

A Dutch way: building bridges between practice and science with stories of

www.patientervaringsverhalen.nl



Elegant



Sofisticated

Stichting CCC
opent bronnen...

www.patientervaringsverhalen.nl
@patientervaring

Coleta Platenkamp



Good



Fitting



Solid

Thinking about how to make it usable, solid
sophisticated, good, fitting, elegant bridges



But first: who am I?

Patientervaringsverhalen.nl

Stichting CCC laat de stem van de patiënt horen via ervaringsverhalen in diverse vormen



2004: Establish the foundation CCC, Coleta's Chronische Circus: period of gathering patient stories, buy books of patient stories, read them (wanted to be a guide), incorporate and put a review on the site **patientervaringsverhalen.nl**, PR, admin. et cetera

Till 2010: Building up and expand a network, bringing in the patients perspective in health, research, education, policy.

2011: Subsidy (One-off) and expanding with volunteers, improve the website, develop a search engine, making discoverable the books and other patient stories zoekmachine.

2017: Result: Books: 4000, Weblogs: 582, (short) Ego-documents: 403, Docu(diaries): 571, Relevant websites: 465. **Visitors:** 700 unique visitors a day in 2017

Coördinator: Coleta Platenkamp. Board: Rob Houtepen, Eef Meijerman, Marie -Josée Smits. Workers: about 14 volunteers. ANBI status.

Niet alleen afzet: disciplinary studies of a new
 - *Disciplinary Studies - Robert Lemley*
 - *discipline van organisatie*, dan wordt ik best met
 - *organisatie van organisatie / organisatie van organisatie*

Kante zijn / welke vertalen / lyrische / onderwerpe
 - *patron / onderwerpe*
 - *schieding? / organisatie van organisatie*
 - *HEG HEG / certificate / WO1* - *Janette Pils*
 - *Klaris Hostma*

Betaald, onbetaald? Dank sluit op legging
 Kan niet structuren symposium
 achterstand.

Drona uitwala (Houto / Houto / Garmis / Katoen)
 Zoek naar nieuwe kennis, anders via Brega

Hydrof, Alledaagsse.
 Jim van Osi beveling *separatist*
 Ali Weerman: *discipline van*
 schied kennis: Dijkhuis / *god Ghislaen*
 (Torhans) / *Streekhand* / *Jan van der Keurs*
 ↓ *geloofwaardigheid* K-Dops

men die informed consent

→ *Het* *onbetaald niet!* *lock* *betaald niet!* *then* *willt* *betaald niet!*

This was the start of this presentation

I hope that I have ordered these thoughts a bit, so that I can tell you in the next 15 minutes about how to built bridges between practice and science with the patient stories:

- How we want to use the collected patient stories.
- Three examples/lessons. Show thereby how scientific studies, theories, if translated, used, can give knowledge and understanding.
- Show some activities, examples and best practices to build bridges.
- Making a plea for patient studies.

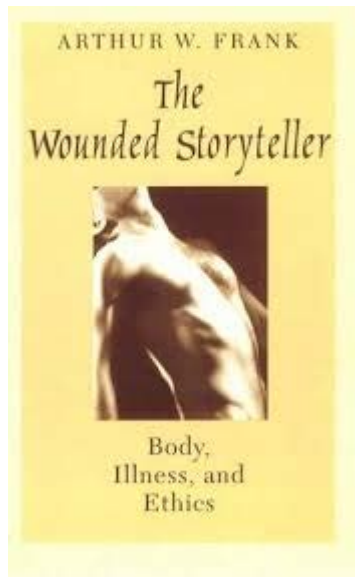


"I've still got 37 more slides to go!"

Lesson one (simple):

There is not one way of showing the art of belonging, but many ways, there is diversity. You can read about them in many ego documents where disabled write about their lives. The ways of belonging differ not only because there are different diseases and handicaps, they vary in many context, with kind of people, networks, families, support etc. But...





Bridge one:

We need tools to read and use this diversity. An example:

Arthur Frank: Story of chaos, Story of recovery, Story of the quest, Testimony.

Possible is a full participation in solutions of health problems instead of being treated as a suffering object which ends when the sick goes out of the institution. Stories / Testimonies complement each other. But it also gives insights to others. We must think about stories as well as stories.



Good practice example full participation: Ont.be

Our New Future is a movement of and for people with mental disabilities. They especially want to show that they are people with their own possibilities. They want to fight injustice and defend our human rights.

Lesson two: See me (simple)

<http://www.youtube.com/watch?v=TmTmBNg2w1o>

Recognise...

Accept...

Know...

... Me

See Me



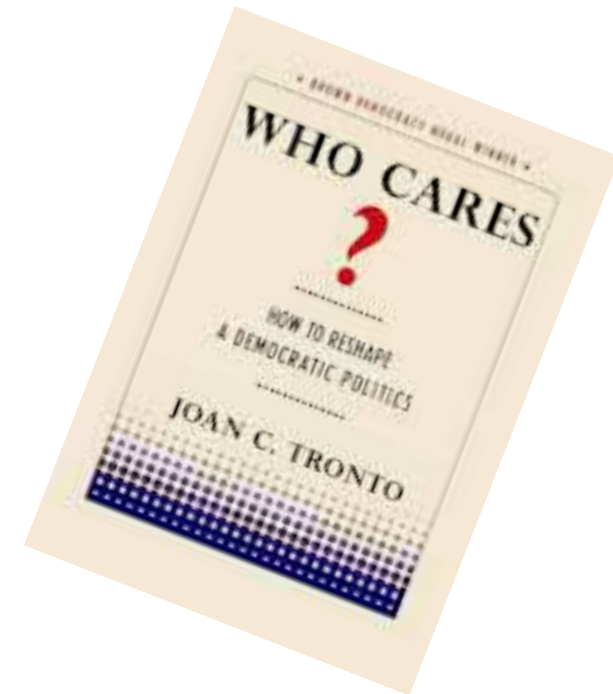
See_me.mp4

But...



Ervaringskennis en wetenschappelijke kennis vanuit het perspectief van mensen met een 'dubbele identiteit':
doorleefd verstaan

What is the right way





Lesson three:
There are no recipes for good care: you can't simply use protocols. Good care asks to improvise, talk with people, see them, know their environment, how they live, and then think about a treatment that fits.

Bridge three: learning from stories about living with diabetes and the scientists Annemarie Mol and Bruno Latour.

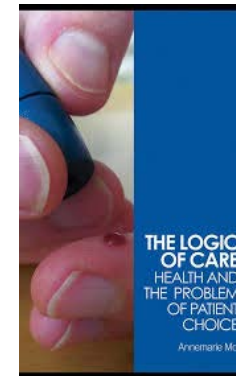
-Latour: you can't simply use a solution that works in one environment and project it on another environment. It needs puzzling, finding a solution which will ensure that due respect is shown for the various, diversity as well.

-Anne Marie Mol: Logic of care, tinkering.

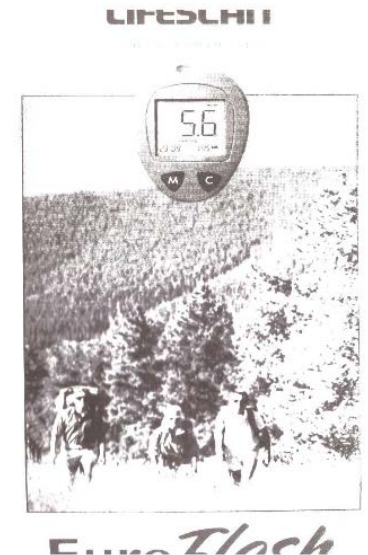


Bruno Latour: The Berlin Key

<https://www.youtube.com/watch?v=UW4jZLEgaiU&list=PLHcX7xeSZg0eWnXY29m0hQF-iBjNFRB3-->



Anne Marie Mol: Logic of Care
Diabetes



What do we need?



A plea for Patient Sciences

- The three examples show that there must be done a lot of translational work: but nothing about us without us. So this is a plea for Patient sciences.

Why:

- We have different types of what is called patient knowledge: recipients, peer counselors, experience based knowledge, scientists who are patients too, writing scientific papers or doing research for and with patients, a lot of sources with patient knowledge.

It must be more than patient participation: a science, an umbrella for all the (now fragmented) patient knowledge, next to Nursing science, and Medicine with an own paradigm.



the body multiple ontology in medical practice annemarie mol



