

Patients as Research Partners



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Radboudumc

part of **TOPFIT**

UNIVERSITY
OF TWENTE.



What's in it? From a patient perspective



A unique insight in
basic research

Site visit

Feeling privileged

Finding a positive
way to contribute
through
experience

Helping other
patients

Helping science

Balancing a 'perk'
out of loss and
pain

Access to
knowledge



What's in it? From a researcher perspective



A view on disease
beyond the obvious

Motivation

Access to collective
experience and
knowledge of patients

Feedback on the
(ir)relevance of
research proposals

New research ideas
from patients

Feedback from
potential end users

Translating science to
lay information

Finding new pathways
for dissemination of
research to the
potential end user
group/stakeholders



How to involve patients as partners?









Patients can be part of the research team in all phases of research

- Deciding on research topic
- Defining research questions
- Writing grant proposal
- Designing research protocol
- Collecting data
- Analyzing data
- Writing papers
- Disseminating results

How to involve patients in the process?

Example!

Phases in process		Role in research / development				
Clinical and basic research	Health technology design	Listener	Informant	Advisor	Partner	Director
Research question	Research question Problem analysis, concept development					
Research design	Context of use and requirements					
Data collection	Design Co-creation of prototypes					
Analysis and interpretation	Testing and Improvement					
Dissemination	Implementation, Evaluation and Dissemination					

Patient Involvement Matrix

3 ICMS partners

- Sint Maartenskliniek
 - patient involvement - STAP
- University of Twente
 - Citizen science - TOPFIT Citizenlab
- Roessingh Research and Development
 - Human-centered design

Citizenlab TOPFIT



Let's connect



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Patient involvement



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Human-centered design



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