

# Patient-driven research in Nutrition

## innovative tools and strategies for (self-)assessment

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**Foundation My Data Our Health**



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Sintra, 13 November 2018



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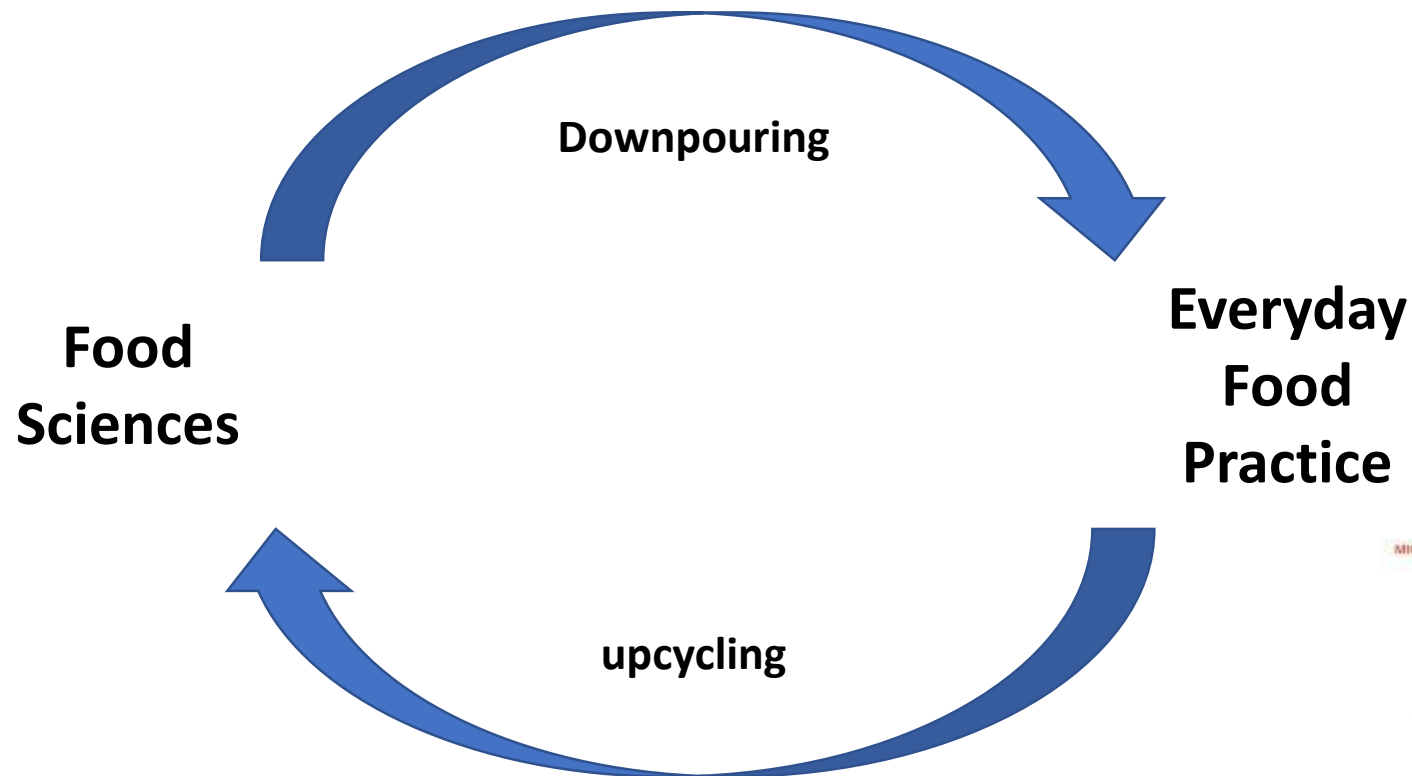
# This presentation

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



MICHAEL BRAUNGART & WILLIAM McDONOUGH

cradle  
to  
cradle



SEARCH KNOWLEDGE

# 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 20<sup>th</sup> 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



**Researcher :**  
change nothing  
but one thing,  
very structured

**CHAOS**

**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



# Single Subject Studies

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)

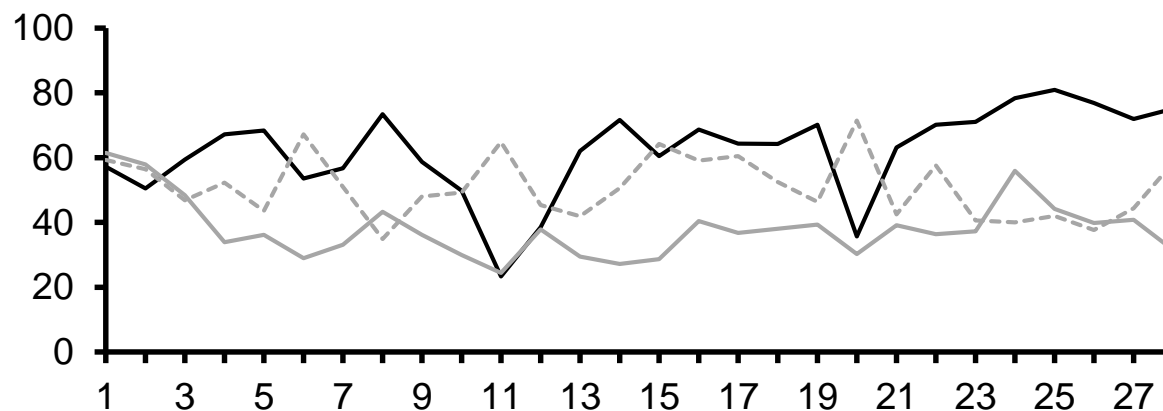
„...capturing life as it is lived“  
(Bolger et al., 2003, p. 579)

# 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.



**MyOwn**  
**Research**  
*intestinal health*

***Funded by***  
***Dutch Collaborating Health Funds - SGF***  
***Topsector LifeSciences & Health***





# The MyOwnResearch Consortium

Scientific lead

Value-for-patients lead



UNIVERSITY OF AMSTERDAM



**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
- Research couple: Patient-researcher and Physician (GP)
- 500-1000 participants
- Self monitoring through EMA-app in a treatment context
- Microbiome analysis, blood analysis
- Intervention with probiotics, DJ Repair or pers m therapy



2

Pattern analysis  
biostatistics op at  
aggregated level,  
subgroup typing

3

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](http://www.BeyondRCT.net)

# www.BeyondRCT.net

## 2018

### keypartners



*noaber* foundation



Samenwerkende  
GezondheidsFondsen



Holland Health  
Data Co-operative

2016

### sponsors



# 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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