

Experts and idiots

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Valorization of Research Insights

Societal Relevance, Impact and Practical Recommendations

"Is that all?" asked Aglaya.

"All? Yes," said the prince, emerging from a momentary reverie.

"And why did you tell us this?"

– Fyodor Dostoyevsky, 'The Idiot'

VALORIZATION

It is customary at the University of Maastricht to add to a dissertation an extra chapter that states the societal relevance of the study conducted, discusses its impact on public debates and provides practical recommendations for implementation. This chapter elaborates on the importance of reflecting on epistemic practices in policymaking and provides some practical tools for doing so. It also describes how the findings from my studies have been disseminated amongst both policymakers and health researchers and what these findings have 'done' in national professional debates and in international academic discussions. In this chapter I also report on my efforts to stimulate reflection on 'practices of knowing' not only in the field of health policy, but also in e.g. science journalism, (urban) sociology, cultural studies and the life sciences.

WHY REFLECT ON EPISTEMIC PRACTICES IN (HEALTH) POLICY PRACTICES?

In these times of soaring health care expenses and limited budgetary resources, policymakers charged with organizing the accessibility, efficiency and quality of health care face a daunting task. Their decisions easily become objects of social contention and public debate. Such decisions need to be well-substantiated and explicitly justified. The academic debate on prioritization in health care entails a long-established discussion about institutional processes, deliberative procedures and technical approaches for making such decisions (e.g. Daniels & Sabin, 1997; Ham & Roberts, 2003; Klein & Maybin, 2012). Most of this academic work on prioritization in health care is prescriptive, focusing on how policymaking ought to be done.

This book takes a different approach. It is descriptive and reports how policymaking actually takes place in practice. It is an ethnographic exploration of the practices of using, assessing and warranting different types of knowledge to substantiate contentious policy decisions in the context of Dutch social health insurance. As such, this research adds to a body of qualitative research on prioritization in health care that focuses on the question how exactly scientific evidence, clinical expertise, patient experiences and stakeholder perspectives are brought together in the daily practice of making complex health policy decisions (e.g. Hodgetts, Elshaug, & Hiller, 2012; Robinson, Williams, Dickinson, Freeman, & Rumbold, 2012; Russell & Greenhalgh, 2009). This type of empirical investigation enables reflection on the adequacy, appropriateness and social inclusiveness of policymakers' epistemic practices in decision-making.

Why is it important to reflect on epistemic practices in policymaking? Policymakers have come to rely heavily on quantified, technical and scientific knowledge to justify actions and to legitimize policy decisions as being 'impartial', 'objective' and 'just' (Ezrahi, 1990; Porter, 1995). Such a technical approach to decision-making is presumed to prevent policymakers' cognitive biases from being triggered and its aim is to avoid discriminatory or prejudiced outcomes in policymaking. However, as

numerous studies in the field of Science and Technology Studies have shown (Felt, Fouché, Miller, & Smith-Doerr, 2017), practices of knowing are never neutral. Any epistemic tradition has its own preferred scientific methods, dominant notions of evidence and epistemic ideals of what counts as ‘objective’, ‘credible’ and ‘trustworthy’ knowledge (Knorr Cetina, 1999, 2007; Murphy, 2006). As such, epistemic practices inevitably contain power relations, attributing ‘credibility’ to certain speakers (those who for example present the right kind of evidence, use the proper language, hold the required certificates or show other features that somehow are believed to guarantee a speaker’s credibility) while the testimonies of other speakers are considered ‘subjective’ or even ‘unintelligible’ because they lack mastery of the privileged style of articulating, presenting and sharing knowledge.

According to philosopher Miranda Fricker, we can do a person (or a group of people) an injustice by not recognizing them in their capacity as a credible and intelligible knower. The term ‘epistemic injustice’ refers to ‘a wrong done’ to a person in his or her ‘capacity as a knower’, by the act of unjustifiably neglecting that person as an epistemic agent in his or her own right (Fricker, 2007, p. 1). The concept of ‘epistemic injustice’ raises particularly urgent questions in the field of policymaking: whose knowledge and what types of testimonies are actually counted as objective, credible and trustworthy contributions to policymaking processes? Someone who is not recognized in their capacity as a credible and intelligible epistemic agent in policymaking is not merely neglected as a knower in his/her own right, he/she – as a result of this – lacks the social power to influence public policy. If people lack the power to influence policy processes, they are potentially deprived of a fair share of public resources and are excluded from the deliberative practices of constructing collective futures.

In order to address potential epistemic injustices one has to become aware of epistemic inequalities between groups of knowers in their access to and representation in knowledge-intensive policymaking processes. That is why ethnographic research into policymakers’ epistemic practices is such important work, as is reflecting on these practices from the perspective of epistemic injustice. The aim of this book is to instigate democratization of knowledge-intensive policy practices in health care so that different groups of knowers have equal opportunities to participate epistemically – as knowers – in policy practices. In order for that process to take flight, those working in the science-policy nexus must ask a set of critical questions regarding the working methods they employ in making public policy (see Box 1). Only by uncovering epistemic ideals in decision-making procedures and by critically reflecting on the societal consequences of these epistemic preferences, can policymakers uncover the epistemic injustices that potentially circulate in their work.

USING POLICY CONTROVERSIES FOR CRITICAL REFLECTION ON EPISTEMIC PRACTICES

Apart from the societal purpose of studying epistemic practices in policymaking, the research reported in this dissertation was conducted to meet a practical knowledge need of the National Health Care Institute.

Building on almost 70 years of experience and expertise with regard to the statutory health insurance system, the Institute is an authoritative voice in the Dutch health care arena, ensuring that good quality health care services remain affordable and accessible to all citizens (Helderman, De Kruijf, Verheij, & Van Thiel, 2014). Due to the public nature of the Institute, its knowledge work centers on the justification of decisions. While the Institute has increasingly legitimized decisions through the scientization of the decision-making process (using evidence-based methodologies and robust scientific instruments), it nonetheless experiences difficulties explaining the foundations of these decisions to a wider public. The public outrage in 2012 that ensued the Institute's 'evidence-based' advice to stop the reimbursement of orphan drugs for the rare diseases of Pompe and Fabry is the most prominent example of this (Boon, Martins, & Koopmanschap, 2015; Schinkelshoek & Martini, 2012; Van den Brink, 2014). It showed that problems regarding the legitimation of difficult policy decisions in social health insurance are not always 'solved' by resorting to technical knowledge or scientific procedures.

In response to a growing recognition of the shortcomings of a technocratic approach in complex decision-making, the Institute set up a research project to investigate whether its knowledge strategies to justify public decisions are adequate in terms of representativeness and relevance, and how the Institute's knowledge strategies could potentially be improved in order to facilitate more socially robust policy decisions. This research project, called '*Public Legitimation of Social Healthcare Insurance in the Modern Risk Society*', was funded and facilitated by the Institute and independently executed by researchers of Maastricht University. This book is the result of that collaborative research (see also Abrishami, 2018) and aims to find answers regarding the relevance and representativeness of the Institute's decision-making practices and how to create trust and social support for its decisions.

While public outrage about policy decisions or judiciary interference in decision-making are sensitive issues for the National Health Care Institute (whose authority and legitimacy lay in its acknowledged expertise and scientific standing), such uncomfortable and confusing events hold important clues for answering questions regarding the adequacy, relevance and representativeness of decision-making procedures. For a long time, technical approaches and formal procedures – for example evidence-based methodologies – have been considered remedies to avoid prejudice or cognitive bias in decision-making. However, my research shows that such technical approaches and formal procedures often contain biases and prejudices of their own. Disruptive events such as lawsuits and public controversies about decision-making procedures are actually touchstones for reflection on such biases and prejudices. Analyzing these events from the perspective of

epistemic injustice (see Box 1) can hold the key towards creating more socially robust policymaking procedures.

Box 1 | Epistemic (in)justice reflexivity tool

A Sample questions for policymakers to reflect on epistemic practices

- What technical procedures do I use to justify policy decisions? What types of testimonies are preferred in these procedures?
- How do I assess/warrant/weigh the testimonies of different groups of knowers in formal decision-making procedures? What forms of knowledge do I recognize as credible and intelligible contributions in my decision-making procedures?
- Which social groups have (or lack) the epistemic resources to make themselves understood and heard in my decision-making procedures? Do different groups of knowers have equal opportunities to participate epistemically in the policy process?
- What might the societal consequence be of devaluing or excluding certain testimonies from policymaking processes?
- In cases involving epistemic injustice: what national and international networks exist in which epistemic procedures for decision-making are used and promoted? And what forums exist in which these procedures can be critically discussed and potentially improved?

B Sample questions for health researchers to reflect on epistemic practices

- What dominant notions of evidence and epistemic ideals of ‘objectivity’ do I use/reproduce in my choice for a research method?
- What forms of knowledge and whose knowledge do I recognize as credible, intelligible and relevant in my research practice?
- In my research, what common-sense ideas do I use/reproduce about the trustworthiness and relevance of specific types of evidence, testimonies, sources of knowledge et cetera?
- What might the consequences be, in terms of representativeness of the researched phenomenon, of including/excluding particular testimonies, evidences, data, and information in my research practices?

In order to stimulate reflection and debate about the issues addressed above, I discussed the findings of my research in several internal debate forums at the National Health Care Institute (see Box 2). Sharing my research findings with policymakers at the Institute allowed me not only to inspire reflection on their epistemic practices, but also to check and refine my analysis of these practices with those who were directly involved.

Box 2 | Invited talks for policymakers

Invited talk '*Understanding the knowledge dynamics in decision-making at the National Health Care Institute*' held at a staff debate forum ['Zorgforum'] at the National Health Care Institute, February 2014

Invited talk '*Researching knowledge practices*' held at a meeting of young professionals ['Jong ZIN'] at the National Health Care Institute, June 2014

Invited talk '*Understanding the knowledge dynamics in decision-making at the National Health Care Institute: the case of bladder instillations*' held at a staff debate forum ['Zorgforum'] at the National Health Care Institute, October 2014

Invited talk '*Epistemic Culture at the National Health Care Institute: the case of bladder instillations*' held at a staff debate forum ['Zorgforum'] at the National Health Care Institute, March 2015

HOW TO STIMULATE REFLECTION ON EPISTEMIC INJUSTICES IN HEALTH RESEARCH?

One of the major findings of my research is that policymakers rely profoundly on a wider network of knowers, knowledge conventions and knowledge products for making complex policy decisions. The scientific methods, dominant notions of 'evidence' and epistemic ideals of 'objectivity' that governing agencies such as the National Health Care Institute employ in decision-making processes are generally not invented by these agencies themselves. Existing national and international knowledge practices define and format the decision-making processes at a national policy level.

My studies show, for example, that policymakers rely on: a) clinical data and information that is readily available in the field; b) the agenda-setting and funding mechanisms in national and international medical research; c) priorities in the development of standards and protocols and d) dominant medical discourses. This means that policymakers' decision-making processes are vulnerable for incorporating epistemic improprieties that actually originated elsewhere.

Box 1 lists a set of critical questions that health researchers can use to reflect on their practices of producing professional guidelines, quality metrics, clinical research *et cetera*. It is essential to raise health researchers' awareness that if they fail to recognize epistemic injustices in research practices, there is a chance that epistemic inequalities generated in medical research are being reproduced in health policies that are based on these studies. In order to stimulate reflection in this regard, I sought opportunities to share and discuss my research insights and theoretical concepts not only with policymakers, but also with health researchers in national and international academic settings (see Box 3).

Box 3 | Invited talks and presentations for health researchers

Invited talk '*Understanding the knowledge dynamics in decision-making at the National Health Care Institute: the case of bladder instillations*' at the Tilburg School of Social and Behavioral Sciences (TRANZO) in September 2015

Presentation '*Evidence contested: An epistemic battle in healthcare rationing*' at the Trading Zones in Technological Societies Conference, University of Liège, Belgium, October 2015

Invited talk '*Evidence-based Policymaking in a Post-Truth era?*' at the Social Science & Health Innovations Conference, Tomsk State University, Russia, May 2017

Poster-presentation and Pitch '*Evidence and doing "epistemic (in)justice" in priority-setting*' at the annual Research Day of the Care and Public Health Research Institute (CAPHRI), Maastricht University, November 2018

IMPACT ON PUBLIC AND ACADEMIC DEBATES

By discussing my research insights with policymakers and health researchers, and by publishing my work in (international) scientific journals (Box 4), I aimed to stimulate both professional reflection and academic debate about the democratic representativeness of epistemic practices in social health insurance, focusing specifically on the role of Evidence-based Medicine (EBM) therein. In particular my study of the lawsuit against the National Health Care Institute, reported in Chapter 1, received significant attention in professional and scientific media (Figure 1). Apart from its uptake in other scientific publications on prioritization in health care (e.g. Ettelt, 2018; Russell, 2017; van Overbeeke et al., 2018), the court case was discussed in national professional media (e.g. Van Maanen, 2016) and used as a case study in a widely discussed report of the Dutch Council for Health and Society called '*No Evidence Without Context. About the illusion of evidence-based practice in healthcare*' (Raad voor Volksgezondheid en Samenleving, 2017). The case study has also been used for educational purposes for health researchers. Students at the Faculty of Health, Medicine and Life Sciences of Maastricht University study the case as part of the course '*Philosophy in Action*'. As such, my study of the lawsuit has been used by a range of policymakers, health researchers, students and medical professionals to reflect on their practices of knowing.

ntvg
NEDERLANDS
TIJDSCHRIFT
VOOR
GENEESKUNDE

EBM voor de rechter
NIEUWS 14-12-2016
Hans van Maanen

**Zonder context
geen bewijs**
Over de illusie van
evidence-based
practice in de zorg

Samenvatting Volledig Artikelinfo Reacties 0

Op 19 november 2014 deed de Amsterdamse rechtbank uitspraak in een opmerkelijke zaak: Interstitiele Cystitis Patiëntenvereniging (ICP) contra Zorginstituut Nederland. Hoewel de ICP in alle opzichten in het ongelijk werd

Trisha Greenhalgh #PeoplesVote @trishgreenhalgh · 16 nov. 2016
I refereed this paper. Not sure it's as simple as "EBM won". I'd say "not all evidence is equal". Worth studying.

Hilda Bastian @hildabast
EBM on trial: Dutch patient group sued over non-reimbursement decision. Studied in real-time: [cambridge.org/core/journals/...](https://www.cambridge.org/core/journals/) Spoiler: EBM won

Figuur 1

Box 4 | Publications in scientific journals

Moes, F., Houwaart, E., Delnoij, D. and Horstman, K. (2016). Contested evidence: a Dutch reimbursement decision taken to court. *Health Economics, Policy and Law*, 12(3), 325–344

Moes, F., Houwaart, E., Delnoij, D. and Horstman, K. (2018). Strangers in the ER: Quality indicators and third party interference in Dutch emergency care. *Journal of Evaluation in Clinical Practice*, 1–8.

Horstman, K. and Moes, F. (2018). 'Wat is dat eigenlijk, context?'. *Tijdschrift voor Gezondheidswetenschappen (TSG, Dutch Journal for Life Sciences)* 1/ 2018

Moes, F., Houwaart, E., Delnoij, D. and Horstman, K. (forthcoming). Collective Constructions of 'Waste': Epistemic practices for disinvestment in the context of Dutch Social Health Insurance. (revisions under review)

Moes, F., Houwaart, E., Delnoij, D. and Horstman, K. (forthcoming). Questions regarding 'Epistemic Injustice' in knowledge-intensive policymaking: two examples from Dutch health insurance policy. (revisions under review)

EPISTEMOLOGY, FILM & TV: STIMULATING WIDER REFLECTION ON EPISTEMIC PRACTICES

The standard view of science is that it is a neutral place where ‘facts’ are uncovered by disengaged scientists and where politics is absent. My studies have shown, however, that scientific research is never neutral and that there is no epistemic practice that does not – at the same time – privilege certain styles of reasoning and articulating testimonies while devaluing others. Insights from the field of Science and Technology Studies have shown that knowledge is man-made and value-laden (Latour & Woolgar, 1979) and that there is no knowledge that does not presuppose and constitute power relations (Foucault, 1995). These are important insights, not only for policymakers, but for anyone involved in producing, using and/or reproducing scientific knowledge.

Apart from reaching out to policymakers and health researchers, I have, therefore, spent the past few years promoting deeper reflection on knowledge practices among a wide range of listeners: lay audiences, journalists, scientists and students ranging from Mathematics, Biology and Life Sciences to Arts, Culture, Sociology and Politics. For instance, when in 2015 Dutch citizens, researchers and industries were invited, within the context of the Dutch National Research Agenda¹, to submit research questions that were important from their personal, societal, scientific or industrial perspectives, I submitted two research questions. One of these questions – “*Are we still asking the right kind of questions?*”, an attempt to raise awareness of the value of philosophical research and education within the business-oriented Dutch academic landscape – was selected by artist Inge Meijer to be part of a short creative film about the Dutch National Research Agenda. In that film I discussed the value of Philosophy of Science in general and Science and Technology Studies in particular with Prof. Trudy Dehue, a science-historian and sociologist of science.

Invited talks and public lectures formed another opportunity to promote deeper reflection on knowledge practices amongst a wider public. For example, I provided guest lectures on the epistemic work of scientists in a ‘Science Journalism’ course for journalists and in a variety of academic settings (see Box 5). On other occasions I made use of popular film and documentaries (e.g. *The Wire*, *O.J.: Made in America*) to show how epistemology works in day-to-day practices. Philosophy of Science is, generally, a compulsory (and often unpopular) part of academic curricula. In several public lectures I used the popular HBO’s tv-series ‘*The Wire*’ to show how concrete epistemic practices – e.g. the production of crime statistics or the construction of court case ‘evidence’ – simultaneously *shape* and *are shaped by* city politics and social urban realities.

In particular the open lecture series on ‘*The Wire*’, held at the University of Amsterdam, received much attention and was widely covered in national media (see e.g. Kist, 2014; Kraak, 2014). Next to giving lectures, I published several articles on this topic for professional, academic

¹ A coalition of universities, university medical centers, technical colleges, the Royal Netherlands Academy of Arts and Sciences (KNAW), the Netherlands Organisation for Scientific Research (NWO) and the Netherlands Organisation for Applied Scientific Research (TNO)

and lay audiences (see Box 6). The goal of the above lectures and publications was to show the transformative power of knowledge practices to arrange and rearrange contemporary societies. The use of popular film and documentary material allowed me to reach and engage a wide audience, and make them acquainted with the philosophical legacy of e.g. Bruno Latour and Michel Foucault, who have done groundbreaking work in dispelling the myth that facts are 'given' by nature and that knowing is a neutral and value-free activity.

Box 5 | Invited talks on knowledge practices for a wider audience

Invited talks '*Wetenschap ter discussie*' for journalists in a science journalism course, organized by Stichting Cursussen Wetenschapsjournalistiek (SCW) in December 2013 and May 2014

Invited talk '*Kennispraktijken in The Wire*', part of a series of public lectures at the University of Amsterdam, April 2014

Invited talk '*Wetenschap in transitie*' for students of Biology, Natural Science and Mathematics in an elective course on the 'Circular Economy' at the Faculty of Science, University of Amsterdam, May 2015

Invited talk '*Bruno Latour & The Wire*', part of a series of public lectures organized by 'Philosophical Café' Felix & Sofie, Amsterdam, December 2015

Invited talk '*Actor Network Theory & The Wire*' for master-students of Art, Culture & Society in the course 'Advanced Sociology of Arts & Culture' at Erasmus University Rotterdam, October 2018

Box 6 | Epistemology, Film & TV: Publications for professional, academic and lay audiences

Moes, F. (2014). 'All the pieces matter'– Latours slowciologie en *The Wire*. *Sociologie*. 10(3). 242–259

Moes, F. (2015) 'All the pieces matter'– Latours slowciologie en *The Wire*. In Van Oorschot, I., M'Charek, A., Harambam, J. & Benschop, R. [red]. *'Monsters in de Sociologie. De wondere wereld van ANT*. Boom/ Lemma, Amsterdam. 28–45

Moes, F. (2016). Blauwdruk van een omgekeerde wereld. *Sociologie Magazine*. 24(3), 10–11

Moes, F. (2016). De stad in actie. Actor Netwerk Theorie. In Van Es, R & Van Rossum, J. [red]. *De stad als organisatie. Lessen uit The Wire*. Deventer: Vakmedianet. 82–92

Moes, F. (2016). De 'Stat Game'. De verborgen krachten van de statistiek. In Van Es, R & Van Rossum, J. [red]. *De stad als organisatie. Lessen uit The Wire*. Deventer: Vakmedianet. 134–150

Moes, F. (2017). Televisie voor Sociologen: 'O.J. Made in America'. *Sociologie Magazine*. 25(1), 22–24.

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