

Beyond RCT's: Towards citizen-driven research strategies in food and health

How do we enlarge the research potential?

Monday 21 March 2016, Van Lanschot Bankiers, Amsterdam

Program

- 9:00 **Opening** by Conference Chair Annabel Thomas
Welcome by Pauline Kreeft, Van Lanschot bankiers
- 09:15 **Key notes**
- **URGENCY**
The societal challenge: from virtual and dependent to real and co-creative patients
Dr. Gaston Remmers (Patient Advocate Inspire2Live / Platform Patient and Food Netherlands)
 - **WHY**
Alternatives to RCT's: results of a recent research project commissioned by ZonMw
Dr. J. Mathijssen, TRANZO - scientific center for care and welfare, Tilburg University
 - **WHY**
Going beyond RCT's: why they don't yield useful results in complex dynamic domains, and why we need alternatives
Prof. Dr. Jan van der Greef, Principal Scientist TNO, Professor of Analytical Biosciences at Leiden University, director of the Sino-Dutch Center for preventive and personalized Medicine (SD-PPM)
 - **HOW**
Comparative Effectiveness Research - Methods and Patient Engagement
Prof. Dr. Claudia Witt, Chair Complementary and Integrative Medicine, University of Zurich
- 10:50 Break
- 11:05 **Pitches: HOW**
New research approaches on highly contextualized data yielding valid knowledge: examples of novel research approaches
- Using the Participatory Narrative Inquiry (PNI) method with Cerebral Amyloid Angiopathy (CAA)
Drs. Marco Koning, StoryConnect and Dutch CAA Foundation
 - Gradual development of an experience-based research cohort in diabetes type 2: the Stichting Voeding Leeft approach
Dr. Peter Voshol, Louis Bolk Institute
 - From citizen-research to an RCT with promising food supplements for Cystic Fibrosis
Samantha Schut, citizen-researcher and mother of a CF-patient.
 - The Big Move: from patient data to Health Data Cooperatives. The 'My Data Our Health' approach
Drs. Roel Kamerling, Director Medical Delta
 - 'Ego-documents' of patients as a source of information for research
Coleta Platenkamp, Founder CCC, www.patiëntervaringsverhalen.nl

- Finding relevant research leads with participant-based observational studies with probiotics
Drs. Isolde Bekkering, Manager Research Partnerships, Winlove probiotics

12:30 **Lunch**

13:30 **Pitches continued: HOW**

New research approaches on highly contextualized data yielding valid knowledge: examples of novel research approaches.

- Coupling citizen science with biomedical research on immune related diseases: the Immunowell approach
Drs. EMIA Tjitske Bezema, Founder Immunowell
- From observation to knowledge in medicine: the case of fibrogene in fluxus postpartum
Prof. Dr. Anske van der Bom, Professor of Clinical Epidemiology, Leiden University

14:00 **Reflection** on the presentations so far by Henk Smid, Director of ZonMw, Dutch Funding Agency for Health and Healthcare

14:15 **MAKING IT HAPPEN:** introduction to the working sessions

14:30 **Working session 1:**

Methodologies: new qualitative and quantitative methodologies that build on citizen based knowledge
Subquestions:

1. **What methodologies are available between n=1 and RCT's? (quali- and quantitative)**
2. **In what stage of the total research process can they be employed?**
3. **What could / should be the role of the citizen / patient in these methodologies? And of researchers?**
4. **What other methodological observations are relevant regarding citizen-driven research in food and health?**

15:30 *Break*

15:45 **Working session 2:**

Making it possible: the roadmap to develop new, citizen centered research approaches
Subquestions:

1. **What are the obstacles that hinder the development of citizen-driven research methodologies?**
2. **What is needed to overcome these obstacles, in order to have citizen-driven research contribute tangibly to the health sector?**
3. **What are good cases / health domains to start developing citizen-driven research?**
4. **What are the first three steps that should be taken now**

15:30 **Break**

15:45 **Working session 2:**

Making it possible: what is the roadmap to develop new, citizen centered research approaches?

16:45 **Plenary Wrap-up**

17:00 **Closure and drinks**