

# From individual to public knowledge in health: preliminary lessons from the patient-led MyOwnResearch project on fatigue and gut health

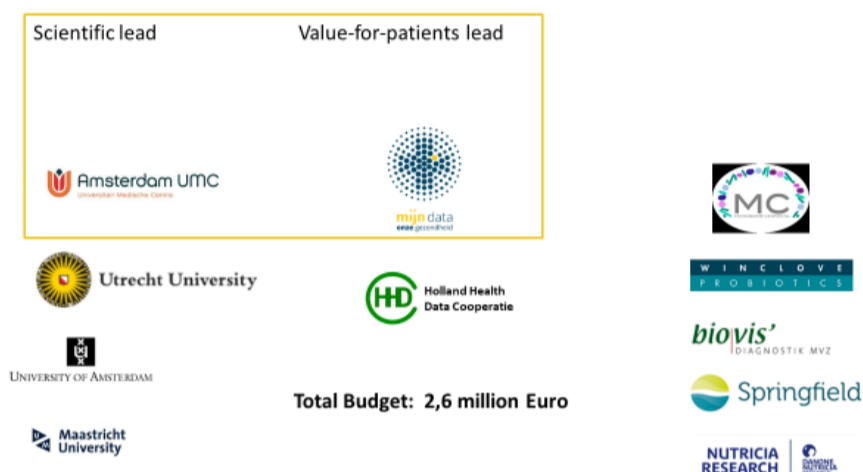
Authors: Gaston Remmers, Foundation My Data Our Health and dr Anje te Velde, Amsterdam UMC (PI's of MyOwnResearch). Dennis Zeilstra, Jan Houtveen, Aletta Kraneveld, Jos Bosch, Henk Duinkerken, Pieter Pekelharing, Kathelijne Dik, Isolde Besseling, Kiauw de Munck-Khoe, Marjan Schellinger, Jako Burgers and Karen Knipping. Contact: [g.remmers@mdog.nl](mailto:g.remmers@mdog.nl)

## Summary

MyOwnResearch is a large, award-winning Dutch patient-led research project, started in 2018, that aimed to develop a new research protocol enabling collective knowledge development out of individual citizen-designed health experiments. At present, the vast majority of these experiments cannot be used by scientists due to a supposed lack of scientific rigor. On the other hand, citizens do not fit in the typical randomized clinical trials required by most medical research. The MyOwnResearch consortium has designed a pathway that answers to the requirements of research and patients. This pathway challenges lots of assumptions in current health research design, and hence the project has met with considerable resistance from the traditional medical health research infrastructure, with issues ranging from methodological design, ethics of patient protection and empowerment to the medical-biological rationale for the project.

The project won a grant issued by the Dutch Collaborating Health Funds aiming for disease-overarching and patient driven research, and was given much praise for its innovative set up. However, as a result of the resistance met with over the course of the project, notably the Medical Ethical Research Review Board (METC), the project had to be aborted one and half year after its start (March 2020). Even though this was a dramatic finish of the project, the experience gained is of great potential value as to re-examine the current medical-ethical framework that governs medical research, specifically in the light of the rise of patient-led research. This ePoster is the first of a series of papers to unpack the lessons learned.

## The MyOwnResearch Consortium

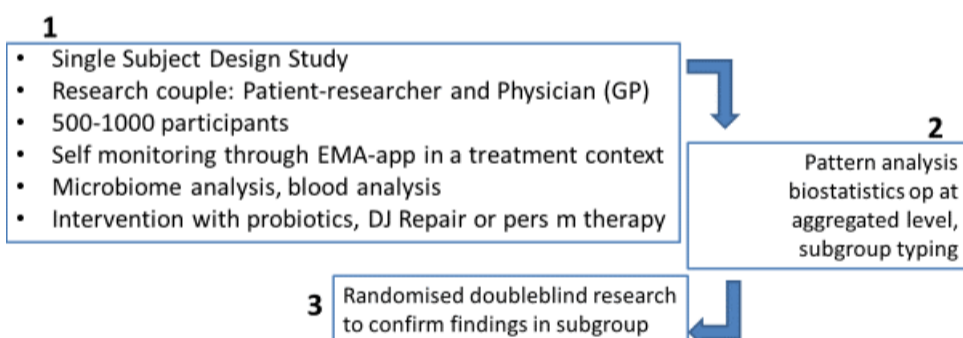


## Two fundamental purposes

- Methodological ->
  - proof of concept of Practice Based Evidence Building
- Biomedical ->
  - new research leads & treatments for patients with gutflora and fatigue issues

## Project set up

*MyOwnResearch: homogeneous subgroup identification in fatigue management across chronic immune diseases through single subject research design.*



## Project phases and Milestones

1. Tender: project idea (June-aug 2017) - Shortlisted among top 5
2. Tender: conceptualization of project idea (sep 2017-march 2018) - submission of project proposal
3. Tender: approval process (march - may 2018) - Project grant achieved
4. Execution (Sep 2018 – Oct 2019) - METC submissions
5. Finalization (oct 2019 - feb 2020) - project aborted after 18 months

## Conclusions

1. Over the course of the project, the voice of participants remains steady within the project consortium, but loses influence in encounters with the established scientific frameworks for ethical oversight and project evaluation.
2. Typical conflicting ethical issues (cf Vayena et al, 2016):
  - self sovereignty of participants in deciding the research burden
  - Participation of industry
  - Voice of patients in ethical oversight bodies is a) only represented indirectly and b) is strongly understood in terms of conventional concerns regarding methodological quality and generalizability of the outcomes
3. Lack of coherence between overwhelming scientific, civic and institutional support for the project in the granting phase, and the absence thereof in the execution phase.

## References

Vayena E, et al. (2016) Research led by participants: a new social contract for a new kind of research. J Med Ethics 2016;42:216–219. doi:10.1136/medethics-2015-102663

ePoster presented at ECSA, 2020

ECSA  
CONFERENCE  
// 2020

**ecsa** | European  
Citizen Science  
Association