



## Questions regarding ‘epistemic injustice’ in knowledge-intensive policymaking: Two examples from Dutch health insurance policy



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### ABSTRACT

In contemporary healthcare policies the logic of Evidence-based Medicine (EBM) is typically proposed as a way of addressing a demand to explicitly justify policy decisions. Policymakers' use of ‘evidence’ is presumed to pertain to ideals of justice in decision-making. However, according to some, EBM is liable to generate ‘epistemic injustice’ because it prefers quantitative types of evidence and – as a result of that – potentially undervalues the qualitative testimonies of doctors and patients. Miranda Fricker's concept of ‘epistemic injustice’ refers to a wrong done to a person in their capacity as a knower. This paper explores the usefulness and limits of this concept in the context of public decision-making. How is evidence-based policymaking intertwined with questions of ‘epistemic injustice’? Drawing from ethnographic research conducted at the National Health Care Institute, we analyze two cases of EBM-inspired policy practices in Dutch social health insurance: 1) the use of the principles of EBM in making a public reimbursement decision, and 2) private insurers' use of quantitative performance indicators for the practice of selective contracting on the Dutch healthcare market. While the concept of ‘epistemic injustice’ misses some key processes involved in understanding how ‘knowing gets done’ in public policy, it does shed new light on priority-setting processes. Patients or medical professionals who are not duly recognized as credible and intelligible epistemic agents, subsequently, lack the social power to influence priority-setting practices. They are thus not merely frustrated in their capacity to be heard and make themselves understood, they are potentially deprived of a fair share in collective financial and medical resources. If we fail to recognize inequalities in credibility and intelligibility between diverse groups of knowers, there is a chance that these epistemic inequalities are being reproduced in our system of health insurance and our ways of distributing healthcare provisions.

### 1. Introduction

Policy decisions regarding the organization of accessibility, efficiency and quality of care need to be explicitly justified in the public arena, particularly in these times of soaring health care expenses and limited budgetary resources. In liberal democracies policymakers working in the field of health care often justify such thorny decisions on the basis of scientific and technical knowledge, e.g. techniques of health economics and the principles of Evidence-based Medicine (EBM). The use of this type of technical knowledge pertains to ideals of impartiality and justice in making policy decisions (cf. Porter, 1994; Porter, 1995).

Yet, while policymakers turn to ‘evidence’ as a strategy to explicitly justify complex decisions, these decisions are ever more contested in the public domain (Bijker et al., 2009; Horstman, 2014; Syrett, 2003,

2007), for example by disappointed patients who feel that their experiences and preferences are being ignored in public policies. It seems that while the use of evidence has become an expectation against which the integrity and justice of policy decisions is assessed, at the same time, the question of what counts as ‘evidence’ and whose knowledge counts as relevant, credible and trustworthy contribution to policymaking processes, has become politically charged (cf. Hoppe, 1999, 2010; Jasanoff, 1990; Lövbrand, 2011; Weingart, 1999).

In this paper we explore the issue of epistemic injustice in policymaking practices. The term ‘epistemic injustice’, introduced by Miranda Fricker in her book “*Epistemic Injustice: Power and Ethics of Knowing*”, refers to ‘a wrong done’ to a person or group of people ‘specifically in their capacity as a knower’ (Fricker, 2007, p. 1). The idea of epistemic injustice (introduced in more detail below) raises questions such as:

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whose knowledge is recognized as credible information in policy-making? Can we do someone (or a group of people) an injustice by not recognizing their testimonies as credible contributions in policy-making? And can the concept of 'epistemic injustice' help us in interpreting why, while policies are increasingly evidence-based, these decisions become ever more contested?

While the concept of epistemic injustice has been widely applied in various academic fields for analyzing interpersonal relationships, few scholars have explored what the application of epistemic injustice to the public arena would look like (Dieleman, 2015). And yet, the issue of epistemic injustice seems particularly relevant in the context of public policymaking. Someone who is not recognized as a credible source of knowledge in policymaking lacks the social power to influence public policy. Those who lack the power to influence policy processes, are potentially deprived of a fair share of collective (financial, medical, social, political) resources and are possibly excluded from practices of deliberating and constructing collective futures.

In this paper we analyze policy practices from the perspective of epistemic injustice. Next, we will, first, explore the concept of epistemic injustice in more detail and elaborate on the role of evidence in policymaking practices. We, then, turn to two earlier published case-studies of knowledge-intensive, evidence-based policy practices in Dutch health insurance (Moes et al., 2017, 2018) and study how diverse groups of knowers participate as epistemic agents in these public decision-making processes. It is important to note that, while epistemic injustice is a normative concept, this is not a normative analysis. Rather, it is an empirical study of how different forms of knowledge are used in policymaking. On the basis of this empirical analysis, we discuss the usefulness as well as the limits of the concept epistemic injustice in analyzing knowledge-intensive policymaking practices and explore whether the concept of epistemic injustice can help us to interpret why policy decisions become contested.

### 1.1. The concept of epistemic injustice

The concept of epistemic (in)justice refers to the question of whether parties are duly recognized 'in their capacity as knower' and have a fair share of our 'collective interpretative resources' at hand in order to manifest what they know (Fricker, 2007, p. 1). Fricker identifies two types of epistemic injustice (Fricker, 2007). The first is 'testimonial injustice', which occurs when prejudice causes a hearer to give a 'deflated level of credibility' to a speaker's words (Fricker, 2007, p. 1). As an example of testimonial injustice, drawing from Harper Lee's book *"To Kill a Mockingbird"*, Fricker cites jurors' failure to believe the testimony of Tom Robinson – a black man in Maycomb County, Alabama, USA in 1935 – because they are prejudiced against black people (Fricker, 2007, p. 23). When someone lacks credibility, 'their assertions are not accepted by those to whom they are directed, and they are treated as lacking what is required to be a reliable informant' (Hookway, 2010, p. 152). This is considered a form of injustice, because this person is then unable to perform certain social and political tasks that demand credibility. According to Fricker, someone's status as epistemic agent affects his/her 'social power', which she defines as the 'capacity we have as social agents to influence how things go in the social world' (Fricker, 2007, p. 9).

A second form of epistemic injustice that inhibits social power is 'hermeneutical', referring to 'a gap in collective interpretive resources [that] puts someone at an unfair disadvantage when it comes to making sense of their social experiences' (Fricker, 2007, p. 1). While in 'testimonial' injustice someone is wronged in their capacity as 'a giver of knowledge' (Fricker, 2007, p. 7) and suffers a 'credibility deficit' (Coady, 2010, p. 110), in 'hermeneutical' injustice someone is wronged in their capacity as 'a subject of social understanding' (Fricker, 2007, p. 7) and suffers an 'intelligibility deficit' (Coady, 2010, p. 110). As an example, Fricker mentions Susan Brownmiller's book *"In Our Time: Memoir of a Revolution"* in which she recounts the situation of Carmita

Wood, 'a women who suffers sexual harassment prior to the time when we had this critical concept, so she cannot properly comprehend her own experience, let alone render it communicatively intelligible to others' (Fricker, 2007, p. 1). This is considered a form of injustice, because someone who cannot make him/herself understood is unable to perform social and political tasks that demand their intelligible contribution. Someone who suffers a lack of conceptual resources to make him/herself understood, is unable to effectively participate in 'practices through which social meanings are generated' (Fricker, 2007, p. 6).

Instead of focusing on the question of how to achieve justice, Fricker proposes a conceptual framework to study how injustices occur in practices of knowing. As such, her work allows for the detection and correction of injustices and for the piecemeal engineering towards justice. According to Fricker we can (and should) fight epistemic injustice by cultivating the virtues of testimonial and hermeneutic justice. This is done by tracing instances of epistemic injustice and guarding against prejudice in assessing and processing the testimonies of others (Fricker, 2007).

Critics have argued that the 'virtue' of epistemic justice cannot reasonably be required (Alcoff, 2010; Langton, 2010; Sherman, 2016). As one critic put it:

'in the contemporary world, we are all constantly bombarded with testimony, from a variety of sources ... We have limited evidence about many of these sources ... Given the pressure of time, and the barrage of testimony, it is nearly impossible for us to make credibility judgments that match the evidence in all such cases. That is more than can be reasonably expected of us' (Maitra, 2010, p. 199).

According to these authors, Fricker's account lacks an explanation of *who* is responsible (in our private, professional, public or political lives?) – and *when* (in what situation?) – for taking on the role of the virtuous listener (Dieleman, 2015; Maitra, 2010).

Against the background of debates about epistemic injustice, this paper explores the relevance of the concept in the context of public decision-making. Fricker's work makes us aware that stakeholders' ability to participate meaningfully in public deliberation is dependent on their credibility and intelligibility (Fricker, 2007). While policy-makers have been experimenting with deliberative spaces to engage citizens more directly in setting the direction for policy decisions (Dieleman, 2015), at the same time, concerns have been raised about the 'epistemological status' that is actually accredited to public knowledge (Irwin, 2006, p. 315). In the context of healthcare policy, it has been argued that patients do not always have the epistemic resources to 'effectively make use of' the possibilities offered to participate in formal decision-making procedures, and that procedures are not always designed to enable 'more than symbolic participation' (Peeters et al., 2014, p. 60). In this paper, we use Fricker's concept of epistemic injustice as a heuristic method to study how diverse groups of knowers participate as epistemic agents in the public arena, and explore the usefulness and limits of Fricker's work in the context of public decision-making.

### 1.2. EBM in policymaking practices

Applying the idea of epistemic injustice to healthcare, Carel and Kidd suggested that 'the structures of contemporary healthcare practice encourage epistemic injustice because they privilege certain styles of articulating testimonies, certain forms of evidence, and certain ways of presenting and sharing knowledge' (Carel and Kidd, 2014, p. 530). One of the contemporary 'structures' in healthcare (both in clinical practice and in policy practices) is Evidence-based Medicine (EBM), an epistemic ideal for decision-making in health care. EBM entails 'the conscientious, explicit, and judicious use of current best evidence' in medical decision-making (Sackett et al., 1996). It was announced in 1992 as a 'new paradigm' for medicine (Evidence-Based Medicine Working Group, 1992, p. 2420), emphasizing the use of

epidemiological, quantitative, experimental evidence in medical decision-making (e.g. Randomized Controlled Trials (RCTs) and systematic reviews). Originally designed for clinical practice, the principles behind EBM have become an epistemic ideal for making policy decisions too: policy should be based on (experimental) evidence of ‘what works’.

While the founding fathers of EBM claim that EBM entails the integration of the best epidemiological evidence with clinical expertise and patients’ preferences (Sackett et al., 1996), critics are concerned that EBM and its focus on quantitative population-based research unintentionally undervalues both doctors and patients ‘as “knowers” capable of making judgements outside the confines of epidemiological evidence’ (Deaton and Cartwright, 2018; Ghinea et al., 2015, p. 28; Greenhalgh, 2002; Greenhalgh et al., 2015). A perennial question, thus, remains: does the epistemic ideal that underpins EBM sufficiently accommodate the different kinds of (local and contextual) knowledge that are also required in clinical decisions (Greenhalgh, 2002) and in public decision-making (Dobrow et al., 2004; Greenhalgh and Russell, 2009). This paper engages with the latter issue: how is knowledge-intensive and evidence-based policymaking intertwined with questions of epistemic injustice?

## 2. Method

This paper draws from ethnographic research conducted at the National Health Care Institute (*Zorginstituut Nederland*), a public knowledge institution that plays a central role in the Dutch health insurance system and is responsible for making priority-setting decisions in the context of the basic benefits package and plays a key role managing the quality of care.

We studied ‘how knowing is done’ (de Laet, 2012, p. 429) at the National Health Care Institute, its ‘epistemic culture’ (Knorr Cetina, 2007). In particular, we looked at the Institute’s practice of creating and warranting knowledge as a basis to justify policy decisions. Due to the public nature of the Institute, its knowledge work centers on the justification of decisions. We studied what types of knowledge (e.g. experimental evidence, expertise, experience of doctors and patients) the National Health Care Institute employs in its efforts to attain impartiality, objectivity and justice in policy decisions.

From October 2013 to September 2017, the Institute’s management provided the first author with an in-house desk, a digital workplace and access to archives to do intensive fieldwork within the Institute. The first author attended public and closed meetings of internal working groups, the executive board, as well as expert meetings of the Institute’s advising committees, staff fora and informal lunches.

Taking a case-study approach, we selected several real-life struggles of the Institute in their knowledge-intensive decision-making processes and our research focused progressively on these case-studies. Two of the case-studies concerned “struggles” in which specific types of knowledge or evidence supporting policy decisions were publicly contested as parties felt that their knowledge was not sufficiently recognized, their voices unheard or that they had not been taken seriously in the policymaking process. We selected these two cases to analyze the issue of epistemic injustice in policymaking processes.

Each case was researched in the same consecutive stages: 1) familiarization with the case through informal conversations with staff and preliminary observations in meetings and fora; 2) supplementary data-gathering through document analysis (emails, minutes, internal and official documents, media articles) and selective overt non-participant observation of relevant meetings; and 3) in-depth research and triangulation through interviews with information-rich informants whom we selected through ‘purposive’ sampling (Green and Thorogood, 2004).

The leading question in analyzing the two case-studies from the perspective of epistemic injustice was: were parties recognized ‘in their capacity as knower’ and did they have a share of our ‘collective interpretative resources’ at hand in order to participate meaningfully in

these knowledge-intensive decision-making processes? In this empirical analysis, we abstain from making any normative claims about the credibility or significance of particular epistemic agents. As is customary in the field of Science and Technology Studies (STS) we remain impartial ‘with respect to truth and falsity, rationality and irrationality, success or failure’ of any particular form of knowledge (Bloor, 1976, p. 7). The abstention from taking such a standpoint (in STS this is called the ‘symmetry’ principle) allows us to conduct a systematic analysis into the way others – such as e.g. policymakers – ascribe credibility and significance to different types of knowers.

No additional data were gathered for the current paper, as we used available research archives from two earlier published cases (Moes et al., 2017, 2018). We do present previously unpublished material from the existing data set. As a ‘member-check’, we sent a written version of the analysis to staff-members and directors involved, to test our analysis with them.

## 3. Questions regarding epistemic injustice in reimbursement decisions

In the Netherlands, private health insurance companies provide standard basic health insurance for all citizens. The 2006 Health Insurance Act (*Zorgverzekeringswet*, Zvw) obliges everybody who resides – or pays payroll tax – in the Netherlands to take out basic healthcare insurance from a private insurance company. Income-related subsidies make basic healthcare insurance affordable for all citizens. Insurers are obliged to accept enrollees regardless of their age or health condition; a risk adjustment scheme compensates them for clients with predictably high medical expenses (Van de Ven and Schut, 2009). Competition was introduced on two levels. First, citizens can choose between competing health insurance companies during a yearly open enrollment period. Second, private insurance companies are expected to negotiate the prices, services, and quality of care on behalf of their insured clients (Van de Ven and Schut, 2008, p. 779).

The National Health Care Institute is tasked with managing the basic benefits package. The Minister of Health formally requests advice from the Institute on the medical–technical content of care that can be reimbursed from the basic health insurance. The Institute subjects major new drugs to cost-effectiveness analysis before coverage is considered (Staal et al., 2015). Such evaluations avoid the automatic inclusion of new drugs for intramural patients in the benefits package (Helderman et al., 2014, pp. 23–25). The Institute provides authoritative standpoints on existing medical treatments and non-pharmaceutical interventions when healthcare professionals lack clarity about the reimbursement of these treatments. The first case-study is about one of these reimbursement decisions (Moes et al., 2017).

### 3.1. The case

In 2013, the National Health Care Institute issued a reimbursement standpoint that bladder instillations with chondroitin sulphate or hyaluronic acid should no longer be covered by the basic health insurance, as there was no quantified proof of the treatment’s effectiveness. Bladder instillations are a medical treatment used for various bladder conditions, including bladder cancer, interstitial cystitis and painful bladder syndrome. During treatment a fine tube (catheter) is inserted into the bladder, the bladder is then filled with a solution (including a pharmacological cocktail of e.g. chondroitin sulphate or hyaluronic acid) and after a period of time the bladder is drained.

To arrive at a positive reimbursement decision, the Institute requires conclusive proof of a treatment’s effectiveness (*College voor Zorgverzekering*, 2007). The Institute uses the principles of EBM to gauge effectiveness, meaning that systematic reviews and double-blinded randomized-controlled trials (RCTs) are deemed to provide more objective information about treatment effectiveness than comparative or non-comparative research or expert opinions (*College voor*

Zorgverzekeringen, 2007, pp. 8–9). Two double-blind RCTs showed improvements after treatment with bladder instillations with chondroitin sulphate or hyaluronic acid, but the difference with the placebo group was not statistically significant (College voor Zorgverzekeringen, 2013, p. 11). The Institute therefore concluded that bladder instillations did not fulfil the reimbursement criteria as there was no quantitative proof of its effectiveness.

The Patients' Association for Interstitial Cystitis (ICP) sued the National Health Care Institute for misconduct against interstitial cystitis patients. Interstitial Cystitis (IC) refers to a spectrum of urological symptoms characterized by (chronic) pelvic, bladder and urethral pain, persistent urge to void or increased urinary frequency, as well as irritative voiding symptoms (Shao et al., 2010). Some IC-patients claim to benefit from bladder instillations with chondroitin sulphate or hyaluronic acid. Also, urologists who frequently use these bladder instillations claim that their experience with this treatment is often positive. Urologists' professional organization, the Dutch Urological Association (NVU), agreed with the Institute that 'at the moment there is insufficient reliable research' that provided quantitative evidence of this treatment's positive effect, but stressed that the two RCTs did 'NOT prove that the washes are NOT effective' (College voor Zorgverzekeringen, 2013, p. 21 emphasis in original).

The ICP's lawyer stated before the court: 'I do not contradict that the efficacy of a treatment is a prerequisite for being eligible for inclusion in the insured benefits package' (hearing#30042014). In making sense of this treatment's effectiveness, however, the lawyer argued that the EBM-method attributed too little credibility to the experience of doctors and patients: 'what everyday practice thinks about something has too little evidential value in the EBM-method' (hearing#30042014). Next, we examine the issue of testimonial injustice: were patients and urologists, indeed, insufficiently recognized in their capacity as knower?

### 3.2. Testimonial (in)justice

The ICP's lawyer introduced several patient testimonies about the experienced effect of bladder instillations with chondroitin sulphate or hyaluronic acid. A patient stated, for example, as follows:

'After a very tumultuous period lasting some months, my bladder has settled down as a result of the bladder instillations with hyaluronic acid. Because of the bladder instillations, my bladder hasn't suffered a 'flare-up' in almost a year' (exhibit 17 #1)

While the Institute did not deny that individual IC patients might benefit from treatment with bladder instillations, they did not take patient testimonials into account. According to the principles of EBM, personal accounts do not suffice to establish a treatment's effectiveness and whether it "works" for the average patient, especially in the case of IC. A staff member explained: 'Some of the patients have a functional syndrome ... and these are subjective outcome measures that you examine, i.e., improvement or reduction in symptoms. We were therefore explicit in saying 'we want randomized studies and not case series' (notes#03032014). In addition, the symptoms of IC fluctuate over time, which makes it even more difficult to attribute changes in symptoms to specific interventions. The Institute therefore decided:

'As interstitial cystitis is a disorder that is characterized by a fluctuating course and there is no standard treatment, randomized studies are needed in which bladder instillation with washes containing chondroitin sulphate and/or hyaluronic acid is compared with placebo washes. As the symptoms and outcome parameters are subjective, double-blind studies are preferred' (College voor Zorgverzekeringen, 2013, p. 10).

Double-blind and placebo-controlled RCTs keep both patient and doctor in the dark about the treatment received. This is considered important in case of subjective symptoms like pain. According to the principles of EBM, this type of experimental design curtails the

possibility of biased cognition and is deemed the most reliable and 'objective' measurement of a treatment's effect. The Institute, following the EBM-method, attributed reduced credibility to the individual testimonies of patients and urologists due to considerations of potential cognitive bias. From the perspective of epistemic injustice, one could say that the EBM-method in this case regards both patients and doctors as – to some extent – 'lacking the ability to make reliable assertions' (Hookway, 2010, p. 152). Not deliberately, but we can at least conclude that patients and urologists were 'marginalized' as credible epistemic agents with the EBM-method (Carel and Kidd, 2014, p. 530).

The Institute explained that 'the fact that individual patients claim to benefit from the treatment is not sufficient to conclude that the treatment complies with [reimbursement criteria]', and that the Institute 'does not issue statements about and on behalf of individual patients' (email#16122013). Rather, the Institute must consider the limited public funds available and ensure that citizens, who pay the premiums, are paying for something that is worthwhile –involving not an individual person, but the public at large. According to one of the directors, using EBM's quantitative methods allowed the Institute to make such calculations.

'the use of non-personal statistical data on a group level makes it possible to weigh up the personal interests of one group of patients against those of another group of patients. Every euro that you spend on bladder instillation liquids is no longer available for spending on care for elderly persons suffering from dementia, to name just one ... ' (notes#25062015)

While the Institute may have recognized patients and doctors 'as possessors and transmitters of knowledge', they did not recognize individual patients' and doctors' testimonies as a format of information that was 'useful in the current context' of making public reimbursement decisions (Hookway, 2010, p. 158).

Is this a form of testimonial injustice? According to Hookway, meaningful epistemic participation requires 'that we be charitable in our understandings, willing to explore the possible uses of the contributions that have been made' (Hookway, 2010, p. 161). Epistemic injustice lurks when the 'hermeneutical offerings' of a patient (or a doctor) is not judged as 'epistemically authoritative' in itself or even treated as an 'epistemically distinctive form of knowledge' (Carel and Kidd, 2014, p. 533). But what can reasonably be expected of policy-makers? It would be impossible to recognize all individual testimonies in a public decision-making context. Effective ways to include patients' knowledge in public decision-making are still being developed and researched (e.g. Lavis et al., 2009), also by the Institute (Kalf et al., 2018; Makady et al., 2017).

The EBM-method seems to provide the Institute with a much-needed 'logic of knowledge consumption' (Knorr Cetina, 2007, p. 368) that allows the Institute to make aggregate decisions on population level, that are justifiable as impartial and 'objective' in the public arena. The more pressing question in this case is whether patients (as a group of knowers) had enough epistemic resources to make themselves 'intelligible' within this EBM-formatted public space. Next, we explore the question of hermeneutical injustice: did patients have a fair share of our 'collective interpretative resources' at their disposal to manifest their experiences within the EBM-method (Fricker, 2007, p. 1)?

### 3.3. Hermeneutical (in)justice

The EBM-method used by the Institute provided two opportunities for IC-patients to make their experiences intelligible in the decision-making process: 1) new positive quantitative research 2) new positive quantitative subgroup research. First, the Institute stressed that 'if new positive studies are published, [the Institute] can revise their standpoint' (email#16122013). This meant that a positive reimbursement decision was possible if patients could present studies that captured their positive experiences with this treatment in a study with the

methodological design of an RCT. Second, the Institute insisted throughout the lawsuit that ‘when [subpopulation] research becomes available, a new assessment could take place that may result in a different opinion’ (statement of defense). The Institute would consider reimbursement for specific groups of IC-patients with proven benefit from this treatment provided that new subgroup studies were published that showed such a positive effect. The Institute recognized that ‘based on the literature [...], there is a vague idea that a subgroup exists’ (email#14012014). (Literature suggests, for example, that this treatment works especially for patients with Hunner’s lesions in the bladder.) This meant that a positive reimbursement decision was possible if IC-patients could make their experiences intelligible in new quantitative subgroup research (RCT). During legal proceedings, the ICP presented several scientific articles and conference abstracts of promising studies. None of these studies, however, had the experimental design of an RCT. Furthermore, no subgroup studies were available. Hence, the Institute did not change its standpoint.

In her final verdict, the judge considered that patients were not wronged in the Institute’s decision-making process. She argued that the Institute had correctly followed the EBM-procedure and had also given patients the opportunity to provide new evidence that the Institute may have missed. The final verdict read: ‘it has been established that *the information that the ICP could have supplied* – and which was supplied during these proceedings – did not lead to a different assessment’ (ECLI:NL:RBAMS:2014:772, emphasis added). With that verdict the court upheld the Institute’s standpoint not to reimburse bladder instillations with chondroitin sulphate or hyaluronic acid.

According to the patients (ICP) and urologists (NVU), however, translating the positive experiences of clinicians and patients with this treatment into the type of experimental evidence required for reimbursement was not possible. Urologists explained in a letter to the Institute that IC is a spectrum of urological symptoms with different (often unknown) underlying causes and its sufferers are likely to respond differently to treatment:

‘In practice of state-of-the-art clinics that treat patients with IC, this means it is not possible to produce such hard scientific evidence to show which treatments work and which do not. Large series are impossible due to the diversity of the groups of patients and the way in which IC presents, which means that hard evidence will never be supplied’ (letter from the urologists’ association NVU).

From the perspective of epistemic injustice: do patients who can only participate in decision-making if their contribution comes in the shape of quantitative, statistical (subgroup) evidence truly get a chance to epistemically participate? According to urologists, the required type of quantitative evidence could not be produced. The above statement shows that urologists considered the opportunity to provide new positive RCT studies methodologically infeasible. Moreover, one of the Institute’s scientific advisory members remarked about the feasibility of subgroup research: ‘who would want to carry out an RCT involving something that doesn’t work?’ (notes#30302014). Whether the research community would ever conduct further subgroup research is questionable. IC does not easily attract research attention or funds (in contrast to, for example, breast cancer or HIV/Aids). This means that IC-patients are often left to the mercy of a few dedicated experts (Shao et al., 2010). This is a group of patients with minimal investigative resources at their disposal to make sense of their experiences. Though the requirement of subgroup analysis may seem hypothetically rigorous from an EBM-perspective, in practice, it is unrealistic.

This means that IC-patients had (and still have) meager research resources to make themselves intelligible within the EBM-method. This is more than a case of ‘circumstantial epistemic bad luck’ (Fricker, 2007, p. 152). Most clinical research has ‘minimal patient input’, which often means that studies reflect outcomes that matter to researchers, rather than those that matter to patients (Greenhalgh et al., 2015, p. 2; Wiering et al., 2017). Consequently, patients participate only

marginally ‘in the collective practice of interpretation and understanding of their medical situation’ (Carel and Kidd, 2014, p. 532) and they have few entry points or resources to generate the required research. It was with this considerable ‘hermeneutical disadvantage’ (Fricker, 2007, pp. 151–152) that IC-patients participated in the EBM-formatted decision-making process.

#### 4. Questions regarding epistemic injustice in performance measurement

Since the introduction of the 2006 Health Insurance Act, private insurance companies play a prominent role in the Dutch healthcare system of managed competition. Insurers and hospitals are free to negotiate prices and selectively contract a range of hospital care products (Van de Ven and Schut, 2008). Insurers can steer their customers away from hospitals that do not reduce their prices or improve quality. Selective contracting is thought to stimulate both quality and efficiency (Bijlsma et al., 2009).

For selective contracting, insurance companies need comparative information about the performance of healthcare providers in order to negotiate price and quality (Delnoij et al., 2010; Enthoven and Van de Ven, 2007). As of April 1st, 2014, the National Health Care Institute is lawfully tasked to provide understandable, comparable and trustworthy information about the quality of care. As part of its official tasks, the Institute promotes the development of quality measures (e.g. quality standards, clinical guidelines, performance indicators, etc.) and stimulates the implementation of quality metrics.

Our second case is about the Institute’s mediation in a dispute between doctors, hospitals and insurers about the use of performance indicators in decision-making on the centralization of emergency care in the Netherlands (see Moes et al., 2018). This case offers the opportunity to analyze questions regarding epistemic injustice that arise in performance measurement.

##### 4.1. The case

In 2013, the Association of Dutch Health Insurers (*Zorgverzekeraars Nederland*, hereafter ‘ZN’) published a set of outcome, process and structure indicators to measure the quality of hospitals’ care for multi-trauma, acute myocardial infarction, cerebrovascular accident, (ruptured) abdominal aortic aneurysm, natal care and hip fracture. The indicators were designed to enable ‘insurers to shape their selective care purchasing’ (*Zorgverzekeraars Nederland*, 2013, p. 5). By the end of 2013, insurers had started to use ZN’s indicators to compare hospitals in the various regions and started negotiating which centers would (preferably) provide services for emergency cardiology, emergency neurology, traumatology, urgent vascular surgical care, and obstetrics. The idea was to centralize these services in specialized centers where indicators suggested that this was desirable (*Zorgverzekeraars Nederland*, 2013).

Insurers’ plans had far-reaching consequences for individual medical centers and caused much debate amongst emergency care professionals. When negotiations between insurers and hospitals started, a disappointed hospital director stated: ‘Emergency room closed, no more obstetrics, nor stroke care, no balloon angioplasty, and even broken hip operations will have to be done elsewhere’ (Visser, 2014a). Professional media reported: ‘In Rotterdam most complex emergency care will move to Erasmus Medical Center. Soon four times as many people will be going there with a stroke. Five hospitals will lose stroke care’ (Van Aartsen, 2014b). Medical specialists feared a “cascading effect”: if a hospital loses its contract for the treatment of, for example, myocardial infarction, general cardiology in that hospital could deteriorate or even vanish completely (Visser, 2014b). Professional media reported that hospitals’ positions in the debate about insurers’ plans were determined by interests: ‘hospitals that lose care tasks often object, while the winners see only the advantages’ of insurers’ plans (Kiers, 2014b).

Doctors, hospitals and professional organizations working in the field of Dutch emergency care contested, furthermore, the accuracy of the indicators and the appropriateness of insurers' use of them. Field parties were concerned about insurers' lack of medical-technical and practical knowledge about emergency care (Kiers, 2014b; Van Aartsen, 2014a). The Dutch Hospitals' Association (NVZ) felt that insurers' plans were 'not properly substantiated' and claimed that such indicators 'must be based on scientific research and have the support of medical specialists' (Kiers, 2014b). Apart from battling about resources, this was a knowledge dispute. It was a fight about whose job it was to determine the parameters for performance.

Next, we analyze the indicator-debate from the perspective of epistemic injustice. In the formulation and interpretation of the quality indicators for emergency care: were different stakeholders duly recognized in their capacity as knowers of emergency care? And did the different stakeholders have the hermeneutical resources to participate meaningfully in the process of drawing up (and putting to use) these indicators?

#### 4.2. Hermeneutical (in)justice

Although representatives of the Dutch professional associations were not directly involved in formulating ZN's quality indicators, ZN did consult medical professionals' knowledge about good quality emergency care as represented in professional and academic literature. ZN based its indicators on a vast number of scientific publications, including RCTs, systematic reviews and cohort studies, as well as Dutch, European and international guidelines (Zorgverzekeraars Nederland, 2013). As such, medical professionals' 'hermeneutical offerings' were actually judged as 'epistemically authoritative' in the formulation of ZN's performance indicators (Carel and Kidd, 2014, p. 533). Medical professionals, as a group of knowers, were part of the collective practice of interpreting and understanding the quality of emergency care and determining parameters for performance. No hermeneutical injustice occurred, as it was not 'a gap in collective interpretive resources' that put medical specialists, hospitals and other professional organizations at an 'unfair disadvantage' in making sense of the quality of Dutch emergency services (Fricker, 2007, p. 1). Any potential epistemic injustice lay elsewhere.

#### 4.3. Testimonial (in)justice

Most parties considered the insurers' initiative a top-down exercise. In professional media, the spokesperson for hospitals in the Northern region claimed, that

'no advance consultation took place with hospitals, the platform for acute care, GPs and patients' organizations. We were confronted with a *fait accompli*. Lists with green and red ticks. And would we formalize the plans within two weeks. You can't simply impose a new model from your ivory tower' (Kiers, 2014a).

While insurers regarded the negotiations as a collaborative process – 'discussions are going well, people are involved' – some hospitals felt that insurers' plans had been 'set in stone' and that insurers were 'not interested in the vision of the NVZ or any alternative plans the hospitals might have' (Visser, 2014a). Hospitals felt that their knowledge about the quality of emergency services had not been heard or taken seriously by insurers.

According to Hookway, epistemically meaningful participation 'is not just a matter of exchanging information; it involves asking questions, floating ideas, considering alternative possibilities and so on' (Hookway, 2010, p. 156). The arguments exchanged in professional media as presented above show that both the professional community and local healthcare providers felt that they did not truly participate in deliberations.

Quality indicators, such as the ones used by ZN, follow the logic that

clinical science can determine 'what works' and parameters based on these scientific findings can form an impartial and objective standard for provider behavior. Academic work has shown that quantified clinical knowledge is 'easily transformed' into a type of 'business knowledge of pathways and protocols' such as performance indicators (Mykhalovskiy and Weir, 2004, p. 1061). For non-medical parties who have no access to the primary care processes – such as, in this case, insurers – this aggregate knowledge provides the easiest way to gain insights into "what works" in clinical practice. The use of such quantified parameters is typically presumed to hold to ideals of impartiality, objectivity and justice in measuring and comparing the quality of different healthcare services.

However, the use of such standardized protocols has also been shown to challenge the clinical autonomy and professional judgement of local healthcare providers (Greenhalgh, 2002; Knaapen, 2014; Lambert, 2006; Timmermans and Berg, 2003; Timmermans and Kolker, 2004). Performance measures, in other words, undermine the 'medical professional's privileged authority to evaluate [his/her] own work' (Knaapen, 2014, p. 829). It is 'testimonial justice' that is at stake when the testimonies of local professionals threaten to be pushed aside by the facts and figures of external parties who attribute more credibility to parameters formulated by the medical profession at large than to the embodied, contextual knowledge of local providers. Next, we study the mediation work of the National Health Care Institute and show how their work reinstated local stakeholders as epistemic agents in the deliberations.

The Institute became involved in the debate based on its role as authoritative public knowledge institution working on providing reliable information about the quality of care. After several rounds of consultations with professional organizations, the Institute problematized two things. First, the scope of the indicator set. Field parties considered the scope of ZN's indicators too narrow and wanted to broaden it to the full spectrum of medical emergencies (not restricted to only six indications). They also considered it important to take into account the patients' trajectory from emergency call to aftercare (not just care that patients received in the ER). Therefore the Institute facilitated the development of a comprehensive 'Emergency Care Chain Quality Framework' (encompassing the full spectrum of emergency services and the entire patient trajectory) designed by all parties involved: professional organizations of patients, general practitioners, ambulance staff, primary healthcare, hospitals, academic medical centers, medical specialists, emergency doctors and health insurers. As such, the Institute explicitly reinstated all the different stakeholders as relevant epistemic agents in deliberating and making sense of the quality and efficiency of Dutch emergency services and how they should be organized.

Second, the Institute installed a group of thirteen experts representative of the professional emergency care community to provide a formal assessment of the original set of performance indicators. While the committee found that there was sufficient evidence supporting most of the performance indicators and that they were 'not unreasonable', they also stressed that the standardized knowledge of indicators alone was not enough to make sense of the quality of emergency services. A committee member explained that the quality of treatment for a heart attack, for example,

'... starts with a patient raising the alarm in good time, after which the GP takes a look, who then refers the patient to hospital in good time, and all of that finally determines the outcome of a myocardial infarction. If you judge a hospital based on, for instance, survival rates for myocardial infarction, well then you would also have to take into account the part of the chain before the hospital ... If people call in the GP too late, or the GP doesn't do his job properly, you will be running the risk that indicators will work against hospitals. You have to realize this, if you are going to make use of this sort of indicator ...'

While ZN's outcome indicators made sense in themselves, the quality of treatment for a heart attack depends on the entire trajectory from incident to aftercare. The committee stressed that the indicators did not suffice to make sense of the performance of individual hospitals. With 'evidence-based medicine as the foundation of the quality movement', the committee's chairperson explained, the focus had moved to 'standardized protocol quality'. But in applying such standards 'local data are important' and collaboration in the region is necessary to exploit sources of local, tacit and contextual knowledge. As such, the chairperson problematized insurers' use of standardized knowledge:

'This was just one party ... and a party that was at a considerable distance ... and because [the insurers] are at such distance, their only weapon is population data from the evidence-based medicine world ... which is standardized ... If someone has no hands-on experience and has never actually been to an emergency room ... then these are the only available data for him to use. But, then he forgets the knowledge sources that are somewhat harder for him to exploit, but that are very important too ...'

Ultimately, the committee emphasized that the performance indicators were to be used by professionals to jointly discuss how best to organize emergency services in the particular regions (Zorginstituut Nederland, 2015, p. 15). The expert committee, by stressing the importance of contextualizing the standardized performance measures with local knowledge, reinstalled local emergency care professionals as relevant epistemic agents in the process of making sense of the quality of regional emergency care services and putting the quality indicators to use.

The fact that this type "repair work" had to be taken up by the Institute is a reminder that testimonial injustice lurks when non-medical parties – who have no access to primary care processes – resort to the use of quantified clinical parameters. The quantitative approach of performance indicators suggests the possibility of separating 'expertise from expert, and knowledge from knower' (Tanenbaum, 1995, p. 102). This has given actors without direct experience of the primary care process the opportunity to 'regulate the field of healthcare and hold it accountable using [...] parameters formulated by the professions' (Timmermans and Berg, 2003, p. 20). Quantified parameters are typically presumed to warrant impartiality, objectivity and justice in measuring and comparing the quality of health services. Chances are, however, that when high levels of credibility are attached to such quantified parameters, the credibility of embodied and non-standardized knowledge of local health professionals is unduly marginalized.

## 5. Conclusion

In this paper we studied the usefulness and limits of Fricker's concept of epistemic injustice in the context of public decision-making. In contemporary healthcare policies the logic of EBM is central to how 'knowing is done' (de Laet, 2012). Evidence-based decision-making is typically proposed as a way of addressing a growing demand to explicitly justify decisions in the public arena (Dobrow et al., 2004; Parkhurst, 2017). Policymakers' use of scientific knowledge – 'evidence' in particular – is presumed to pertain to ideals of impartiality, objectivity and justice in decision-making and to guard policymakers against the suspicion of arbitrariness or bias (Porter, 1994). However, according to some, EBM 'privileges' certain types of evidence, certain ways of presenting knowledge and certain styles of articulating testimonies, and is, therefore, 'liable to generate epistemic injustice' (Carel and Kidd, 2014, pp. 530–531). In this paper we analyzed two cases of EBM-inspired policy practices in Dutch social health insurance and studied how knowledge work in policymaking is intertwined with questions regarding epistemic justice.

Our analysis of the first case illustrated that the embodied knowledge of patients and urologists was (unintentionally) marginalized as credible and useful information in the Institute's EBM-based

reimbursement decision. In particular, patient testimonies are still seen as subjective, 'anecdotal', limited to the 'private realm', 'context-dependent', 'as numerous as patients', and, therefore, difficult to use in public decision-making settings (Carel and Kidd, 2014, p. 535). And yet, can policymakers reasonably be expected to hear all patient testimonies in a public setting where different interests are at stake? EBM's principles provide policymakers with a much needed 'logic of knowledge consumption' (Knorr Cetina, 2007) to make aggregate decisions on population level that are explicitly justifiable as 'objective', 'impartial' and 'just' in the public arena. These quantified procedures are actually designed to facilitate the conscious exercise of counteracting bias and to prevent discriminatory outcome in policymaking. But, while formal institutions and their procedures for policymaking may be considered just, impartial and objective, this does not ensure that epistemic injustice is not occurring. Our analysis showed that patients had meager resources to produce the 'hard evidence' with which they could make themselves intelligible within the EBM-formatted public decision-making. If this type of hermeneutical marginalization is not recognized in policymaking, decisions may be regarded as upholding ideals of procedural fairness, but may still be epistemically unjust and potentially lead 'to misrepresentations in collective preferences' (Bernal, 2018, p. 23) (Moes et al., 2017).

The second case illustrated that questions regarding meaningful epistemic participation are equally relevant in making decisions in the context of the healthcare market. Performance indicators follow the same logic as EBM: clinical science can determine 'what works' and parameters based on these quantified findings can form an objective standard for provider behavior (Eddy, 2005; Tanenbaum, 2012). The use of performance indicators based on quantified clinical knowledge has given non-medical parties the possibility to act independently in a field where – originally – they had no epistemic authority (see Tanenbaum, 2012). The second case illustrated that when the protocolled and quantified medical knowledge of performance metrics aligns to match the logic of the insurers' market, the embodied, contextual knowledge of local professionals is potentially silenced. In that case it is questionable whether indicators still serve to promote the quality of care.

Both cases show the frustration that certain groups of knowers experience when they are not being recognized as credible epistemic agents in policy practices. This 'epistemic' frustration may help to interpret why policy decisions become contested in the public domain. Application of the concept of epistemic injustice to policy practices shows that when groups of knowers (whether patients or local professionals) are not duly recognized as epistemic agents, they subsequently lack the social power to influence priority-setting practices in which their interests are at stake. These groups are not merely frustrated in their epistemic capacity to be heard and make themselves understood, they are – as a result – potentially deprived of a fair share in our collective financial and medical resources. If we fail to recognize inequalities in credibility and intelligibility between diverse groups of knowers, there is a chance that these latent epistemic inequalities are being reproduced in our system of health insurance and our ways of distributing healthcare provisions.

It is important to stress that both international literature and the National Health Care Institute have long moved beyond a naive faith in the ability of EBM to straightforwardly guide complex priority-setting decisions (Russell et al., 2011). Aware of the shortfalls of EBM's strict hierarchy, the Institute now makes use of, for example, GRADE (see Guyatt et al., 2008), an EBM-method that allows more flexibility within the original hierarchy. The Institute is also exploring how to use 'real-world data' (Makady et al., 2017) and patient experiences from social media in health technology assessments (Kalf et al., 2018). This "repair and maintenance work" shows that policymakers continue to search for ways to meaningfully combine patients' and professionals' embodied, qualitative knowledge with aggregate, quantitative knowledge in policymaking. Epistemic injustice, however, often precedes such repair

work. It is, therefore, important that our priority-setting practices are continuously evaluated from the perspective of epistemic injustice.

The concept of epistemic injustice, however, also misses some key processes involved understanding how 'knowing gets done' in public policy processes. This has much to do with the infrastructure on which policymaking – in this case priority-setting – draws: current (international) procedures, conventions, regulations, stakeholders, etc. Fricker focusses on the role of the virtuous and unprejudiced listener, emphasizing the interrelational aspects of epistemic injustice. However, in the context of public decision-making, epistemic injustice typically does not originate between agents, but in the knowledge infrastructure from which agents draw. It is often through the work of policymakers that deeper, structural epistemic inequalities are made visible, and it is important not to reproduce these inequalities in priority-setting. Where were these injustices produced in the first place (Epstein, 2007)? Who is actually responsible for the widespread lack of credibility attributed to patient testimonies? In order to apply the concept of epistemic injustice adequately in the public context, we need to explore much more thoroughly the question of what 'epistemic justice' as a virtue requires of social institutions (Anderson, 2012). What does epistemic responsibility look like in a collective context (cf. Isaacs, 2011)? If we want to further develop and use the concept of epistemic injustice to investigate policy practices, these questions require our explicit attention.

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