholder challenge - Questions to be resolved...



What is common?

A large, light green oval with a thin green border is centered on the slide. It contains the word 'UNCERTAINTY' in green capital letters.

UNCERTAINTY

...Patients are most experienced with dealing with uncertainty...

Patients say: Get a life!



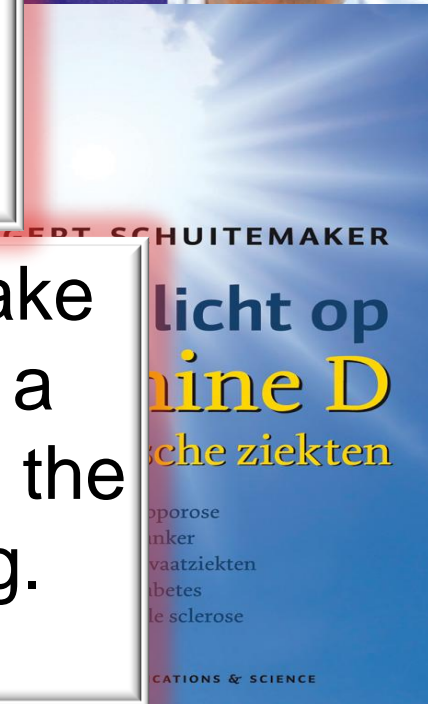
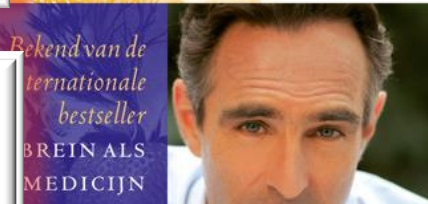
Patient Movement on Food

100.000 new cancer patients
each year in Netherlands

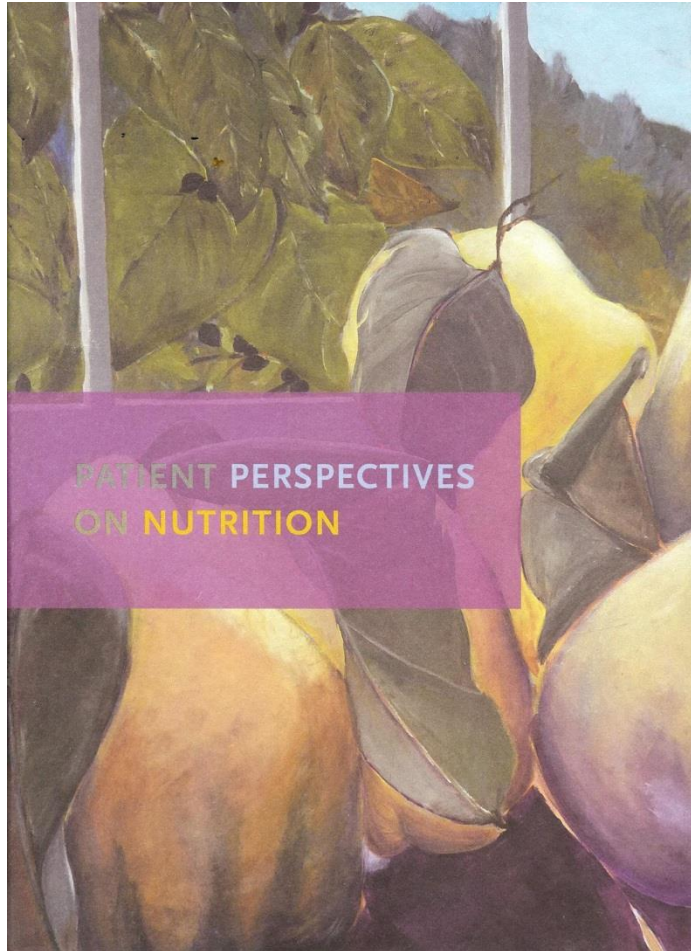
50 % uses food supplements
or alternative food habits
(Meijer et al, 2004)

Own questionnaire:
2/3 experiments with food, $\frac{3}{4}$
willing to donate DNA for R&D
in Pers Food (n=288)

Unease not only applies to the intake
of different food, but also reveals a
search for different perspectives on the
link between food and health (e.g.
ayurveda)



European Patient agenda



2013:

Agenda developed by two patient groups:

European Patients Forum (EPF) and European Genetic Alliance Network (EGAN),

with a professional (para-)medical network

European Nutrition for Health Alliance (ENHA)

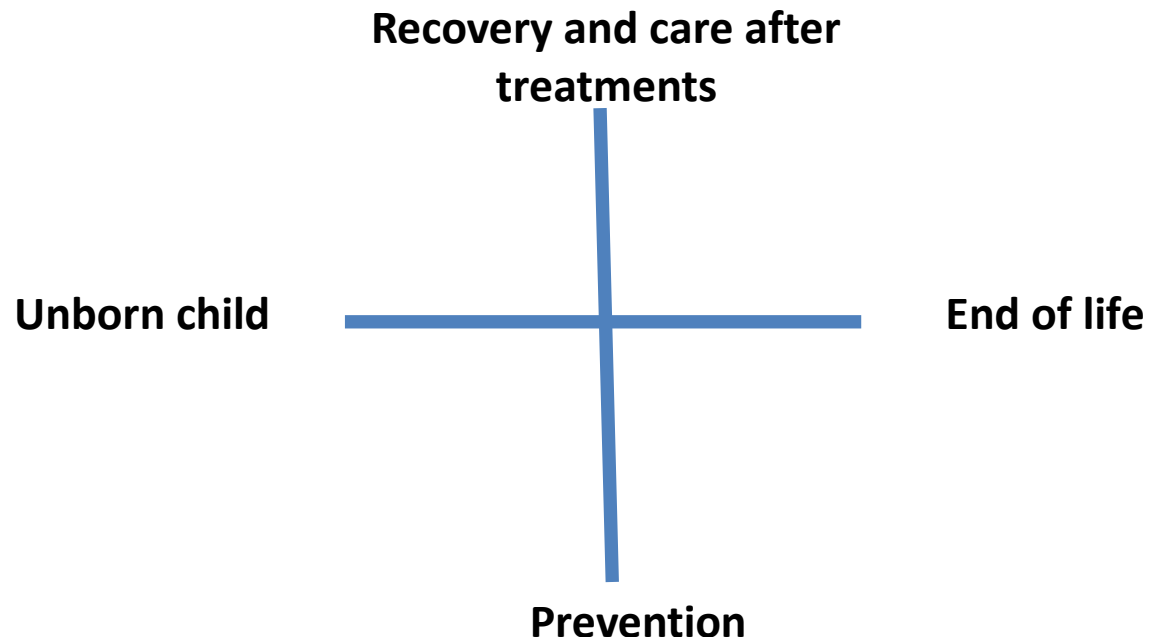
Valuable kick-off, yet little focus as of yet on role of fresh food and prevention

Dutch Patient agenda

Builds on the 2013 report and expands it

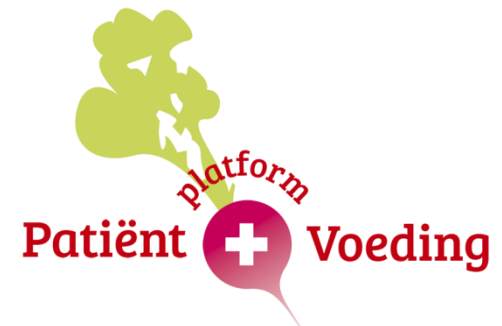
Key points:

- Actors in food and health system to collaborate in order to empower food to become an acknowledged medical prevention and intervention strategy, tuned to the stage in the treatment process and the phase of life one is in**



Dutch Patient Agenda (2)

1. Better (early) diagnostics , incl DNA
2. Build on experience based knowledge of patients
3. Take serious and validate alternative visions on food and health
4. Better dietary advice
5. Food research to focus on synergistic health effects of food
6. Better food products
7. “Salutogenic society” : healing environments at all levels
8. Build up of patient movement



Roadmap for the development of Personalised Food from a patient perspective (Platform Patient and Food)

Dutch Patient agenda (3)

Platform Patient and Food – currently involved organisations

- **Cancer: Inspire2Live, Levenmet Kanker**
- **Kidney patient organisation**
- **Heart & Vessels groups**
- **Obesity organisation**
- **Diabetes Lung patients organisation**
- **ME/Chronic Fatigue Syndrome**
- **Muscle disease organisation**
- **Dutch CAA Foundation**
- **VSOP rare and genetic illnesses organisation**

Working towards transitions: Stepping Stones

- Patient experimentation on food and health
- Food coalitions

Patient experimentation on food and health

- Goal: to establish a trusted platform
- Challenges:
- How to extract knowledge from highly contextualised data?
- Widen the methodological research scope, beyond (and before...) RCT's:
 - Qualitative Narrative research techniques, story analysis, combined with hard data (QS)
 - Grounded theory – no virtual patients
 - Uncertainty is a given, learning based paradigm
- Learn from other domains: agriculture, spatial planning
- Eventually: Health Data Cooperatives – ownership is crucial



Food coalitions

- **Foodsupplement Prostate Cancer - PROSTAPREV**
- O.a. Vit E, lycopene (tomatoes), soy isoflavonoids
- Doubling time of PSA levels delayed with factor 2.6
- Research dates back to 2005 (Schröder)
- Even patented, but not on the market
- Thru patient involvement:
 - Coordinating group established
 - Now available, plus follow-up
 - Financial feedback mechanism



Voedingssupplement Prostavrev

Prostavrev - 90 capsules

Multisupplement met bioflavoiden, soja-isoflavonen en lycopeen uit tomatenextract. Prostavrev bevat daarnaast vitamine C, E, B2, B12 en B6 en belangrijke mineralen zoals zink en selenium.

Gebruiksadvies:

3 maal daags 1 capsule. Ook geschikt voor vegetariërs.

Houd u aan de aanbevolen dagelijkse dosering.

Een gevarieerde, evenwichtige voeding en een gezonde levensstijl zijn belangrijk.

Voedingssupplementen zijn geen vervanging van een gevarieerde voeding. Buiten bereik van jonge kinderen bewaren. Een evenwichtige voeding bevat voldoende vitamines.

Pranayur steunt Stichting Wetenschappelijk Onderzoek Prostaatkanker (SWOP). Van elke verkochte verpakking van dit product doneren wij 1 euro aan de SWOP.

Koel en droog bewaren

Pranayur
Postbus 242, 8200 AE Lelystad
www.pranayur.nl



Inhoud per:	1 caps.	3 caps.	% ADH
N-Acetyl-L-Cysteine	167 mg	500 mg	
Vitamine C	75 mg	225 mg	281%
Sylimarin	53 mg	160 mg	
Vitamine E	25 mg	75 mg	625%
Soja-Isoflavonen	21 mg	63 mg	
Bioflavonoiden	6,3 mg	19 mg	
Zink	6 mg	18 mg	180%
Lycopeen	5 mg	15 mg	
Mangaan	1,7 mg	5,1 mg	250%
Q10	1 mg	3 mg	
Carotenoiden	1 mg	3 mg	
Koper	1 mg	3 mg	270%
Vitamine B6	1 mg	3 mg	186%
Vitamine B2	1 mg	3 mg	179%
Foliumzuur	133 µg	400 µg	200%
Selenium	43 µg	128 µg	233%
Vitamine B12	1 µg	3 µg	120%

% Aanbevolen Dagelijkse Hoeveelheid

Ingrediënten: N-Acetyl-L-Cysteine, Ascorbinezuur, Sylibum

Pranayur supports the Foundation for Scientific Research on Prostate Cancer (SWOP). Of all sold packages € 1,- is donated to SWOP.

Dynamism Foodsupplement Prostate Cancer

2005 **Research**

Research group Erasmus MC + Numico /Danone

**Working recipe for
foodsupplement**

**Elaborate diet /
Foodpattern
(incl patients views)**

2014

Coordinating Group
established

Appraisal

Personalised
Food

Production

Ars Pro Pharma

Sales

Holisan



2015

Additional research

Research group Erasmus MC

Phase 4

Are results
replicable?

Experim.
Research w.
mice

Which
compounds
are active?

2016

Pilot

**"I chose my Food for
My Health"**

Broadend coalition

- 100 patients
- intense coaching programme by food experts
- Home delivery of specialised food
- Scientific monitoring of PROM's
- Innovation process

Community build up

Coordinating
committe

PC Patients – I2L /
PC Foundation

- Urologists
- Oncologist



Coordinating Group

- **Foodsupplement Prostate Cancer - PROSTAPREV**
 - Rotterdam Erasmus Medical Centre
 - (prostaat) Kankerpatienten (Inspire2Live, PC Foundation)
 - Holisan / Ars ProPharma (sales / production)
- **Pilot ‘I choose my Food for My Health’**
 - Horticultural producers Westland production area
 - Municipality Rotterdam
 -

So, what can you build on?

UNCERTAINTY

CO-CREATION

PATIENTS

Thank you!

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HABITUS

