Patient-driven research in Nutrition
innovative tools and strategies for (self-)assessment

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Optimal Nutritional Care for All Conference
Sintra, 13 November 2018

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This presentation

1. My Background
2. The Challenge
3. The Solution
The challenge

• **Conventional Feedback vacuum**
  • Much of the good work of dieticians and nutritional therapists and also researchers remains hidden because of a lack of appropriate measurement and follow-up of the outcome.

• **Innovation Feedback Vacuum**
  • At the same time, much of the own efforts and observations of patients in need of dietary advice or special food strategies remains underused.
Circular Nutrition

Downpouring

Food Sciences

upcycling

Everyday Food Practice

Cradle to Cradle
Similar trends

Agricultural Knowledge System

Spatial Planning System

Medical / Nutritional Knowledge System

Tend to look for and to impose generic rules and solutions

....

Very much 20th century
Patients are gateways to innovative health products & nutrition therapies

Samantha Schut
Mother of son with Cystic Fibrosis
Brew of turmeric, black pepper and apple sauce
Son regains appetite, weight and overall health

Wendy Reijen
Multiple Sclerosis
bioresonance, mesology, kinesiology, exclusion diets, food supplements
After years of struggles she is medication free and free of symptoms

Loes Visser
Asthma and severe sinusitis
Anti-inflammatory foods and Keltic Sea salt
Got rid of medication altogether
Striking a balance

Citizen/Patient
change several things at the same time in a complex life

CHAOS

Researcher:
change nothing but one thing, very structured

CAGE
The solution

Co-operative Citizen Science

Examples
Food basket for Prostate Cancer
Single Subject Studies
MyOwnResearch in bowl + fatigue
Food Basket for Prostate Cancer

• Unique blend of professional expert knowledge and experienced based knowledge
• RCT-trial including 250 men
• QoL and serum concentrations of specific carotenoids
• Start sept 2018
Enhanced self monitoring by clients
Ecological momentary assessment (EMA) / experience sampling

Repeated assessment 'on the spot' in 'real life'

„...examining ongoing experience as it occurs in the ebb and flow of everyday life“
(Reis & Gable, 2000, p. 190)

„...capturing life as it is lived“
(Bolger et al., 2003, p. 579)

Credits: Jan Houtveen
How does this work?

• Personalised Ecological Momentary Assessment
• 4-5 measurements / day
• 4-5 short personalised questions
• Before, during and (if desired) after the (dietary) intervention
• N=1 statistics on the data-cloud, allowing for hard evidence on the effectiveness of the intervention
Looking at the whole movie

Credits: Jan Houtveen
Added value

Relevant for patients
• It provides you with immediate feedback if ‘something’ (the intervention) has worked for you or not

Relevant for therapists / researchers
• Greater possibilities to follow and guide your client
• Gives you a good insight in the effectiveness of your approach
• It enables you to show evidence of your approach to sceptics
• If done together with colleague-dietitians, you contribute to evidence-building for the whole professional branche
MyOwnResearch

Homogeneous subgroup identification in fatigue management across chronic immune diseases through single subject research design.

Funded by
Dutch Collaborating Health Funds - SGF
Topsector LifeSciences & Health
The MyOwnResearch Consortium

Scientific lead

Value-for-patients lead

Amsterdam UMC

Utrecht University

Holland Health Data Cooperatie

Total Budget: 2.6 million Euro
September 2018 – August 2021
MyOwnResearch

Homogeneous subgroup identification in fatigue management across chronic immune diseases through single subject research design.

1. Single Subject Design Study
2. Research couple: Patient-researcher and Physician (GP)
3. 500-1000 participants
4. Self monitoring through EMA-app in a treatment context
5. Microbiome analysis, blood analysis
6. Intervention with probiotics, DJ Repair or pers m therapy

1. Pattern analysis biostatistics op at aggregated level, subgroup typing
2. Randomised doubleblind research to confirm findings in subgroup
A growing interest

BeyondRCT-2
Towards Co-operative Citizen Science in Food and Health

International Conference
Amsterdam, 25-26 September 2018

www.BeyondRCT.net
Take away messages

• Patients / citizens are crucial knowledge partners
• There are research methods available to conduct n-of-one research
• There is a tool available to monitor the effectiveness of a nutritional intervention
• There is a growing movement developing co-operative citizen science – be part of it!

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