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# With the patient as the end-user, of course!

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Veronica van Nederveen

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## Veronica van Nederveen

motto: health care is for patients, not the other way around

NL Ministry of Health
Cancer treatment 1997/98
Patient Advocate: since 2013 (retirement)
Patientenstem.nu: Chair and co founder
Dutch Clinical Research Foundation: chair Patients Group, chair working group Recruitment, member working group Participants Information Form
Center Personalized Cancer Treatment: member of the Patient Advisory Board
Asterix: EU/IMI research project, member Patient Think Tank (2013-2017)
EUPATI, member midterm review committee (2014)

# With the patient as the end-user, of course!

**Dutch Clinical Research Foundation** (DCRF) is the meeting point of all stakeholders in clinical trials: hospitals, research organisations, pharma, biotech, patients, government.
Mission: better clinical research climate in NL

Working groups for practical exchange of experience to improve the results
e.g. forms for study participants information, local agreement template in hospitals, information about patient friendly access to clinical trial results, new EU regulation about CT's.
Low overhead budget, mostly for working groups and annual congress

Overall impression in the working groups:
We know what we have to do, but we don't act on it. It is culture, education, routine.
For better results we must give more attention to psychology of taking decisions in the daily work.

# With the patient as the end-user, of course!

- Patients are looking for help to recover
- Research is essential for good treatment
- Scientifically proven: involve the end-user from the start of the innovation
- ➢ Patient participation is vital for better results of research

**Patients and researchers are equal partners, different input, same goal**
**Patients and researchers need to know each other and to understand each other**

1. Learning about the wishes of the patient and about what is possible to work towards
2. Patients need information about clinical studies that is easy to find and understandable for lay persons in their own language
3. In recruitment the conversation between the researcher and patient is key

# With the patient as the end-user, of course!

Patients and researchers need to know each other and to understand each other

**1 Learning about the wishes of the patient and what is possible to work towards**

- What does quality of life mean for patients? Let them tell you.

Longer life, less pain, less itching, walking around, moving arms, using a computer (with eye’s), having a job, being a part of society, self management in their life?

- Which medical solution would be possible to help the patient? Discuss this together.

Pharmaceutical, chemical, technical, combination
How and when?

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**2 Patients need information about clinical studies that is easy to find and understandable for lay persons in their own language**

DCRF working group ‘Recruitment’ asked for advice about information that patients want to have
https://dcrfonline.nl/wp-content/uploads/sites/12/2018/10/Adviesrapport-patiëntvriendelijke-info-mwo_EN-UK.pdf

- Clinical trial information should be easily available: one entry point, suitable keywords, easy to search through, current and reliable information, addresses.
- Patients want the researchers to hand over this information to them, with easy access to find this information later by themselves
- Well informed patients are more compliant to the study.
- DCRF provides support to make the information understandable. That is a lot of work, all information should be translated in collaboration with experienced patient advocates.

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**3 In recruitment the conversation between the researcher and patient is key**

Recruitment is a big issue. About half of the trials have too few participants compared to the design. So the results will not be scientifically appropriate.
That is very sad for the participants – they were unnecessarily exposed to the experiment.
Expensive in terms of goodwill, money, time.

DCRF provided a pilot training for better recruitment: Excellent conversation.
The training gives the researchers more confidence in their own skills to ask patients to join the trial. This is a matter of attitude, psychology of asking, time management and civilisation.
In half a day they learn not to think *for* the patient but to start with entering in the world of the patient and than give them suitable and understandable information about the study.
Trainees give the training a good score. And have better inclusion.

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For the best results

We need involvement of patients as equal partners in all preparations of the study; subjects, design, distributing the study results. Patients are likely to do so.
We need training for researchers to conduct an excellent conversation.

Good collaboration between patients and researchers will improve the results: better matching the patients wishes, better and quicker results for patients, better scientific output, less costs, quicker market access.
**Assessing the Financial Value of Patient**
**Engagement: A Quantitative Approach from CTTI's Patient Groups and Clinical Trials Project**
Bennett Levitan, MD, PhD1, Kenneth Getz, MBA2, Eric L. Eisenstein, DBA3, Michelle Goldberg, MBA4, Matthew Harker, MPH, MBA5, Sharon Hesterlee, PhD6, Bray Patrick-Lake, MFS7, Jamie N. Roberts, MPH, MA7, and Joseph DiMasi, PhD2

And more satisfaction for every one!