

Between heaven and earth: where are we now, two years after BeyondRCT-1?

Gaston Remmers

Towards Co-operative Citizen Science in
Food and Health

Amsterdam, 25 September 2018

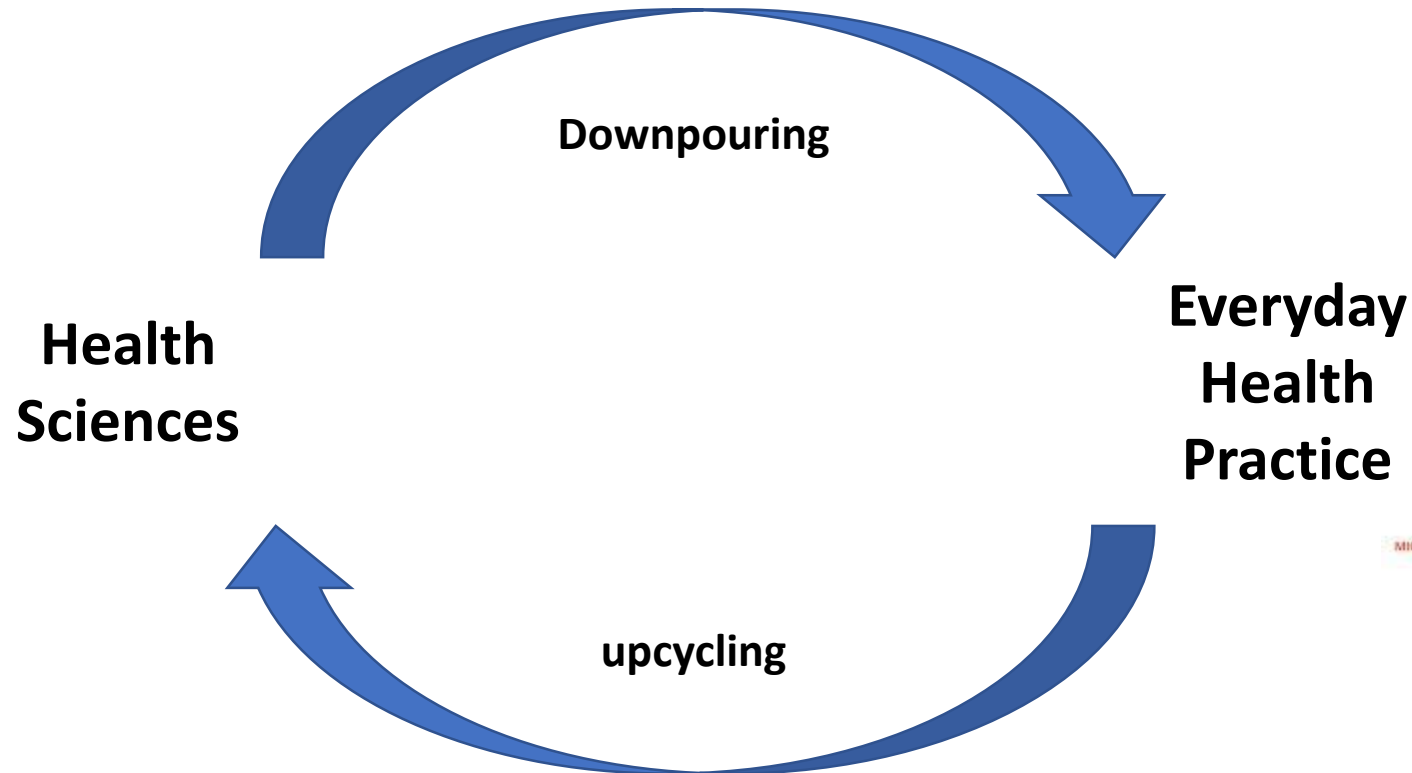
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mijn data
onze gezondheid

Circular Health



MICHAEL BRAUNGART & WILLIAM MCDONOUGH

cradle
to
cradle



Similar trends

Agricultural
Knowledge
System

Spatial
Planning
System

Medical
Knowledge
System

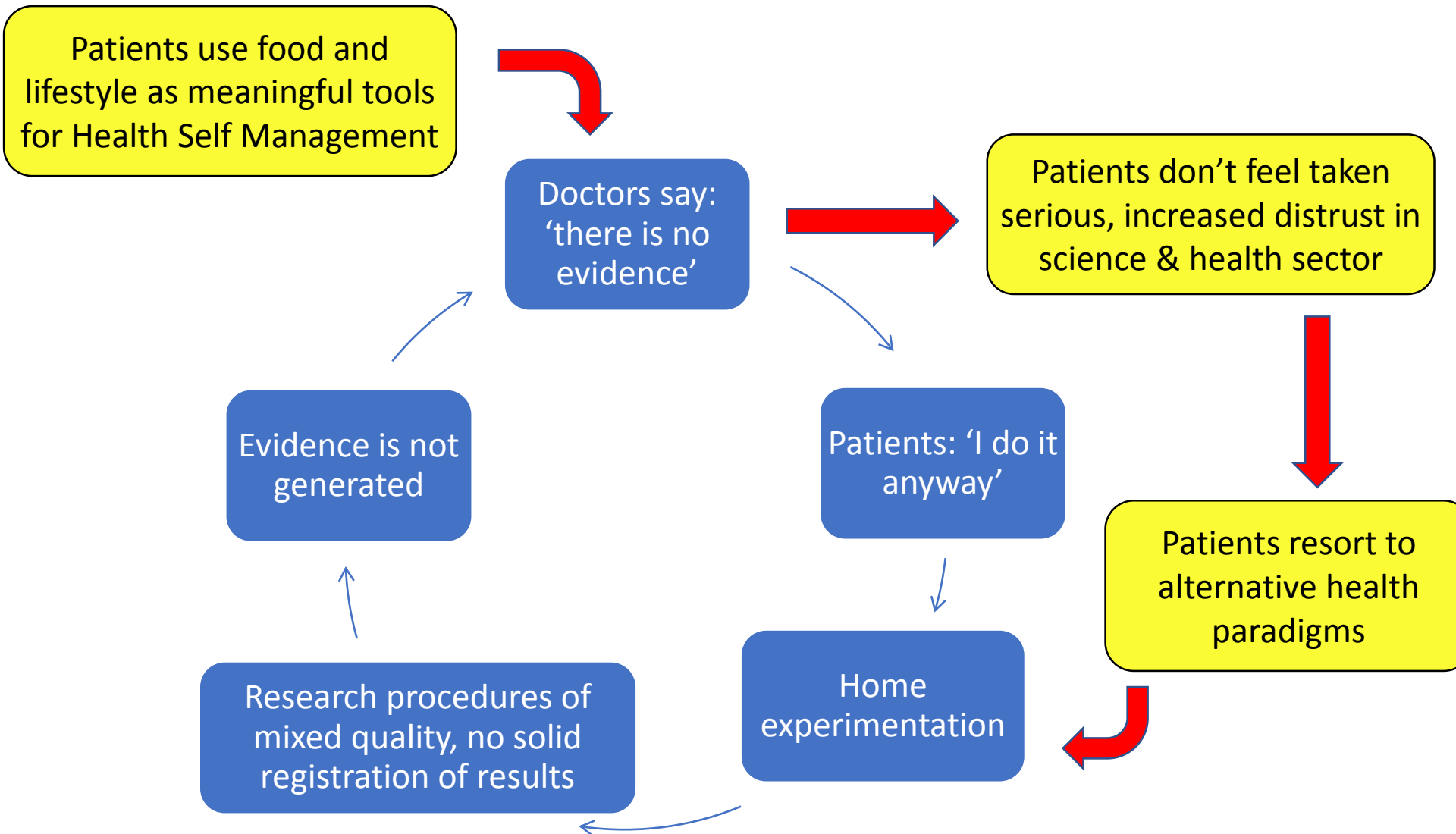
Tend to look for and to
impose generic rules and
solutions

....

Very much 20th century



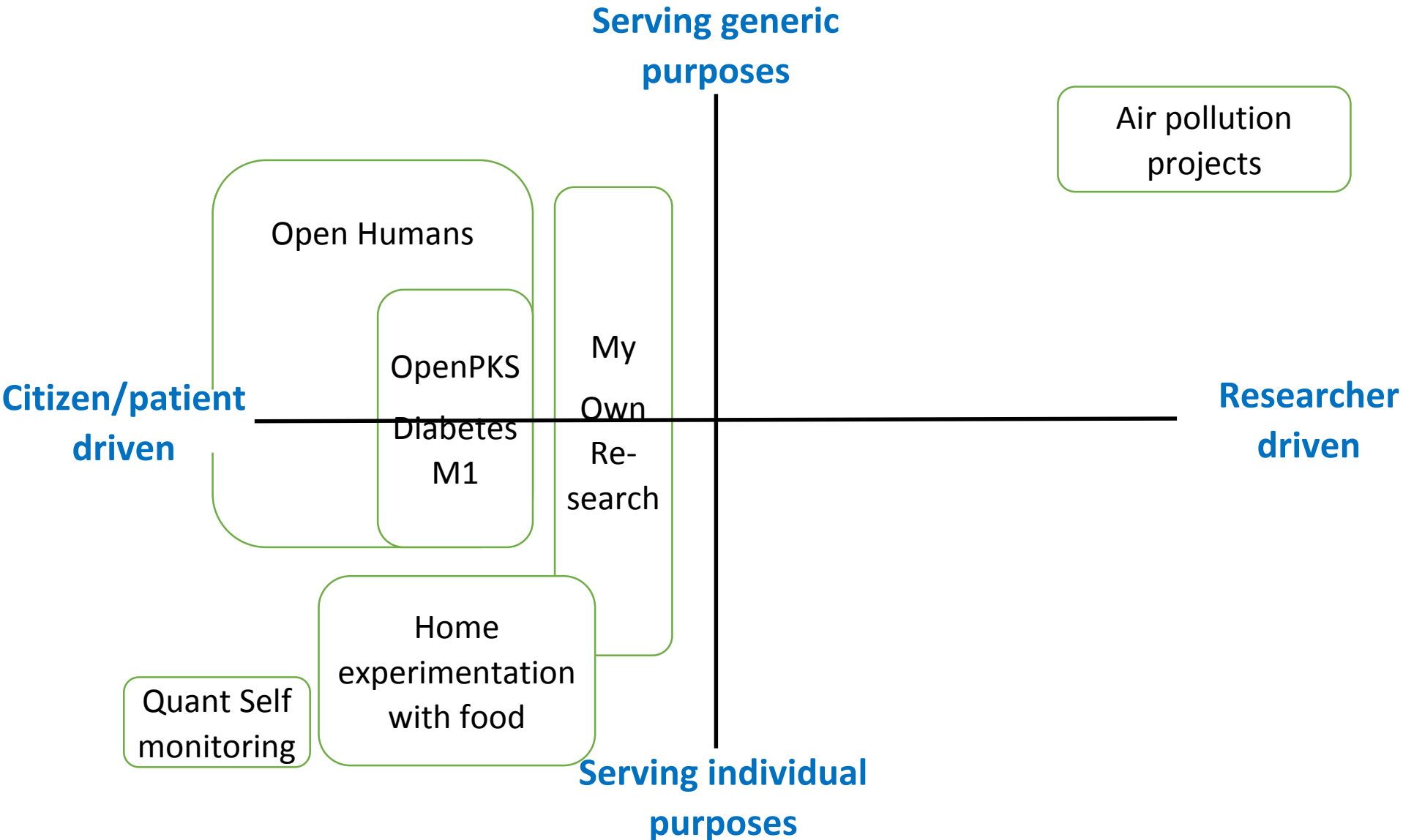
Medical system seems to have particular problems – the HEXIT



We care about health care



The potential of Citizen Science in Health



Patients are gateways to innovative health products & 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

citizen science -> co-operative citizen science

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



Researcher :
change nothing
but one thing,
very structured

N-of-one does not make a whole summer (één vlucht maakt nog geen zomer)

citizen science -> co-operative citizen science

Key issues of BeyondRCT

- 1) Good data collection**, data management and research by citizens in the health domain
- 2) Appropriate research methodology** to extract wisdom from n-of-1 and to upgrade it to collectively applicable knowledge, products and advice
- 3) An adequate data infrastructure** that allows data traffic between different sources, and that functions technically effectively and socially ethically

Heaven

- Inspiring examples of citizen research in health
- Increased interest among scientists
- Great variety of tools, gadgets, apps, health products and therapies that allow for n-of-one experimentation
- Standardized protocols for data exchange (MedMij, FAIR, PHT)
- Digital health vaults
- Increased support from a diversity of organisations

Heaven (2)

2018

keypartners



Samenwerkende
GezondheidsFondsen



Holland Health
Data Co-operative

sponsors



Earth

- Bits and pieces are not connected
- No mutual reinforcement
- Hence don't deliver the value implicit in them



- Multiyear program Co-operative Citizen Science
- Linking passion, focus, funding, expertise and regulation

Back to where it all starts...

the beginners mind

