



**TRANSFORMING
THE HEALTH
RESEARCH
SYSTEM**

EMBEDDING PATIENT
ENGAGEMENT IN
DECISION-MAKING

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Rector, ladies and gentlemen. Dear friends, family and colleagues, I am pleased that you are present at my defence. In the next ten minutes, I will briefly explain my research.

Opening (Slide 1)

My research adventure started in Canada, where I came into contact with an innovative way of scientific research. Namely doing research with patients, instead of about them. I hear you thinking, doesn't that make sense given that health research is meant for patients? Perhaps logical, but not usual.



Research & Innovation (Side 2)

The development of new knowledge looks more or less like this: researchers have an idea, develop a study, carry it out and then share results with mostly scientists. This is also known as a supply-oriented system.

It is expected that people living with an illness or disability will be able to use the knowledge and products that emerge from research. Although research has brought us many new treatments, in recent years we have seen that new studies do not always lead to better care or health. Studies often do not meet the needs of patients, which among other things means that people do not want to participate in research and the questions that patients have remain unanswered. This causes research waste and dissatisfaction.



An example (Slide 3)

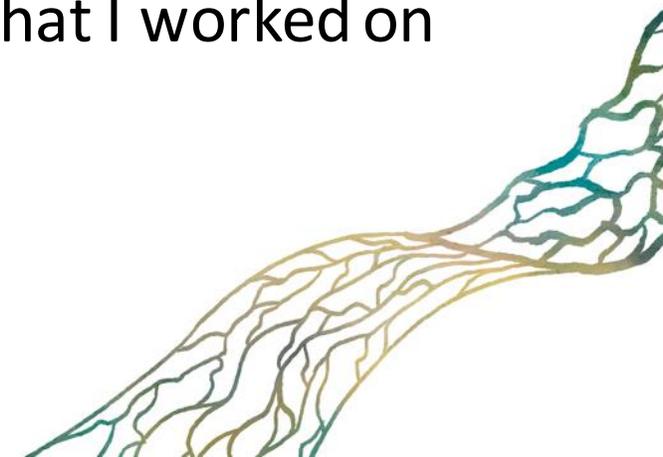
This is Max, a 16-year old boy. Max has a rare disease and uses a wheelchair. He is a research participant in a study for new treatment methods. For this, he has to go several times a week to the hospital and has to fill out questionnaires. This costs Max a lot of energy and does not fit well into his daily life. The researchers mainly look at medical outcomes. For example, the amount of a certain protein in this blood or how many meters Max can walk. Max would like to be able to control his wheelchair well. He would also like to know whether he will be able to eat a meal independently. And if he has less pain in a day. Questions that remain unanswered.



Decision-making with experiential knowledge (Slide 4)

What if we reverse the process and start with the end-users? After all, research that wants to make an impact starts with asking the right question. In my dissertation, I describe a needs-oriented research system, in which patients have a say in decision-making processes. For example: what research is being done, which outcome measures are important, how to set up a study, how and with whom to share results, etc. In every phase of the research process, patients and their carers can offer unique insights because they know what it is like to live with an illness or disability.

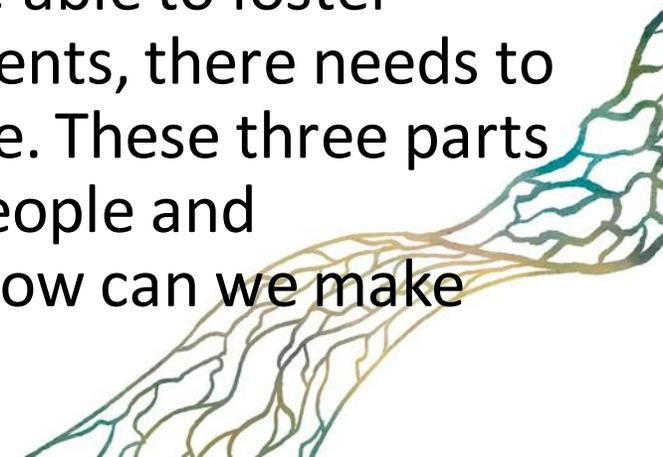
I hear you thinking, if they can offer so many insights, why aren't patients structurally involved? A simple question, and a complex answer that I worked on with Canadian and European partners during my dissertation.



System change (Slide 5)

When implementing patient engagement, we quickly ran into barriers. Many clinician-researchers indicated that they saw no added value in collaborating with patients, as they thought they know what patients need. We decided to look for researchers who did see the added value of experiential knowledge. We found them, but they also encountered barriers. They didn't know any patients or felt impeded to contact patients because of regulations. Patients who were involved in research often felt unheard and saw little change.

In short, the entire health research system does not appear to be able to foster interactions between researchers and patients. To empower patients, there needs to be a drastic change in the research culture, structure and practice. These three parts form the foundation of my dissertation. We already know that people and organisations tend to stick to existing routines. The question is, how can we make patient engagement the new normal?



Innovation networks (Slide 6)

Worldwide, initiatives have been launched that bring different parties together to influence system change. During my dissertation I was involved in two initiatives:

1. The Strategy for Patient-Oriented-Research, an initiative set up by a Canadian research funder in collaboration with partners
2. PARADIGM, a collaboration between European patient organisations and biopharmaceutical companies

An assumption was that by jointly developing tools and infrastructures, patients can be more meaningfully and structurally involved in research. We worked on three infrastructures: (1) Matchmaking, (2) Training and (3) Monitoring and Evaluation. I will now explain each of these.



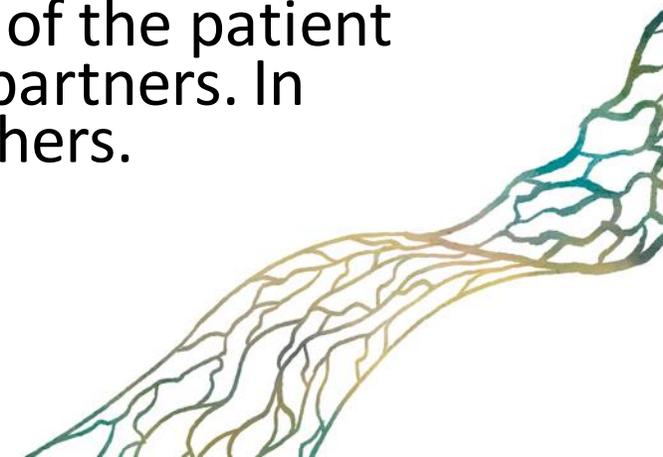
Matchmaking (Slide 7)

In Canada, I worked on removing a practical barrier, namely the lack of connections between researchers and patients.

We developed a matchmaking infrastructure. A kind of dating agency for relationship mediation between patients and researchers. We connected patients to research teams and committees. We also created a patient advisory board that researchers could turn to for input from patients.

To what extent does this contribute to system change?

Over time we saw a change in attitude, most researchers who were connected to patients indicated that they found the collaboration valuable. A matchmaking infrastructure removes several obstacles in the current structure, such as the lack of time to make connections. A point of attention is the diversity of the patient population, mostly higher educated women applied as research partners. In practice, many relationships arose between patients and researchers.



Training (Slide 8)

People had questions about “how” to establish and maintain meaningful collaborations. In the current educational structure, people do not learn the competencies necessary for patient engagement.

In Canada, we therefore created a learning environment where researchers, professionals, policymakers and patients learn about doing research together. I delivered many training sessions with a patient partner. We evaluated the curriculum development process and its outcomes. The collaborative learning model was seen as an important success factor.



Training (Slide 8 - continued)

To what extent does such a learning environment contribute to system change?

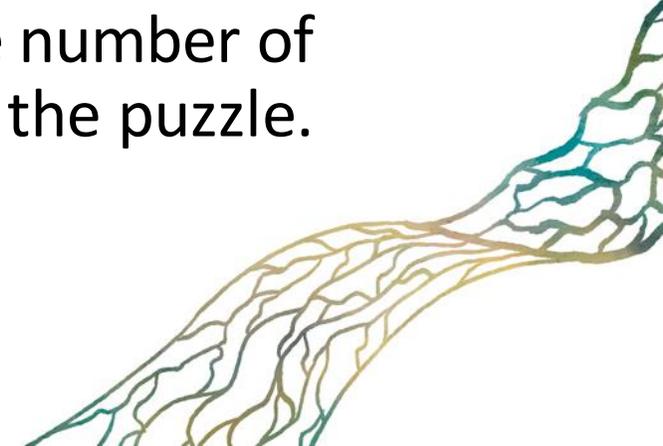
The focus on not only developing knowledge and skills but also coming into contact with different stakeholders resulted in insights and understanding of each other's knowledge. A point of attention is the sustainability of the training modules, these are often not integrated into the current educational and organisational structures. In practice, we noticed that most researchers and patients who attended training sessions started to collaborate.



Monitoring and evaluation (Slide 9)

At one point a patient asked me: *am I making a difference?* Interesting question. If you want to know how well the collaboration is working, we have to monitor and evaluate this. But how do you measure the value of a relationship? After all, every relationship is different and the value depends strongly on personal values. In addition, you often do not know in advance what you will learn from someone else.

In the literature, we found studies that said something about the value of patient engagement, often from one perspective or focused on one outcome. For example, what effect do collaborations with patients have on the number of people willing to participate in scientific research? One aspect of the puzzle.



Monitoring and evaluation (Slide 9 – continued)

To understand the impact of patient-researcher relationships, we need to connect different perspectives and aspects of the collaboration. The art is to collaboratively form a total picture.

Together with biopharmaceutical companies and patient organisations, we developed a monitoring and evaluation framework. You can see this as a card with different dishes from which you can compose a menu. This offers parties a structured way to make the change process and its impact visible and open to discussion.



Monitoring and evaluation (Slide 9 – continued)

Participating parties gained insights into the value for various stakeholders and ways to measure this. We saw that people found it difficult to create a 'menu' together because they are used to standards. It was also difficult to find suitable measuring instruments. In practice, we observed that the evaluation approach stimulated collective learning about patient engagement. More work is needed to implement the evaluation approach.



Conclusion (Slide 10)

Then the question remains, where do we stand? Is patient engagement the new normal or still an exception to the rule? I conclude that the infrastructures we developed as part of my dissertation contributed to system change. We are moving towards a more needs-oriented research system, but we are not there yet. By co-creating a culture and structure to continue patient engagement, we are making the engagement of patients in decision-making the new normal. So that Max's questions can also be answered.

My dissertation is therefore more of a start of a journey than a final destination. And not just a product of mine but of all those who contributed. I would like to thank everyone I have worked with for your inspiration and support during this journey.

