Erasmus School of
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& Management

Patient Sciences:

Collecting, Translating and Including Patient Stories in Decision-Making

Professor Hester van de Bovenkamp

Erasmus University Rotterdam
Making Minds Matter

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Colophon

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Madam Rector Magnificus,
Dean,
Colleagues, family and friends,
Esteemed guests,

1. Introduction

"Well, you have a lot on your plate and you've reached your limit! And that's not surprising, of course: with a busy job, a toddler at home and various rounds of IVF behind you, it's little wonder that you're not feeling great. There may also be something going on physically, but it's all manageable and can be sorted with a little pill; there's no need to be overly dramatic." This is what my GP told me when I went to see her about symptoms including extreme fatigue and abdominal pain. "Fortunately, you have a great husband", she said, looking at Hans, who had come with me for moral support. The pill was to treat the symptoms of a benign brain tumour, which was playing havoc with my hormones. After trying for months to find the right dose for that undramatic pill, some of the symptoms had gone and the side effects were reasonably under control. Being overwhelmed by all the things I had on my plate therefore turned out not to be the problem. However, the pill also affected my cycle and, among other things, I was suffering from increasingly severe abdominal pain. When I saw the GP about this – a different one this time – I explained that I recognised the abdominal pain and believed it was due to my endometriosis. The response was: "No, it can't be that, as then you'd only have pain during menstruation and not in between." I was, however, referred to the gynaecologist. I tried to explain my story to the gynaecologist in a matter-of-fact way, helped by the improvement in my hormones since starting the medication; I was also keen to avoid being told that I had "a lot on my plate" again. I received an ultrasound and was given the verdict: "It doesn't look great. It's strange, as in this condition I wouldn't expect you to be so upbeat."

What story do we tell?

I have just described some of my own experiences as a patient in the healthcare system. Together with colleagues, I have been researching these kinds of experiences for some years now. Our research focuses on the question of what the experiences of patients and their loved ones can teach us about how healthcare could be done differently and better and how these lessons can be used to develop new practices and policies. My own experiences reinforce my belief in the importance of such an approach.

What can we learn from these experiences? Based on the brief description of my own experiences, you may be thinking about one of the following lessons.

Perhaps you would conclude from this description that doctors do not take their patients seriously enough, do not look and listen enough, and are too paternalistic in thinking that they know what's good for them.

Or maybe for you it's just the umpteenth example of women in particular not being taken seriously; an example of the way in which, both inside and outside the healthcare system, they are quickly stereotyped as overly emotional and the seriousness of their symptoms is downplayed, as well as an example of the lack of knowledge about conditions that affect women in particular. All this while a man immediately gets a pat on the back and is considered a great guy just for turning up somewhere.
You could also interpret these experiences as a story about insufficient attention being paid to and a lack of knowledge about comorbidity in healthcare. What actually happens if we treat a patient for one condition and they also have another one? This is a question that does not receive sufficient consideration.
Lastly, the healthcare professionals among you may be thinking: erm, hello, what we do is incredibly complex, we are constantly having to figure out what is happening with patients who have all kinds of things going on in their lives and can be a little calculating in how they tell us their story.

These various interpretations are all valid. To me they all demonstrate the added value of patient experience stories, as they can be used to reflect on what matters in healthcare and how healthcare could be improved. At the same time, sharing and analysing these experiences raises all manner of questions. I made a number of choices in the way I just described my own story. I mainly shared the less positive experiences, for example, even though I did also have positive experiences with the same doctors. The same was true of the doctors in the emergency department when we had to go there with our young son Olaf. He was very sick and the doctors did not know why, and therefore whether it was serious or not. They asked us back repeatedly and gave us their time, telling us "we take the maternal instinct very seriously". I did not hear them mention the paternal instinct, but let's keep focusing on the positives (for the importance of recognising the role of fathers see Petit-Steeghs et al. 2024). I am also thinking back to Olaf's nurse, who, when he got upset at the hospital, drew him a picture of a gnome riding on a dinosaur to cheer him up. Lessons can also be drawn from these experiences, but they provide an entirely different picture of healthcare.

What story do we hear?

The experiences I started with demonstrate that interpretation is needed to be able to draw lessons from them. In the words of the philosopher John Dewey: *"We do not learn from experience…we learn from reflecting on experience"* (Dewey in Halloy et al. 2023). The lessons we learn are also dictated by our existing interpretative frameworks. In other words, how we interpret a story is partly determined by the other stories or the personal experiences that are already in our head (Frank 2010). Learning from experience is therefore a rather complex task. And that is before I have even touched on questions such as: how can we do justice to diversity among patients and loved ones? And how can we ensure that knowledge about these experiences actually plays a role in decision-making within healthcare?

Collecting stories, translating them and including them in decision-making processes
These reflections are a prelude to the core message of this inaugural lecture, which is also, in my view, what the discipline of Patient Sciences should be about: namely that experiences of patients and loved ones offer added value in healthcare and we can learn lessons from them about how care and support could be changed and improved, but also that this does not happen automatically and an effort has to be made to collect stories, translate them and subsequently include them in decision-making processes.

Before I go into more detail on these three points, I would first like to touch briefly on the background to the discipline of Patient Sciences.

2. Towards Patient Sciences

For decades now there have been calls for patients and clients to be involved more in decision-making (Trappenburg 2008, Van de Bovenkamp 2010), so that the care they receive can be better tailored to their individual needs and wishes. These calls remain relevant today. For example, one of the pillars of Appropriate Care, the current dominant policy discourse aimed at ensuring that the Netherlands continues to offer good, accessible healthcare, is that patients determine together with their doctor what the best treatment is (Zorginstituut Nederland 2024). In its multi-annual policy plan, the Health and Youth Care Inspectorate also calls for human-centred care that pays attention to the person behind the patient or client (Inspectie Gezondheidszorg en Jeugd 2024).

So these appeals are certainly topical. At the same time, however, they have also been around for a while. There has been quite some development over the years. Some excellent examples can be found in the dissertation by Jolanda Dwarswaard. She explains that in the 1960s the prevailing view still was that a good professional should not inform patients about the fact that they did not have long left to live. It was believed that knowing this would make their illness infinitely more difficult to cope with than if they remained unaware of it (Dwarswaard 2011). An approach that will be hard to imagine for many of you today.

If you want to incorporate the human dimension and appropriateness of care at the individual level, you need to adapt your practice and policies accordingly. To do so effectively, you also need to make space for patients' perspectives at the collective level. A lot has changed in this respect too. In the 1960s, healthcare, particularly in the field of psychiatry, became part of a broader democratisation movement. Patients belonging to the anti-psychiatry movement mobilised, demanding a say in all kinds of decision-making bodies, among other things (Oosterhuis & Gijswijt-Hofstra 2008). Nowadays, there are opportunities for patients to participate and be represented at various levels of decision-making. Numerous experiments are being conducted, focusing on methods of involving patients in the healthcare organization's policy, quality improvement processes, research agendas, guideline development and government policy (Van de Bovenkamp et al. 2010, Van de Bovenkamp & Zuiderent-Jerak 2015, Heerings 2022, Van der Wouden et al. 2022, Dedding et al. 2023).

A laborious process

In spite of these changes, research reveals that involving patients and taking their perspectives into account is easier said than done. It is a laborious process. In the words of Coleta Platenkamp, sociologist and chronic pain patient: "a lot is being done, but not a lot is necessarily being achieved" (Platenkamp 2018). It was partly for this reason that, in 2018, she called for the introduction of Patient Sciences, so that a more serious effort could be made to unlock patients' knowledge. This is a plea that I fully endorse as I take up this chair.

Other academic disciplines, in particular medicine, are also concerned with patients, of course. Patient Sciences differs from them in that it focuses specifically on obtaining an in-depth insight into patients' and loved ones' experiences of healthcare and everything associated with it, as well as, more broadly, their experiences of living with a condition and its impact. It also focuses on how this insight can be incorporated into decision-making. These topics have already been the subject of research for some time. In my view, however, a broader perspective is needed that brings together insights from various academic disciplines, including healthcare research, disability studies, sociology of science, narratology, public administration and political science, as well as insights from practice.

Taking such a broad view better reflects the complexity behind issues associated with learning from patient experiences. This complexity is due, among other things, to the fact that it is by no means always clear what 'good care' is, as well as to the diverse range of experiences and knowledge, the institutional structures that influence decision-making, the layers of decision-making involved and the political considerations that have to be made in the area of healthcare.

Critical science

Focusing on this complexity from various perspectives makes Patient Sciences a critical science, one that critically examines the considerations made in research and practice when it comes to shaping how we learn from patient experiences. A science that also brings into focus underlying structures that influence patient experiences and how these experiences can or cannot be reflected in the decisions that are made. This kind of critical perspective is needed to ensure that learning from experiences does not merely become a theoretical article of faith, but a well-founded practice that does justice to the complexity of the problem.

Social scientists often talk about complexity. The danger here is that we risk making every topic unnecessarily complicated. In my view, our role is to clarify this complexity. I am convinced that we will then be able to do things that allow us to achieve more.

The rest of this inaugural lecture deals with three aspects of the work needed to learn from patient experiences: collecting stories, translating them and including them in decision-making processes.

1. Collecting stories: this is about the potential of stories and the work needed to collect them and draw lessons from them.
2. Translating stories: this is about how stories are translated through participation and representation.
3. Including stories in decision-making processes: this is about how knowledge obtained from stories can have an impact on collective decision-making in healthcare through more reflexive governance, regulation and policymaking.

3. Collecting stories

First of all, I will discuss the importance of collecting stories, how stories can be turned into a collective source of knowledge and how I aim to contribute to this.

Measuring won't tell you everything

If we want to know more about the experiences of patients and loved ones, we need to ask ourselves how we find out what these experiences are. This immediately leads us on to the question of how individual patient experiences can be effectively turned into a collective source of knowledge.

One way of doing this is to make these experiences measurable in a quantitative way by asking patients to complete questionnaires. This approach is in keeping with a broader desire within healthcare to obtain, and learn from, insights into quality of care through quantitative indicators (Bal 2008, Wallenburg, et al. 2021). Today, this trend can be seen, for example, in discussions about *value-based healthcare* (Lingsma 2023, Steinmann 2023). The associated "measuring machinery" is not without its critics, however (Lingsma 2023). In her inaugural lecture, my colleague Diana Delnoij pointed out that various aspects of quality of care and quality of life are carved up if we measure patient experiences in this way, even though they actually form one cohesive set of experiences in a person's life (Delnoij 2019). Continuously collecting all kinds of data without having a clear idea of what it will be used for also creates an administrative burden in healthcare practice (Van de Bovenkamp et al. 2020). This applies not only to healthcare professionals, but also to the patients who must complete all these questionnaires. Research by the Netherlands Institute for Health Services Research (Nivel) on using patient experience measurements in specialist medical care also shows that, although the intention is to use these questionnaires for learning and improvement, in practice they are mainly used for monitoring. Moreover, the results of the measurements are not used to facilitate patient choice or benchmarking, which were also on the list of objectives (Doorduijn, et al. 2022). One further consideration is that, although you may be able to pick out points from this information that indicate where you are scoring less well as a healthcare provider, the reasons why will not yet be clear (Vennik, et al. 2016).

It is partly for these reasons that increasing attention is being paid to the potential that patients' and loved ones' stories have in terms of revealing what is important to them. Instinct tells us that taking account of stories is also entirely logical. It is human nature to tell stories and through them we give meaning to our lives (Kearney 2001, Frank 2010). If you ask people how they are doing, not many will reply with a number. The same is true if you ask them about their experiences of healthcare. However, they will share their stories. In healthcare, these stories are increasingly coming under the spotlight. Take, for example, the attention being paid to narrative

medicine and to the life stories of clients and residents in the field of long-term care (Charon 2006, Berendonk, et al. 2017). The idea behind this is to give meaning to what matters to people and adapt healthcare in line with this (Frank 2016).

Collecting stories

It is important, however, that attention is not just paid to stories at an individual level. Stories can also be recorded, collected and used as a collective source of experiential knowledge. This knowledge can teach us to look at the world through different eyes. In the words of sociologist Arthur Frank, who also has experience of being a patient himself and has written a great deal about the value that these stories have as a supplementary collective source of medical scientific knowledge: *"Telling stories of illness is the attempt, instigated by the body's disease, to give a voice to an experience that medicine cannot describe."* (Frank 2013, p.18).

Stories can therefore help to uncover aspects of illness that would otherwise risk being overlooked. I will provide a number of examples of this. However, as I already mentioned at the beginning of this inaugural lecture, learning from stories is not something that happens automatically. A certain amount of interpretation is required. To ensure that stories are used effectively as a collective source of knowledge, reflecting on that work is important. If we are serious about using stories, we must not regard them as beyond criticism – something that risks happening in discussions that place the value of stories above that of numbers. Stories do not provide access to the "objective" reality of "the patient". After all, they always incorporate an element of bias. Arthur Frank emphasises this in his relevant book Letting stories breathe. He makes clear that stories are told in a particular way, determined by the narrator's frame of reference and the choices made about what and what not to tell, as well as about how to give meaning to this (Frank 2010, Frank 2013). Stories are also received in a particular way. People hearing or reading a story also do so based on their own frame of reference and therefore place the emphasis on what they consider to be the essence or lesson of a story (Frank 2010, Frank 2013). If stories are not, or not allowed to be, questioned, this can have negative consequences: dominant stories can stifle and silence other stories and perspectives (Frank 2010, Van der Scheer & Stoopendaal 2018, Mäkelä, et al. 2021, Berg, et al. 2024). All this means that learning from stories should be an ongoing, reflexive process, so we can see what we are learning and whose story we are in danger of discarding.

Available stories

There is a wealth of patients' and loved ones' stories available that could serve as an important basis for this collective source of knowledge. Patients and loved ones share their stories in all kinds of ways: in books, blogs, TikTok videos, various art forms and many others. Familiar examples are the books written by sociologists who were also patients themselves, such as Susan Sontag (Sontag 1978) and the previously mentioned Arthur Frank (Frank 1992), or by Dutch celebrities such as Clairy Polak, who wrote about living with a partner suffering from Alzheimer's (Polak 2021). These stories are collected in various places in the form of story banks, the idea being that together they represent a source of collective experiential knowledge (see, for example, www.patientervaringsverhalen.nl, www.psychiatrieverhalenbank.nl, www.pratenovergezondheid.nl).

Coleta Platenkamp, who I mentioned earlier, started collecting written stories following her own experiences as a patient suffering from chronic pain. She quickly concluded that other patients could also benefit greatly from the knowledge that these stories contain. She set up a foundation that collected stories and described them on the website www.patientervaringsverhalen.nl, and has published works and given presentations on the knowledge gleaned from them. In this way she has made a crucial contribution to unlocking this knowledge and ensuring it is taken into account (Platenkamp, et al. 2014, Platenkamp 2018, Platenkamp & Schouten 2018).

When Coleta retired, Erasmus School of Health Policy & Management (ESHPM), together with the Erasmus University Library, took over the collection of written patient experience stories. We continue to expand the collection and describe it on the website, and it now comprises over six thousand written stories. In addition, we are focusing on collecting stories of people who are not inclined to write about their experiences. The methods we are using here include interviews and observations, as well as capturing stories in the form of photos or films (De Graaff, et al. 2022, Heerings 2022, Gräler 2024).

What can we learn from stories?

While keeping the comments I made earlier in mind, I would now like to briefly discuss a number of general lessons that can be learned from the stories of patients and loved ones. Generalising these lessons, and therefore making reductions of these stories, is important, for the very reason that patients' and loved ones' stories can challenge other dominant stories or ways of thinking in healthcare and policy-making. They also show that what 'good' is when it comes to care and support is by no means always clear. These stories can therefore help to identify ways to do things better (Mol 2008).

Importance of emotions

The first lesson that I would like to mention here is that emotions are important when you are living with a condition. You can see from the stories of patients and loved ones that, as is the case in the other areas of our lives, being a patient evokes emotions. It is associated with feelings of fear, relief, sadness and loneliness (Frank

1992, Woolf & Lorde 2021, Scholtes, et al. 2022). Healthcare is therefore not just a rational and technical matter, but an emotional one too. This is a point that by no means always receives enough attention, in a healthcare system that is geared towards medical diagnosis and treatment. In fact, the emotion that stories contain and their subjectivity are sometimes used to cast doubt on their value, the argument being that emotions present an obstacle in the search for objective knowledge. Josje Kok, David de Kam and other colleagues demonstrate this in their study on involving patients and loved ones in incident investigation in healthcare. Healthcare organisations carry out incident investigation if something has gone wrong in the provision of care, to find out how this happened and what they can learn from it. Patients or loved ones are being involved more and more in such investigations. In these situations their stories are highly emotional. That is understandable, as people will be angry or distressed if something has gone wrong. However, these emotions mean that their contribution has little impact, as emotions do not fit easily into a search focused on uncovering "the facts" (Kok, et al. 2022).

I believe that the emotion in stories is actually one of their important attributes and one to which we should pay more attention, precisely because the emotional impact of illness and care can be so great. Paying attention to emotions is therefore paying attention to what matters in healthcare. One way to take more account of emotions is to focus on emotional touchpoints, a concept introduced by organisational scientists Paul Bate & Glenn Robert. Emotional touchpoints are those things that sometimes seem minor in healthcare, but can nevertheless be very important for patients, in both a negative and positive sense (Bate & Robert 2007, Heerings 2022, Scholtes, et al. 2022, van Keulen, et al. to be published). Examples include the little gestures by healthcare professionals that really make the difference in terms of whether you feel seen and heard, such as drawing a gnome on a dinosaur, or, conversely, make you feel like you are being reduced to the status of a medical object (Ten Haaft 2010, Byvanck, et al. 2022, Scholtes, et al. 2022).

Everyday hassle and "sickness work"

The second lesson that we can learn from patient stories is that suffering from a condition can have a significant impact on your day-to-day life. This goes far beyond the medical symptoms alone. Gerard Nijhof (2002), another sociologist who underwent treatment himself as a patient, emphasised the everyday "sickness work" that patients do and the impact it has (Nijhof 2002). A good example is the work arising for patients in connection with waiting; Nada Akrouh gave a presentation on this during the symposium that preceded this inaugural lecture (Akrouh, Wehrens et al. 2024). "Sickness work" and its impact is also conceptualised as the burden of sickness, treatment and support (May, et al. 2014, Sav, et al. 2015, Heerings, et al. 2023). In this case it covers all aspects of the burden and – as Meralda Slager neatly put it – hassle that you face as a patient in your everyday life (Slager 2020, Kamp, et al. 2022, Liabo, et al. 2022, Pols 2023, Rietjens 2024).

One example of these day-to-day struggles is the stress associated with administering your own medication at home via a drip. Truus Teunissen, a chronic patient, researcher and patient representative, gave an evocative account of this very task:

"Hopefully the infusion pump alarm won't go off again like last time because then I'll immediately be shocked, and I have to call the online nurses with trembling fingers about what to do. I feel very unsafe at such a moment with the needle in my body connected to an IV and an alarm bell that keeps going off..... it is difficult for me not to panic completely." (Teunissen & Abma 2024, p.2)
maar dat voelt nu niet zo." (Teunissen & Abma 2024, p.2)

Patients' loved ones can be affected just as much by this everyday hassle and the care tasks they take on. Leonoor Gräler recently highlighted this neatly in her dissertation (Gräler 2024).

Stories can provide an insight into where "sickness work" lies and the burden it can place on people. This burden also changes over time. After all, new therapies (De Graaff, et al. 2022), new techniques (Wiedemann 2021) or new policies (Van de Bovenkamp & Dwarswaard 2017, Heerings, et al. 2023) can bring benefits for patients and loved ones, but also give rise to new forms of burden or hassle. It is therefore important to monitor these experiences with a critical eye on an ongoing basis and reflect on what they mean for care and support. Especially when we consider that this everyday hassle is only growing, due to all the self-management that patients and their loved ones are increasingly expected to take on. If we lose sight of this, there is a risk that the burden associated with sickness and treatment will remain unseen amidst all the hurrah words.

How to deal with this burden and hassle

Thirdly, lessons can be drawn from stories told by patients and loved ones about how to deal with an illness or disability: stories about what helps patients, how they can find ways and practical tricks themselves to help them live a good life with their condition, and what values are important here (Pols 2014, Van de Bovenkamp & Dwarswaard 2017, Heerings 2022, Pols 2023). That may mean getting your illness more under control from a medical perspective, but also living better with an illness or disability, even if you know you will never recover.

In her moving book Tussenland: *over leven met de dood in je schoenen* (No-man's land: on living with death in your shoes), Jannie Oskam talks about her own experiences of life and care in a situation when you know you will never get better. She also includes stories of fellow patients. These experiences are explained by laying bare

shortcomings in how healthcare is provided. She describes how, as a cancer patient, she ends up in "no-man's land". She writes: *"anyone who cannot be cured ends up in 'no-man's land': a transition zone between life and death where you don't know the way and don't speak the language"* (Oskam 2021). Her story puts into words the problems she encounters and gives substance to what patients experience and what they believe is missing from healthcare, as well as the impact that the lack of understanding they come up against in their daily lives has on them. Through her story she not only brings home these problems, but also provides an insight into how things could be done differently. In this way, her experiences and ideas can help to improve the care provided to other patients in a similar situation. She refers to the importance of signposts to guide patients through this "no-man's land" and of providing palliative care well before the final months of a person's life. After all, patients may find themselves living in "no-man's land" for years.

Diversiteit onder patiënten

One thing that clearly emerges from these stories is that there is no such thing as *the* patient, just as there is no such thing as the healthcare professional. This may seem obvious, but it is nevertheless worth mentioning. What patients see as important in terms of living with their condition, the care and support they receive, what troubles them and the impact this has, and what helps them can differ to some extent from one person to another. Whereas for one person seeking out information may be important to try to get a handle on the disease process, for example, another person may prefer not to know and put their trust in the expertise of the practitioner (Scholtes, et al. 2022). Although an increasing emphasis is being placed on the importance of patient centredness (Cramm 2022, Rietjens 2024), at the same time there is a tendency in policy documents to talk about the patient and *the* patient's perspective. Patients' stories demonstrate that it is vital to challenge one-sided discourse on what patients see as important.

Exposing blind spots

When giving presentations on patient experiences it is often clear that lots of people recognise what I am talking about. Sometimes I also hear the question: but didn't we know this already? That may be partially true. However, patients are evidently still coming up against the same issues when receiving care and support, such as the feeling of being reduced to the status of a medical subject, or a one-sided emphasis on self-management and self-reliance that puts a great deal of pressure on people and risks increasing inequality further. Knowing what to do is not enough, explained the Netherlands Scientific Council for Government Policy in a report criticising policies that aim to encourage citizens to be self-reliant, but are based too much on their cognitive abilities (WRR 2017). I think something similar is going on with policymakers and healthcare professionals.

So while certain lessons that we may be able to draw from patients' and loved ones' stories may not be new, we are by no means always acting on them yet. But the question is also: do we really know it? Are we actually aware of these lessons? The stories of healthcare professionals who have become patients themselves demonstrate that this is far from always the case (Ten Haaft 2010, Byvanck, et al. 2022). Gonny ten Haaft's wonderful book *Dokter is ziek* (Doctor is sick), but also stories shared more recently, are interesting examples of this. These stories provide an excellent insight into how your perspective changes when a healthcare professional turns patient, and how patient experiences can expose blind spots. This is not a criticism of healthcare professionals or policymakers; there are some things that you only see and understand once you experience them for yourself or are made aware of them in another way.

Let me give an example of a situation in which I lacked insight myself. Before I started working with Kyra Mulders, one of our students at EUR who has a physical disability and relies on a wheelchair, as a lecturer I had not actually given much thought to how poorly accessible our education is for disabled students. It was only after talking to Kyra and doing a few rounds of the campus that I realised just how inaccessible the campus is in various ways for students with a disability. You must overcome quite a few obstacles to get from one part of the campus to another in a wheelchair. Doing so in the fifteen minutes that students have between lectures and tutorials is sometimes an impossible task. And having to repeatedly talk to lecturers, study advisors and Examining Boards to proactively arrange adaptations for every course drains a great deal of your energy – energy that as a student you would rather be devoting to your actual studies or student life.

It is therefore important that as healthcare professionals, managers and policymakers, but also as lecturers, we become more sensitive to what matters to patients. Teaching the healthcare professionals, managers and policymakers of the future, while they are in training, to read and listen to stories of patients and loved ones could help in this respect. Thinking about how these stories can challenge our own assumptions and the dominant ideas in a particular professional field should also form part of this.

Collecting stories: making meaningful reductions

As we have seen, an initial goal of Patient Sciences is to analyse the stories of patients and loved ones and thereby provide an insight into what matters to patients and the diverse nature of living with a condition. These insights can then be used to shine the spotlight on a different way of looking at care, support and policymaking. But what lessons can be picked out from the mountain of stories available? To identify them, we need make reductions of these stories in one way or another. An important consideration here is how this can be done in a meaningful way (Akrouh, et al. 2024).

The research agenda relating to these stories therefore has a clear methodological side to it. One important aspect is the question of how we collect stories. The way we select them naturally means that some are included, but others excluded. It is therefore important to experiment with different ways of collecting stories and to monitor these experiments with a critical eye. Books offer an in-depth insight into patient experiences. However, not everyone writes a book. Many stories are shared on social media or in everyday conversations. These deserve our attention too. Researchers also have an important role to play in shining a light on stories that are not easy to tell, because they are too chaotic or fractured due to the impact of living with a condition (Frank 2013). This calls for creativity. One possibility, for example, is to focus attention on small, everyday stories, a task in which observations can play an important role (Sools 2013, Berendonk, et al. 2017, Heerings 2022, Pols 2023). Arts-based methods can also be used (Groot, et al. 2019, Kool 2022, Abma 2023, Dedding, et al. 2023, https://politiekvandeaandacht.nl). Together with Roman Giling, Marjolijn Heerings, Zsuzsu Tavy and Dipex colleagues Andrea Fokkens and Manna Alma, we are experimenting with recording stories on film, for example. The advantage of these kinds of methods is that they make it possible to present themes that are difficult to capture in words. They appeal to the imagination and can encourage reflection. In this way they provide an insight into the emotional impact of illness, among other things. The question to be answered in the years ahead is what knowledge is unearthed by different methods and what consequences the choices we make in this regard have for the story and message put under the spotlight.

The knowledge that stories bring to the surface also depends on the methods of analysis used. To make meaningful reductions, it is important to reflect on what these various methods highlight regarding different lessons. Together with Nada Akrouh, Rik Wehrens, Marjolijn Heerings, Nienke van Sambeek, Anneke Sools, Monique Floothuis, Marilie Odding, Mariët Faase and Diana Kwast, among others, I am currently involved in a study in which we are working with various methods, such as thematic analysis, narrative analyse and text mining, individually or in combination. Also relevant is the question of who analyses the stories and what their background is. As researchers, we do this from various backgrounds, with varying degrees of experience as patients, and also together with patients and loved ones.

Analysing different stories using different methods can provide further answers to the epistemic question of what patient knowledge is and how it can be made visible (Platenkamp, 2018)

In short, by collecting and analysing stories, we can turn patient knowledge into more of a collective source of knowledge. As part of this process, it is important to examine how we can make meaningful reductions of stories.

4. Translating stories through participation and representation

First and foremost, stories of patients and loved ones are about everyday life with a condition and their direct experiences of care and support. The individual care relationship between patients and healthcare staff plays an important role here. Stories are a means by which healthcare professionals can learn what is important for their patients in this relationship. However, if they are to have a real impact, the lessons drawn from stories must also be learned elsewhere. It is too easy to say that healthcare professionals must solve all the aspects involved in improving care and support within the care relationship if this relationship is also influenced in all kinds of ways from the outside, by the governance, organisational and social contexts.

One way to make sure stories are heard is through patient participation and representation at the collective level. And that is already happening. Take, for example, the role played by patient associations and client councils in quality improvement projects, organisational policy, guideline development, scientific research and government policy. There are also patients who engage in protest and challenge existing practices through activism. Well-known examples from the past include the anti-psychiatry movement and AIDS activists who succeeded in reforming research practices (Epstein 1998, Oosterhuis & Gijswijt-Hofstra 2008). The patients who suffered from long-term symptoms after contracting COVID-19 are a more recent example. By actively sharing their stories, they drew attention to Long Covid and eventually managed to get it recognised as a disease (Bovo 2021, Callard & Perego 2021).

As participation and representation can play an important role in translating stories to the collective level, they are a key part of Patient Sciences. By focusing on the system of participation and representation, we can learn more about the structures that affect the form that participation and representation take, how taking a broad view of representative claims creates scope to hear a diverse range of stories and, lastly, how different participation and representation initiatives influence each other.

Steering structures

Participation and representation at the collective level are frequently the subject of research, usually in the form of case studies. These show that turning participation and representation into influence is far from straightforward. The space made available for a different type of knowledge and different types of contributions is influenced by the context in which participation and representation take place. This context is by no means always supportive. Participants often have to sit on formal

decision-making bodies, for example (Trappenburg 2008, Van de Bovenkamp, et al. 2016, Oldenhof & Wehrens 2018). Margo Trappenburg commented on this some 15 years ago, referring to all the skills, time and energy that patients need to participate in this way (Trappenburg 2008).

Formal decision-making structures also determine what is considered legitimate knowledge. Guideline development, for example, is heavily influenced by the dominant paradigm of evidence-based medicine (Van de Bovenkamp & Zuiderent-Jerak 2015, Felder, et al. 2021). Regulation is also heavily influenced by regulatory frameworks that are based to a large extent on professional standards (Rutz, et al. 2018, Weenink, et al. 2021, Kok, et al. 2022, De Graaff, et al. 2024). If what is regarded as legitimate knowledge is highly institutionalised in this way, there is limited scope for patient knowledge. Patient contributions are used to legitimise decisions if these contributions are in line with the opinion of other actors. In the event that the contributions conflict with the viewpoint of these other actors, they are easily disregarded (Trappenburg 2008, Van de Bovenkamp & Zuiderent-Jerak 2015, Rutz, et al. 2018, De Graaff, et al. 2024). If the way in which decision-making processes are organised means that certain patient contributions are not considered relevant, patients' stories will not resonate as clearly. The earlier example of patients who were considered too emotional to participate in incident investigation demonstrates this (Kok, et al. 2022).

If the knowledge of patients and loved ones is to be translated into decisions, space must be created for different types of contributions (Fricker 2007, Sergeant 2021, Dedding, et al. 2023, Leemeijer 2024). PhD student Lizette Krist is currently researching this in relation to the participation and representation of people with so-called misunderstood behaviour. She is examining how participants and representatives do all kinds of things themselves to create this space. They adapt stories, for example by making choices about which parts of their story to tell, depending on the forum in which they are telling it (Liabo, et al. 2022, Miller, et al. 2024). They also contribute to overarching discussions on what is regarded as legitimate knowledge. A good example is Gaston Remmers, a citizen scientist in the area of healthcare, who is calling for much greater recognition of the practical knowledge of patients and professionals alike. He is doing so by positioning practice-based evidence as a legitimate knowledge base alongside evidence-based medicine. In addition, he is carrying out all kinds of institutional work to challenge existing research structures that present an obstacle to citizen science in healthcare. In short, patients and their representatives are pushing against existing systems and rules to create space for their own contributions.

Both the influence of existing decision-making structures on patient contributions and the strategies needed to remodel these structures are key topics to include on the Patient Sciences research agenda.

Representative claims

Another important topic is research focusing on the representative claims made with regard to patients.

Patient involvement in collective decision-making is often viewed through the lens of participation. Considered from this perspective, questions quickly arise about the representativeness of the participants: do the patients concerned accurately reflect the wider patient group? In most cases they do not. To some extent this is a consequence of the structures I have just described. Participating in formal decision-making processes or having any involvement at all in different kinds of decision-making processes is simply not in line with many people's preferences or skills (Hibbing & Theiss-Morse 2002, Callon & Rabeharisoa 2004). Direct forms of participation are therefore by no means always inclusive. This is apparent from various forms of direct participation inside and outside healthcare (Michels 2011, Bovens & Wille 2017). The same applies to new forms of participative governance that are very much in the spotlight at present, such as city labs, as explained in Sabrina Rahmawan-Huizenga's dissertation (Rahmawan-Huizenga 2024). This problem is all the more relevant in the field of healthcare, however, as illness can present an obstacle to participation (Teunissen & Abma 2024). The danger is that the different possibilities for participation at the collective level that place great demands on participants could result in certain voices receiving extra attention while others remain unheard (Hirschman 1981, Bovens & Wille 2017).

For this reason, I previously argued, together with political scientist Hans Vollaard, that more effort should be made in healthcare and the social-services sector to consider how representation could play a role in democratising decision-making, focusing on representatives who are not the usual suspects and who claim to represent patient groups who are less eloquent and whose voices are less often heard (Van de Bovenkamp & Vollaard 2018).

By looking at all the different actors who claim to represent a particular group, instead of only actors who do so in a formal capacity, we can bring many more representatives into the picture (Saward 2010). Alongside formal patient representation channels, such as patient organisations and client councils, these also include all kinds of self-appointed representatives who are drawing attention to the stories of groups that risk being overlooked. These self-appointed representatives may be individual patients or users of the healthcare system. One well-known example is Jason Bhugwandass, who actively shared his own story in various places about abuses in youth care. He also linked his story to those of other young people by actively recording them and drawing lessons from them (Bhugwandass 2024). Self-appointed representatives may also be ombudspersons, regulators, doctors or other healthcare professionals who, in their day-to-day practice, identify problems affecting a group of patients whose voices are seldom heard and who have little visibility. They may also

flag up problems that, while not overlooked, are only considered through a frame that excludes such groups. Michelle van Tongerloo, a street doctor in Rotterdam, is an interesting example of such a representative, constantly drawing attention to people who are falling between the cracks of the system.

Such claims to represent patients could potentially be based on shared experiences – for example in a case where one patient claims to be able to speak for others – on knowledge of the experiences of a particular group or on a combination of the two (Van de Bovenkamp & Vollaard 2018). The research that we are conducting on patient experience stories and that draws lessons from them is also a form of representation. After all, just as other parties are doing through their representation activities, we are interpreting stories to demonstrate what matters and articulating this in various places (Frank 2010).

Not every representative claim is a good addition to the democratic debate, of course. After all, anyone can claim to represent the people, or in this case the patient. It is important to examine these kinds of claims critically and challenge any that suggest univocality among the population when this does not actually exist. Insights from political science can help in this regard. They demonstrate the importance of responsiveness. Responsiveness is about authorisation and the accountability structures linked to representative claims (Urbinati & Warren 2008, Montanaro 2012, Nuske 2022). In my view, an important aspect of the authorisation on which representative claims are based, or, in other words, what entitles a person to speak on behalf of patients, is an in-depth knowledge of the group concerned, that is to say, an in-depth knowledge of their stories. The process of deciding what matters and what is put forward in policy discussions always involves interpretations and choices. For that very reason, it is important that there is accountability with regard to these choices. This can be achieved by discussing claims and the basis for them openly and challenging them in the debate. Reflexivity, which involves reflecting critically on your own claims, whether they are based on your own experience or knowledge or that of others, is also important to ensure that good considerations are made when deciding which story to highlight and on whose behalf (Nuske 2022, Teunissen & Abma 2024).

Interactions within the system of participation and representation

One thing that we do not yet understand properly is what impact these different participation and representation practices have on decision-making (Michels 2011, Voorberg, et al. 2015, Hendriks & Michels 2021). It is important to look beyond specific cases and try to identify interactions within the system of participation and representation. A crucial question here is how different initiatives impact on each other and what unforeseen consequences this has. After all, the different forums in which participation and representation take place have the potential to increase or reduce inequality. They can increase it if certain voices are heard repeatedly and risk drowning out others (Bovens & Wille 2017), but they can also reduce it if different participation and representation channels complement each other and are linked at various levels (Van de Bovenkamp & Vollaard 2018). In our research I am therefore keen to focus on participation and representation practices at different levels, paying attention to which stories play a role there and how they are told. I want to examine what choices participants and representatives make, how the way in which participation and representation are organised guides these choices and what consequences this has in terms of which stories receive attention and which do not. Linking this line of research to that of patient stories also allows us to seek out the 'silence' in decision-making processes, by ascertaining which stories are not being told or are not being heard sufficiently at the collective level. This requires a reassessment of diversity in decision-making. In policy discussions in particular, there is a desire to ensure that the patient perspective is included – as if this is something that is clear and unambiguous (Fischer 2022). As I argued earlier, however, that is not the case (see also, for example, Smit, et al. 2022).

An example of the diverse nature of patient groups emerged during the research that I carried out together with Bert de Graaff, Roland Bal and Karin Kalthoff on the topic of representation during the COVID-19 pandemic. Here different patient groups had different interests. However, because representatives were not sitting around the same decision-making tables, the resulting dilemmas and how they could be dealt with effectively were not properly addressed (Van de Bovenkamp, et al. 2023).op tafel (Van de Bovenkamp, et al. 2023).

With the importance of considering a diverse range of perspectives in mind, it is essential that these different perspectives are actually put forward, so that policies and their potential consequences can be better thought through (Van de Bovenkamp, et al. 2023). The question of how to do this effectively leads me on to my third point: including stories in decision-making processes.

5. Including stories in decision-making processes

If we want the lessons learned from stories to have an impact on decision-making, or, in other words, to play a role in decision-making and the way these decisions are implemented, governance, supervision and policymaking need to be organised in a more reflexive way. This ties in with topical discussions on the themes of reflexive governance and regulation (Sabel & Zeitlin 2012, Rutz 2017, Grit & Pot 2023), narrative accountability (Jerak-Zuiderent 2013, Ubels 2015, Van de Bovenkamp, et al. 2023) and shared leadership (Van der Scheer 2023). The common thread running through these discussions is the question of challenging existing structures and assumptions. They also acknowledge the need to take different perspectives into account. Lastly, they are focused on learning through experimentation and keeping a critical eye on the new practices that result from this process. I would now like to discuss the role that stories can play in this.

Potential of stories in promoting reflexive governance

From stories we can draw lessons about what issues patients and loved ones come up against, what helps them when it comes to living with a condition and the care they receive, and what impact policies have in practice. It is important that these lessons are included in discussions about healthcare governance and policy. A crucial aspect here, from the perspective of reflexive governance, is looking beyond the specific problems that these stories tell us about.

Our analysis of stories told by people who were regarded as 'confused' in policy and public discourse demonstrates the importance of the way society deals with being different. Framing the problem as a question of social conventions allows other possible solutions to emerge than if we view it through the dominant policy frame, which frame this group to be a danger to itself and society (Petit-Steeghs, et al. 2021).

In our research on patient representation during the coronavirus pandemic we also saw the potential that representatives had, based on stories from the people they were representing, to challenge the dominant crisis narrative and the emphasis on safety in combating the virus. They did so, among other things, by drawing more attention to the question of quality of life and community life and the need to find space to allow exceptions to the rules (Van de Bovenkamp, et al. 2023). One of these representatives also challenged the 'visiting rules' by questioning the frame on which they were based. According to this representative, by regarding loved ones as visitors, you reduce them to people who occasionally pop round for a coffee, which fails to do justice to relationships between people who have been in each other's lives for a long time.

Healthcare policy is based on political considerations. Stories, and reflecting on stories, make it possible to take these political considerations better into account. Whether we are talking about the specifics of self-management, self-reliance or custom or person-centred care, or about informal care, in our research we see that it is often left up to healthcare professionals, patients and informal carers to decide how to deal with these political considerations in practice (Linthorst & Oldenhof 2021, Heerings 2022, Gräler 2024, Schmidt 2024). This has negative consequences for patients and their family. They have to rely on their own skills to ensure that discussions about care and support are resolved in a way that is favourable for them, which can lead to inequality. It also has negative consequences for healthcare workers, who are faced with all kinds of dilemmas without receiving any support in how to deal with them effectively. Much more attention therefore needs to be paid to political considerations made in practice, as well as in the areas of governance and policymaking.

Often, however, the political aspect of these considerations is obscured in policy documents due to a rhetoric of inevitability (Trappenburg 2016) or by rationalisation (Stone 2012), both of which imply that the problem and solution can be determined clearly and objectively. The consequence is that insufficient attention is paid to the underlying choices and value trade-offs (Stone 2012, Van Bommel, et al. 2015, Meurs 2022, Rahmawan-Huizenga 2024). Stories can help make these choices and value trade-offs transparent. Earlier I explained that stories can challenge existing, dominant ways of thinking. To put it in a slightly more abstract way: they offer ways for us to look at a certain situation through a different frame. In this way stories contribute to imagination (Mol 2008, Pols 2023).

The examples show that alternative frames unlock discussion about what is important in public services. By placing them alongside other frames, we can see that what makes a good public service is by no means always clear-cut. To achieve a better service, we need to think about the underlying political value trade-offs. This calls for an approach that integrates stories into the reflection process.

Earlier this year, a group of women who wanted to be considered for breast reconstruction after receiving treatment for breast cancer explained that they had had to supply photos to their insurer. Their stories caused widespread outrage (Stikkelorum 2024). This example shows that the emotional appeal that stories can convey are capable of triggering change: the practice in question has now been adapted. You could then simply say "great, that's sorted" and leave it at that. From the perspective of reflexive governance and regulation, however, we need to do more with these stories. They should cause us to reflect on underlying structures that allowed these practices to develop in the first place, as well as on the political considerations on which they were based. This might involve examining whether fraud policy and risk management have possibly been taken too far. The next step would be to think about where else the negative consequences of this focus could be felt and to put forward alternatives.

To be clear, my argument is not that patient stories should always guide the process or that another type of information does not matter. Numbers can also have an important role to play in decision-making. However, they also need to be interpreted by looking at the story behind the numbers (Bal 2008, Stone 2020, Wallenburg, et al. 2021). What I am arguing is that the stories told by patients and loved ones should form part of the discussions on what matters and what that means for the way we organise, govern and regulate healthcare. To this end, it is important that these stories are discussed and are related to other stories, including those of healthcare professionals (Frank 2010, Sools 2013).

How do you achieve this?

'Reflexive governance' sounds great, but the question is, of course, how do you put it into practice? That is by no means straightforward, precisely because the underlying principles demand a great deal of the people concerned. After all, if you do it well, existing ways of working are called into question. Anyone who works or studies somewhere knows how difficult it is to change structures and habits. At universities we stubbornly continue to give lectures in 2 x 45-minute blocks, with the emphasis on sending information, even though we know that students actually retain a disappointingly small proportion of it (Chi & Wylie 2014, Deslauriers, et al. 2019).

Reflexive governance is also complicated by the fact that different perspectives are put forward that are based on different values, and it therefore also exposes dilemmas (Rutz 2017, Van de Bovenkamp & Dwarswaard 2017, Heerings 2022). We should also not be naive. Power relationships play a role within these decision-making processes and not everyone's knowledge is given equal value, as I discussed earlier.

At the same time, experiments are being carried out in practice with different forms of decision-making and accountability that give cause for optimism. Research on these experiments is revealing what the important aspects are.

The first is sharing and learning from each other's stories and working together to bring about improvements. An excellent example is the Als je het ons vraagt dan... (If you ask us, then...) method, which was developed in projects led by my colleague Marjolijn Heerings. This method is used within teams in the field of long-term care. Here, filmed stories of patients, loved ones and healthcare professionals, some of which were produced together with Theater Babel, form the starting point for reflection. This method helps patients, loved ones and healthcare professionals become more aware of each other's perspectives. This leads to greater understanding and facilitates discussion about the dilemmas that arise from these differing, and sometimes conflicting, viewpoints. By then reflecting together on how these dilemmas could be handled better, you can work together to come up with alternatives and improve quality. This approach means that you are not just reflecting together, but that these reflections are also being transformed into new practices that enjoy broad support. What this research also shows is that the facilitating role played by experts by experience can help to address unequal power relations (https://alsjehetonsvraagtdan.nl/).

A second lesson is that learning together, across the different levels of healthcare organisations and the healthcare system as a whole, is important if we want stories to have an impact on policy. One example of such an approach within healthcare organisations is the Beelden van Kwaliteit (Images of Quality) method (Reinders 2019). This method records stories from healthcare practice by observing practices and, based on these observations, holding up a mirror to healthcare professionals. A broad panel, made up, for example, of members of management boards, supervisory boards or client councils, also reflects on the question: what actually is good care? By discussing this with people from different levels of the organisation, this approach also becomes part of the accountability process relating to quality of care, as my former colleague Annemiek Stoopendaal demonstrated (Van de Bovenkamp, et al. 2018).

If stories are to have an impact on underlying structures, these discussions also need to be linked to the work of actors outside healthcare organisations. After all, you can try to change all kinds of things within your own organisation, but national policy or the regulatory approach can thwart the change you want to achieve. Making the shift towards reflexive governance requires change from all parties in the field, as well as reflection on underlying problems.

Research by my colleagues Jonathan Berg, Jeroen van Wijngaarden and Lieke Oldenhof on new accountability practices at local authorities relating to custom support in the field of social services reveals that policy learning and changes to rules at local authority level are possible if professionals and policymakers reflect together on how custom support is delivered in practice and the rules and assumptions that stand in its way. However, unless underlying collective problems like the housing shortage and the limited accessibility of homeless shelters are addressed with the help of other parties, the delivery of custom support will remain largely dependent on inventiveness and improvisation at local level (Berg, et al. 2022).

Linking together different decision-making forums is therefore important to achieve reflexive governance. We are currently researching how this can be done effectively. The projects RUN (led by Anne Margriet Pot and Josje Kok) and Be-grip (led by Violet Petit Steeghs), as well as projects of my colleague Lieke Oldenhof focusing on the healthy city, are examples of this. Citizens' stories are an important part of these studies. After stories have been collected, the studies examine how they can bring about changes not only in processes within and between healthcare organisations, but also in the work of regulators and policymakers.

In short, it can be done. These examples make that clear. Of course, this does not mean that anyone who is involved in care and support in some way or other will now have to spend the whole day reflecting. It is also important to act. However, reflexive governance requires all parties involved in healthcare to learn to stop and think about how they go about their work, why they do it in that particular way and how it relates to the work of others. They need to be given space in practice to allow them to do so. Over the coming years our research will be able to help people take further steps to put this approach into practice.

6. In conclusion

To sum up, during this inaugural lecture I have discussed the need for Patient Sciences and the key points that this discipline needs to address. In doing so, I have explained the importance of collecting stories and making meaningful reductions, translating them through participation and representation, and including them in decision-making processes, so that they can also influence collective decision-making in the healthcare sector.

My story also includes an appeal for this to be done in an open and critical way. Experimenting and learning are therefore just as important for the further development of this discipline as they are for healthcare practice which is keen to make greater use of these stories. Being open to plurality instead of thinking dichotomously, for example in terms of stories versus numbers, one form of representation versus another, experiential knowledge versus other types of knowledge, and patients versus researchers or professionals, is part of this.

Making sure you are also open to other scientific disciplines is another. Today I have made a start by using insights gleaned from the literature from different disciplines, including health research, narratology, public administration, sociology of science and political science. I do not claim to have done justice to all relevant insights that are currently available. Insights from disciplines such as disability studies, history and philosophy of science are also essential to further complement the points I have made here. Over the coming period I am keen to work together with other academics and practitioners to identify new connections and develop new forms of knowledge.

The same naturally applies when it comes to working with patients and their representatives within this field of research, something we often do in practice already. The themes covered in this inaugural lecture were partly inspired by discussions with them. Working together on projects with experts by experience, and analysing and discussing patients' stories together with the patients concerned, offers all kinds of new insights. At the same time, a certain amount of experimentation is needed to work out how to do this well. I am looking forward to continuing these experiments and to learning together how we can take them forward.

By taking up this chair, I hope to contribute to the advancement of this discipline so that, in Coleta's words, it "achieves a little more". This will naturally be made possible by carrying out research. However, the education pathway is just as important. After all, if we want attention to be paid to different types of knowledge and want to find a place for this knowledge within new forms of governance, we need to train the reflexive healthcare professionals, managers and policymakers of the future. Paying

such attention to patients' experiences and being sensitive to the structures and systems that influence whether these experiences are taken into account in health-care practice is another aspect that I would like to focus on over the coming years.

7. Acknowledgements

To conclude, there are many people I would like to thank. Giving an inaugural lecture is a rather strange thing. You are standing here on your own, even though science by definition is all about teamwork. I'm afraid that I cannot thank everyone personally, but there are a number of people who I would like to mention.

First of all, my thanks go to the Executive Board of Erasmus University Rotterdam, as well as to the ESHPM board for making this chair possible. In particular, I would like to thank Roland Bal and Werner Brouwer for all the work they put into this.

Margo, it was you who guided me into the field of science. Thank you for that, I am enjoying it immensely. With your sharpness, your originality, your outstanding bullshit meter, your no-nonsense way of making your point and your humour, you remain a real role model for me. As far as I'm concerned, you have nothing to worry about when it comes to gravitas.

Jolanda, my other rock from the very start of my working life. Thank you for being there all these years, both professionally and in the other areas of my life. Although for some time now we have no longer been able to enjoy our loud chats and laughs in the same office, I am pleased that we still get to do this in many other places.
Roland, we have come a long way. When I first got to know you I found you and your STS posse pretty incomprehensible. And in your eyes I was just a naive public administration girl. Over the years I have really come to value you for your sharpness, your inspiring suggestions, your enthusiasm and your ability to keep spotting new opportunities, but above all for your dedication to helping others, and me in particular. I am incredibly grateful for this.

Coleta, founder of Patient Sciences. During the opening of the collection in the University Library I quoted Newton and I would like to do so again today. *"If I have seen further, it is by standing on the shoulders of giants."* With this quote I want to underline that the work we do involving patient stories is mainly possible thanks to you. After all, without you there would have been no collection at all, and without you there would also not have been such a well-developed understanding of its potential.

There also would have been no collection, of course, without the patients and loved ones who write about their stories. My sincere thanks also go to all the authors, patients and loved ones who share their stories with us in other ways. It is a privilege to work with them and I feel a sense of responsibility to do them justice.

Iris, I can best describe you using the metaphor of a campervan. Campervans are the perfect example of togetherness and good company, always on the move and with a longing for freedom. Thank you so much for the opportunity to share your campervan on our work journey. Lieke, thank you for always being willing to share your thoughts with me, but in particular for being my own positivity guru. Susan, mother hen, oiler of the wheels, social animal – without you the section simply would not function. And everyone in the department agrees with me on that. Am I right? Or to put it like a true Rotterdammer: *Ja toch, niet dan?* Marina and Christa, thank you for all your work in organising the symposium and the inaugural lecture.
I would also like to thank all colleagues and former colleagues from the Health Care Governance section for their wonderful and inspiring work. Our daily discussions and the projects we work on together provided an important basis for this inaugural lecture. But I would like to thank you in particular for the fun and friendly atmosphere in the department.

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Members of the MT, thank you for the excellent collaboration and for all the work you do to make sure ESHPM is relevant. Members of the Patient Sciences thinktank who have provided their input on the development of the discipline, thank you so much for your countless insights and spirited discussions. The same goes for all the people involved in consortia, which I believe are important for developing Patient Sciences, including *RUN, Be-grip, Als je het ons vraagt dan..., Praten over Gezondheid, Collelo*, the Patient Participation Network and *ZONN*. Colleagues from the University Library, thank you for all the work you have done to compile the collection and make it accessible and for the text-mining expertise that you enthusiastically offered. Thanks also to Gert van de Beek of Boekscout for helping to make it possible to share so many patient experience stories.

All students and lecturers, thank you for your dedicated and enthusiastic attitude to making healthcare better. Especially in these times, you can make an important contribution in this area as reflexive professionals.

Dear friends and family, thank you for all the love, good company, laughs, support and everything else that is important in life. Marieke, an extra thank you to you for the wonderful slides of today.

Dear Mum and Michiel, thank you for always being there for me. Mum, it is thanks to you in many ways that I am standing here today. There are all kinds of sentimental things that I could say, but I won't do that. After all, if we are honest, the main reason is that question that you have been asking me for years. It started when I graduated: does that mean you are going to get a hat now? When I obtained my doctorate this question came up again and once again I had to disappoint you. Well, now here it is, and I have worked hard to get it, especially for you.

Dear Hans, the GP was definitely right about one thing: you are a very good guy. There are also many reasons why it is thanks to you that I am standing here today. Above all, however, I am just so happy to have you and to be able to share all of the ups and downs in life together with you. Fortunately, there are plenty more ups than downs. That is partly thanks to our Olaf, of course. Dear Olaf, thank you for being the loveliest, funniest, sweetest and often also the wisest of us all. That bodes extremely well for your future, which I am looking forward to enormously.

Lastly, I would like to dedicate this inaugural lecture to my father, who is sadly no longer with us. I am doing so because it is thanks to him, a COPD patient for many years and an extremely modest man, that every day I have at the forefront of my mind that although not every patient tells their story, the quiet ones among us definitely have something to say. Above all, however, I am dedicating this inaugural lecture to him due to his unconditional love.

I have spoken.

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Hester van de Bovenkamp is Professor of Patient Sciences at Erasmus School of Health Policy & Management (ESHPM), Erasmus University Rotterdam. Her work focuses on the role of patients and their loved ones in decision-making at different levels. Her research has addressed topics such as self-management and patient autonomy, the representation of patients and family caregivers in policymaking, and new forms of governance and oversight that give attention to the stories and experiences of patients and their loved ones. She manages the collection of patient stories and the website www.patientervaringsverhalen.nl. In addition, she serves as Head of the Health Care Governance section at ESHPM.

For decades, there have been calls to involve patients and clients more closely in decision-making. This applies not only to decisions about their own care, but also to a wide range of organizational and policy-related issues. In practice, however, this has proven easier said than done.

The aim of the field of **Patient Sciences** is to understand how knowledge derived from the experiences of patients and their loved ones can improve care and support. At the heart of this field are **stories**—the natural way in which people share their experiences. Learning from experiences first requires collecting these stories, with attention to diversity, and analyzing them so that they can become a collective source of knowledge.

The next step is to examine how patients' stories are translated into participation and representation, and how the knowledge contained in these stories helps shape decision-making. In this way, we can learn how patients' stories can genuinely contribute to different and better forms of care.

In her inaugural lecture, **Hester van de Bovenkamp** explores how healthcare can learn from the stories of patients and their loved ones, and outlines the associated research agenda for the field of Patient Sciences.

Erasmus University Rotterdam
Erasmus School of Health Policy & Management
Bayle Building
Burgemeester Oudlaan 50
3062 PA Rotterdam, the Netherlands
T +31 10 408 8555
E communicatie@eshpm.eur.nl
W www.eur.nl/eshpm