

# A Dutch way: building bridges between practice and science with stories of [www.patientervaringsverhalen.nl](http://www.patientervaringsverhalen.nl)



Elegant



Sofisticated

Stichting CCC  
*opent bronnen...*

[www.patientervaringsverhalen.nl](http://www.patientervaringsverhalen.nl)  
@patientervaring

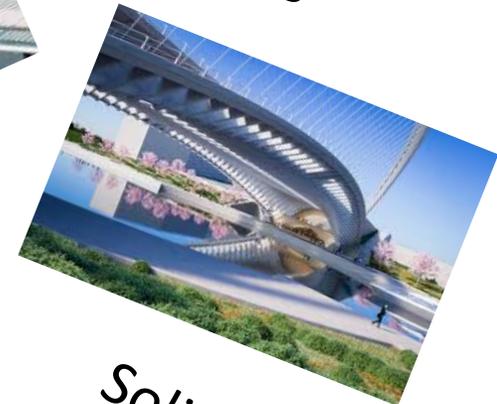
Coleta Platenkamp



Fitting



Good



Solid

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



But first: who am I?

# Patient ervaringsverhalen.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 **patient ervaringsverhalen.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.



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.

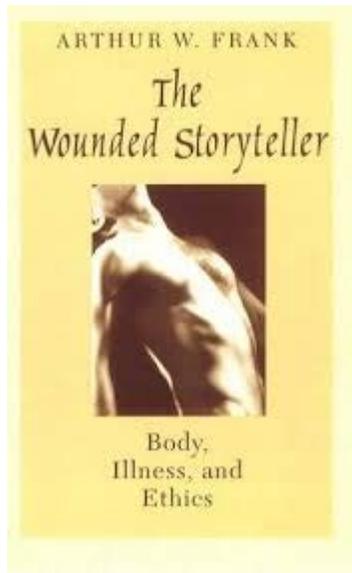


"I've still got 37 more slides to go!"

## **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**



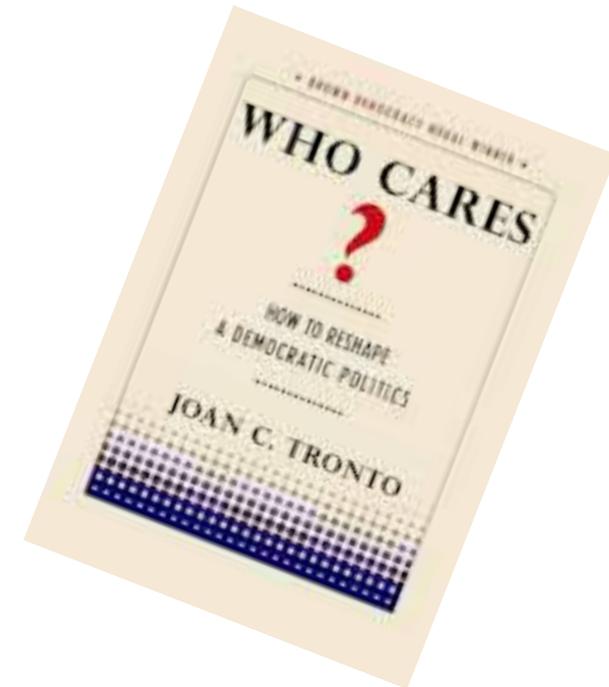
See\_me.mp4

**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.**

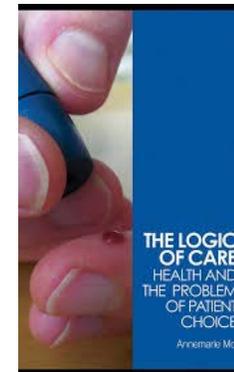
**-Latour: you can't simply use a solution that works in one environment and project it on another environment. It needs puzzling, finding a solution which will ensure that due respect is shown for the various, diversity as well.**

**-Anne Marie Mol: Logic of care, tinkering.**

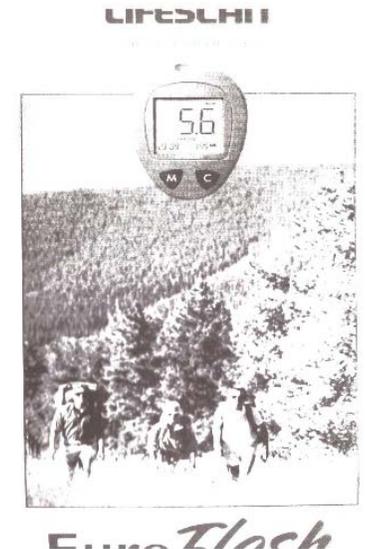


Bruno Latour: The Berlin Key

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



Anne Marie Mol: Logic of Care  
Diabetes



# What do we need?

