



BeyondRCT -2: towards co-operative citizen science in food and health

The Netherlands

Share in your network ↗

International Conference, Amsterdam, 25-26 September 2018

Why BeyondRCT?

The dominant way by which 'Evidence Based Knowledge' is generated in biomedical research, mainly by randomized, placebo controlled trials, does not serve all needs.

Very often the causal relations are multifold and more difficult to determine in these type of trials. Furthermore, it is difficult to transfer results from studies with very homogeneous study populations and standardized interventions into usual care and prevention.

Other study methodologies are available and in development, which are only slowly adopted in research on complex domains such as food, stress, the immune system etcetera.

Hence, the potential of research for innovation and product development lags behind.

Currently, patients increasingly want to play an active role in biomedical research, grounded in their own experience and highly contextualized expertise. They develop solutions for themselves that hold potential for others too; they discover products and therapies that are badly known to the health community. Hence, they demand new and more inclusive research strategies, in which their experiences will tangibly impact the generation of knowledge.

The 2016 edition of BeyondRCT yielded the following recommendations:

1. Invest heavily in awareness building, networking, education and knowledge exchange, regarding the potential and possibilities of Citizen-Driven Research (CDR), for all stakeholders involved
2. Speed up CDR learning and practice by developing inspiring, tangible and collaborative cases and projects around citizens / patient initiatives
3. Establish a safe and fair tool / interface / platform where citizens can drop their insights and data

Since then, many developments have taken place, both within The Netherlands and beyond. Both Quantified Self and e-health devices provide ever more possibilities to track highly personalised data. The examples of patients organizing their own, successful experiments with food and health are mounting. Statistics that enable to draw sound conclusions on n-of-1 type of research is one of the

hottest academic fields. The power to aggregate highly contextualized data and draw conclusions through BigData techniques is increasing. The questions and new proposals related to ethical and efficient data management are rising at the same speed. Companies active in the health sector increasingly recognize that engaging in new ways with their target audience provides them with better clues for more tailor made product development.

In sum: the potential of citizen science in the health domain is becoming more tangible. However, the building blocks are only loosely organized and visible. The collaborative networks are under developed, and lack the power to make a real impact. Hence the motto of the 2018 edition of BeyondRCT: towards co-operative citizen science in food and health. The underlying questions are: how can we as quickly as possible, link individual research with collective benefit? How do we foster new research strategies that include the interest of patients, serve the standards of science and help to strengthen business?

The core purpose of the BeyondRCT-2 symposium is to produce a workplan Co-operative Citizen Science for the period 2019-2021.

The BeyondRCT-2 symposium is a multi-stakeholder event that consists of two days.

- On September 25th, an inspiring mix of plenary key-notes, rapid fire talks and hands-on workshop will showcase state-of-the-art knowledge and practice regarding citizen science in food and health. This day is open for all stakeholders: scientists, companies, policy makers, patients and citizens.
- On September 26th, a focused session will be organized that aims to produce a workplan for co-operative citizen science for 2019-2021. It will draw upon lessons and insights from the previous day, and is open to any organization that is seriously interested in taking the next step in co-operative citizen science. (the session will be in Dutch)

Organization

The conference is organized by Foundation Mijn Data Onze Gezondheid (My Data Our Health). MDJOG is a Dutch, patient-driven NGO. The conference is organized in collaboration with a number of key partners, like the Dutch Funding Agency on Health Research, Topsector Life Sciences & Health, and others.



More info:

www.MDOG.nl/BeyondRCT

Dr. Gaston Remmers

g.remmers@mdog.nl

+31-6-41 37 41 02



Good Practices from The Netherlands



Nutritious chocolates designed for women during pregnancy

The Netherlands

[Read more](#)

23 shares ↗

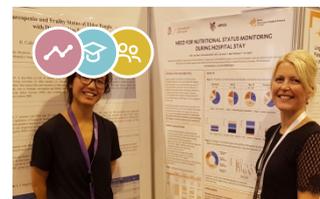


Dietitians across Europe are taking action to combat malnutrition

The Netherlands

[Read more](#)

12 shares ↗



Ongoing efforts to fight malnutrition in The Netherlands

The Netherlands

[Read more](#)

5 shares ↗

[View more](#)