

**AN ETHICAL FRAMEWORK FOR PRESENTING
SCIENTIFIC RESULTS TO POLICY-MAKERS**

*S. Andrew Schroeder
Claremont McKenna College*

*Accepted for publication in the Kennedy Institute of Ethics Journal
(Please see the KIEJ website for the final, copy-edited version.)*

Abstract. Scientists have the ability to influence policy in important ways through how they present their results. Surprisingly, existing codes of scientific ethics have little to say about such choices. I propose that we can arrive at a set of ethical guidelines to govern scientists' presentation of information to policymakers by looking to bioethics: roughly, just as a clinician should aim to promote informed decision-making by patients, a scientist should aim to promote informed decision-making by policymakers. Though this may sound like a natural proposal, I show it offers guidance that conflicts with standard scientific practices. I conclude by considering one cost of the proposal: that it would prevent scientists from acting as advocates in a way that is currently common in certain fields. I accept that the proposal would restrict scientists' political advocacy rights, but argue that the benefits of adopting it — promoting democratic governance — justify the restriction.

I. A PUZZLE

The Global Burden of Diseases, Injuries and Risk Factors Study (GBD) is “the single largest and most detailed scientific effort ever conducted to quantify levels and trends in health.”¹ More than 2300 researchers from more than 130 countries collect and analyze data on more than 300 diseases and injuries, aiming to put together a comprehensive picture of global health from 1990 to the present.² Not surprisingly, its results are widely reported and discussed by scientists, policy-makers, and the public at large. Probably the most high-profile of its results is its summary ranking of the world’s largest health problems, ranked by disability-adjusted life years (DALYs):³

2016 rank	Disorder	DALYs (millions)	2016 rank	Disorder	DALYs (millions)
1	Ischemic heart disease	174.6	9	Neonatal preterm birth compl.	62.0
2	Cerebrovascular disease	116.4	10	HIV/AIDS	57.6
3	Low back & neck pain	91.8	11	Skin diseases	57.4
4	Lower respiratory infections	86.6	12	Diabetes	57.2
5	Diarrheal diseases	74.4	13	Malaria	56.2
6	Road injuries	71.4	14	Congenital defects	50.4
7	Sense organ diseases	66.7	15	Neonatal encephalopathy	47.0
8	COPD	63.4			

Adapted from Hay et al. 2017

A striking thing about this list is the absence of cancer. One might conclude from this that, perhaps contrary to our preconceptions, cancer is not a major global health problem. That, however, would be the wrong lesson to draw. Cancer *is* a major global health problem. According to the GBD, it was responsible for 213.2 million DALYs in 2016 - far more than ischemic heart disease. Why, then, is it missing from the list? Because the GBD team chose to rank cancers separately by site. Thus, lung cancer ranked 19th, liver cancer 32nd, stomach cancer 36th, and so forth. Adding all cancers together, however, would see them rise to the top.

¹ <http://www.healthdata.org/gbd/faq>

² <http://www.healthdata.org/gbd/about>

³ DALYs, a close relative of quality-adjusted life years (QALYs), are a composite measure of the morbidity and mortality attributable to a particular event or pathology. The details of their construction are not relevant to this paper. See Murray (1996) and Schroeder (2017b).

The choice by the GBD team to rank cancers separately might seem curious for two reasons. First, a quick glance at the list appears to show an inconsistency. Although some items on the list represent pathologically unified categories (HIV/AIDS, malaria, etc.), there are other categories which seem to lump together pathologically heterogeneous items. Why break up cancer into various subtypes, while having catch-all categories like “road injuries,” “sense organ diseases,” and “neonatal preterm birth complications”? Second, the GBD team’s decision here is not based on any uniform disciplinary standard. Many epidemiological studies do aggregate cancers. The U.S. National Vital Statistics Report, for example, considers cancer to be a single category when ranking causes of death in the U.S. (Heron 2016, 5). What could the GBD team say in order to explain their ranking, since it appears to be inconsistent and not grounded in a disciplinary standard?

Questions like this are important. In deciding how to present their results, scientists are deciding what information readers will have access to, and what information will be functionally hidden from them. More importantly, we know — from common sense, as well as a wealth of research by behavioral economists, psychologists, advertising firms, and political pollsters — that the manner in which information is presented can have a huge and predictable impact on how it is received and on what subsequent decisions are made. The GBD team boasts that its data are used by governments, NGOs, and others in decision-making processes; and in particular singles out lists like the one above as being of great importance (Murray *et al.* 2012, 2198-99, 2201; *cf.* Murray 1996, 1-2). The decision to disaggregate cancers likely affected the flow of millions or billions of dollars in global health funding.

Questions like this are also not unusual. There have been many recent episodes in which decisions by scientists about how to present results have generated controversy. Climate science has seen high-profile debates about how to group countries for presentation in summary analyses (Victor *et al.* 2014; Dubash *et al.* 2014; Edenhofer and Minx 2014), how to present uncertainty (Mastrandrea *et al.* 2010), and (more generally) whether and how to “frame” climate research (Nisbet and Mooney 2007). In a very public debate concerning a proposal to change how scientists report *p*-values, participants recognized that much of what was at issue was simply how results are described — yet that did not make the discussion any less heated (Benjamin *et al.* 2018; Resnick 2017). And mode of presentation is a core issue in debates about the choice of model parameters such as the economic discount rate, as well as whether to adjust (or “weight”) economic measures to reflect various social or ethical values — e.g., a preference for a more equal distribution of income or health (Schroeder 2019).

Choices about how to present scientific results can affect the progress of scientific fields, direct the flow of billions of dollars, and influence major policy decisions. That clearly makes them ripe for ethical assessment. They also raise distinctly political concerns connected to democratic governance, as political theorists, philosophers of science, and (especially) STS scholars have long noted. Scientific

information and assessment is critical to nearly all major policy decisions, but policy-makers often lack the expertise to independently evaluate the scientific information available to them. This creates situations where legitimate decision-making authority and the information needed to make those decisions lie in two separate groups. It is often impossible (given realistic constraints of time and resources) for scientists to fully communicate their knowledge to policy-makers. And it is not clear whether decision-making authority can legitimately be delegated by policy-makers to scientists. Thus, we have a situation where it is not clear how informed, democratic governance is possible.⁴

In this paper, I want to propose a framework that could be used to guide scientists in choosing among alternate ways to present their results to policy-makers, in a way that I believe does a better job than the status quo of promoting democratic ideals. (I leave it open how broadly such a framework should apply, though I intend it to apply at least to scientific testimony to policy-making bodies, advisory committee reports, and other scientific publications, e.g. journal articles or white papers, with an explicit policy focus.) I will begin by looking to existing codes of scientific ethics, showing that current standards leave scientists with uncomfortably wide latitude in deciding how to present their results (§II). I will then offer my own proposal, suggesting we can take advantage of an analogy with the physician-patient relationship to construct a set of guidelines for scientists that are based off of existing bioethical principles of informed consent (§III). The remainder of the paper will be dedicated to working with the analogy: explaining why the principles it suggests are appealing ones for scientists (§IV), refining it through the use of existing work in bioethics and political theory (§V), and finally demonstrating both its utility and its revisionary nature through a series of brief case studies (§VI-VII).

II. A GAP IN SCIENTIFIC ETHICS

What norms or principles should guide a scientist in choosing among alternative ways to present her results to policy-makers? The natural place to look for an answer to that question would be to existing codes of scientific ethics — those found in textbooks, those endorsed by professional societies, and those adopted by journal editors. The relevant parts of such codes typically place a strict requirement of honesty at their center, sometimes supplemented with requirements of clarity.⁵ This,

⁴ For concerns of this sort, see Dewey (1927), Jasanoff (1990), Brown (2009), Kitcher (2011), and many others.

⁵ See the discussion in NAS-NAE-IOM (2017), the Singapore Statement on Research Integrity (2010), and Bullock and Panicker's (2003) survey of the ethics codes of scientific societies. For representative codes, see American Chemical Society (2015) and American Geophysical Union (2017).

however, still leaves scientists with a huge amount of latitude. In the GBD case, for example, it is true both that cancer causes more health loss than HIV, and that HIV causes more health loss than any specific type of cancer, so neither presentation raises any concerns connected to honesty. And both of those claims can be presented in a perfectly clear manner.

Next, many codes include a requirement that information be presented in a way that conforms to disciplinary norms. This, again, often isn't helpful. For one, disciplinary norms often permit the same information to be summarized in many different ways (as in the GBD case). Second, the principles that govern the presentation of information should be able to, at least sometimes, tell us what norms *should* exist, so that we can criticize existing norms and propose new ones. Obviously, a principle that tells scientists to conform to existing norms can't help with that.

Third, many codes include a set of requirements connected to openness: requiring scientists to be “transparent” and/or to present results “completely” or “fully”. What this is supposed to mean isn't entirely clear. Some codes do specify that results must be described in sufficient detail to allow others to verify or replicate the study's conclusions.⁶ This, however, is a relatively weak form of transparency that will leave scientists with considerable latitude. (In the GBD case, it could be satisfied by simply stating what disease classification system was used.) Many codes also call for scientists to make their raw data, source code, and unedited images available. But, especially when it comes to interactions with policy-makers, this seems insufficient. Policy-makers typically don't have the time or expertise to work with raw data or to dig through source code, so meaningful openness with policy-makers must involve sharing more accessible information — an explanation of scientists' reasoning, references to alternative methods of analysis, discussions of other possible interpretations of the results, and so forth (Elliott *forthcoming*). The problem, though, is that there are countless different respects or dimensions in which scientists could be transparent and therefore many alternative ways of achieving transparency (Elliott 2020). Without further specification — which existing codes of ethics don't typically provide — scientists will be left with quite a bit of freedom to choose what information to share or highlight, and what to leave out or bury in an appendix. If the GBD team, for example, were questioned about why they didn't highlight the fact that cancer was a leading cause of global health loss, they could point out that all of the data was available online, and that the methods section of the paper did explicitly lay out the disease classification system they used and provided a sentence of explanation. Such a response wouldn't, I think, demonstrate any failure to comply with existing requirements of openness or transparency or completeness, given the lack of specificity in those requirements.

⁶ See e.g. American Chemical Society (2015).

Finally, some codes of ethics include a second hard-to-interpret requirement calling for objectivity, neutrality, impartiality, and/or lack of bias. According to one understanding (which is probably the most common one among scientists, policy-makers, and the public), scientific objectivity is characterized by a lack of values, or a perspective-independent “view from nowhere” (Reiss and Sprenger 2014). Though that sort of objectivity may have a role to play in other aspects of scientific research, it is a non-starter when it comes to scientific communication. In deciding how to present results, scientists must consider factors like importance, usefulness, and relevance — but those concepts are all defined relative to a set of values or goals. What is important, useful, or relevant depends on what matters or on what one is trying to achieve. Philosophers, historians, and other scholars of science have identified a wide range of alternative conceptions of objectivity (Douglas 2004; Daston and Gallison 2007; Lloyd and Schweizer 2014; Reiss and Sprenger 2014). These conceptions, though, are not equivalent or reducible to one another. If, then, requirements of objectivity are to be meaningful, they need to be spelled out, to clarify what sort of objectivity is being called for. Unfortunately, existing codes of ethics don’t offer such elaboration.

The upshot of all this is that existing codes of scientific ethics have rather little to say about how scientists should choose among alternative presentations of their results, either in general or specifically when communicating with policy-makers.⁷ Requirements of honesty, clarity, and conformity to disciplinary norms will rule out some options, but they leave scientists with many options to choose among. This is where requirements of openness and objectivity could potentially step in. But the lack of specificity in existing codes of ethics leaves it unclear how those requirements should be interpreted. There are, of course, respects in which they do constrain scientists, for example striking presentation choices that would clearly count as biased or non-objective on many different accounts of objectivity. But in many more cases

⁷ For further support of this claim, consider the influential 1992 report on “Responsible Science” from the National Academies of Science and Engineering and the Institute of Medicine. Despite offering guidelines on several issues related to the presentation of research, it makes no mention of the issue discussed in this paper. Indeed, it explicitly notes that “differences in opinions involving the interpretation of data” do not count as instances of scientific misconduct (NAS-NAE-IOM 1992, 5). The 2017 update to that report does note that “misleading statistical analysis that falls short of falsification” does count as a “detrimental research practice” (2017, 74). But the report never explains what this means, and there is nothing clearly misleading about either way of presenting cancer statistics, for example. The issue similarly receives no discussion in most books on scientific ethics. (See e.g. Shamoo and Resnik 2015.) And even codes of ethics that do explicitly comment on the public communication of scientific results don’t typically say anything about how information ought to be presented, beyond the requirements of honesty, clarity, openness, and objectivity already discussed. See e.g. the Singapore Statement (2010), American Geophysical Union (2017), American Chemical Society (2015).

their ambiguity will provide scientists with a great deal of latitude. Scientists will be left with the freedom to choose among many different ways of presenting their results.

One reaction to this observation is to embrace it, saying that if scientists have satisfied basic requirements of honesty and clarity, and avoided clear and serious violations of openness or objectivity, they should be free to present information as they see fit. Call this the *laissez-faire model*. The *laissez-faire model* can be defended based on the idea that truth or good outcomes are best served by giving the strongest possible voice to each side in an argument — perhaps on the model of a court of law (Pielke, Jr. 2007, 11-16). Or it can be defended by reference to the individual rights of scientists to free speech and political advocacy (Schroeder 2017). Whatever the justification, the relative silence of current codes of scientific ethics on these points leaves the *laissez-faire model* as the *status quo*.

Nevertheless, although some scientists have embraced something like this view (a point I'll return to later), most appear to reject it. The reason for this, I think, is that the *laissez-faire model* permits scientists to choose a particular mode of presentation because it is more likely to promote the values and goals that they (or their employers or funding sources) favor. This type of strategizing generally seems inappropriate, in large part because it gives scientists a kind of influence over others that can be hard or even impossible for those others to detect. Imagine, for example, that it was revealed that the GBD scientists had chosen to disaggregate cancers while aggregating road injuries because their friends worked in transportation safety, while their professional rivals were cancer researchers. That would clearly seem wrong. Such strategizing still seems inappropriate, I think, even when used in the service of unselfish goals. Suppose the GBD scientists had chosen to aggregate preterm birth complications because they regard the lack of attention to maternal and child health as a grave injustice, and so intentionally created a broad, heterogeneous category in order to draw attention to that issue. It would be surprising, I think, to see scientists openly admit to doing that, which I take to be a sign that many consider it inappropriate.⁸

How, then, can we move beyond the *laissez-faire model*? There are several possible paths. One would be to expand disciplinary norms or conventions, so that conforming to those norms would seriously constrain scientists' presentation choices.⁹ A second would be to look at philosophical work on transparency and objectivity, to try to identify interpretations of those concepts that are well-suited to guide scientific

⁸ I think that this is essentially what some found concerning about the “climategate” emails: the appearance that scientists were strategizing about how to present results in order to promote desired policy outcomes.

⁹ For one attempt to create such standards, see the EQUATOR network (equator-network.org).

communication.¹⁰ Perhaps existing codes of ethics could offer clearer guidance to scientists, if they were supplemented by specific accounts of transparency and/or objectivity. A third path would be to try to construct an independent systematic framework, by reflecting on the role scientists ought to play in the policy-making process. I think all three of these paths are worth pursuing, and suspect that they will end up complementing one another. In the remainder of this article, though, I want to explore a version of the third strategy.¹¹

III. A PROPOSAL: THE INFORMED DECISION-MAKING FRAMEWORK

I suggest that we should model the ethical norms governing scientists' communication with policy-makers on the ethical norms — already well-explored by bioethicists — governing clinicians' communication with patients. This idea is not entirely new. Several scholars have mentioned it in passing (Martin and Schinzinger 2010; Resnik 2001), and Kevin Elliott (2006; 2011) has discussed it at some length.¹² They frame the proposal as applying the “informed consent” standard to scientists. This is an unfortunate choice of terminology, since in most cases a scientist is not asking a policy-maker to *consent* to anything when providing her with information. So let us instead take these ethicists to suggest that, just as clinicians should aim to

¹⁰ This is a path suggested by Elliott (2020; *forthcoming*), and indeed some of his earlier work provides an example of how this might be done (McKaughan and Elliott 2013; 2018). Transparency also plays an important role in the way many other philosophers propose handling value-laden aspects of science (e.g. Douglas 2009). I am less optimistic that transparency will provide a general solution to concerns connected to the role of non-epistemic values in science (Schroeder 2019; *forthcoming*). See also John (2018).

¹¹ I save for another occasion a commentary on the relationship between my proposal and the (relatively few) alternatives that have been put forward in the literature. The more-developed existing accounts include Jasanoff (1990), Turner (2003), Pielke, Jr. (2007), Brown (2009), Fischer (2009), Kitcher (2011), and Edenhofer and Kowarsch (2015). Although the practical recommendations I offer will in certain contexts coincide with those offered by other scholars (especially Kitcher, Brown, and Edenhofer and Kowarsch), I arrive at those recommendations via a very different argumentative route — a route that I believe has the potential to yield a more extensive set of specific recommendations that can more readily be implemented without large-scale changes to social or political institutions.

¹² Judging from their repeated references to work on informed consent in bioethics, the idea also seems to be implicit in Keohane, Lane, and Oppenheimer (2014) and John (2019). John's proposed “value-apt ideal” has much in common with my proposal, though he grounds his conclusions in a general argument that respectful communication requires tailoring that communication to the audience's values. Unless this obligation is a very weak, *prima facie* one, John's claim strikes me as too strong. In any case, it doesn't explain why it is especially critical for scientists (and clinicians) to tailor their communication to their audience's values — an obligation I don't think applies nearly as strongly to most other professions.

promote informed decision-making by patients, scientists should aim to promote informed decision-making by policy-makers. Applying that to the case at hand, it would say, roughly, that scientists have a *prima facie* duty to present their results in whatever way will best promote informed decision-making among policy-makers. That is, scientists should present policy-makers with information in a manner that enables those policy-makers to make the decisions facing them in an informed way. Call this the *informed decision-making framework*.

I think that this proposal has a lot going for it. But I also think that it hasn't yet been adequately developed. For one, arguments for it are lacking. A detailed case hasn't yet been made that the informed decision-making framework will yield a plausible and attractive set of ethical principles for scientists.¹³ Second, the details haven't been worked out. Although it is tempting to simply take the well worked out bioethical principles governing informed decision-making in the clinic and apply them to scientists, there are many differences between the cases. Even if this analogy is useful, developing specific principles for scientists will require paying close attention to these differences.¹⁴ Third, I don't think that existing work convincingly shows that this proposal can be used to provide concrete advice to scientists that goes beyond existing principles of scientific ethics.¹⁵ Indeed, it may seem as if scientists already endorse something like the informed decision-making framework, at least implicitly. As a result, I don't think the case has yet been made that the informed decision-making framework is actually useful. These are the deficits I will aim to correct in the next three sections of this paper.

IV. THREE CONSIDERATIONS IN FAVOR OF THE FRAMEWORK

A complete defense of any principle of professional ethics must depend on its real-world impact. The real-world impact of adopting the informed decision-making framework is an empirical matter which can't be settled until its details are worked out and it is put into practice. In this section, therefore, rather than attempting to offer a conclusive argument, I will instead offer three considerations, each of which I believe suggests that the analogy between physicians in the clinic and scientists in the

¹³ Resnik (2001) supports the informed decision-making framework by appeal to a range of factors but doesn't describe them in much detail. Elliott (2011) does offer a brief argument for it, but elsewhere I explain why I don't find Elliott's argument persuasive (Schroeder 2017a).

¹⁴ This is a point noted by Elliott (2006), but he says that exploring it would go beyond the scope of his paper.

¹⁵ Thus far, Resnik (2001) has used it argue against paternalistic deception in the provision of public health information, but such deception straightforwardly conflicts with the generally-accepted requirement of honesty. Elliott (2006) has applied it to a case — a commentary in *Nature* — that is exceptional in a number of respects.

policy sphere is a helpful one. Collectively, I hope they will suggest that the informed decision-making framework can provide appealing principles to govern scientists' presentation of their results; and, accordingly, that it is worth the effort to explore, develop, and refine the view.

First, the informed decision-making framework coheres with many scientists' understanding of their role when it comes to policy. Michael McPhaden, then-president of the American Geophysical Union, for example, said, "To be a credible voice for the power of Earth and space science *to inform policy*, transform our understanding of the world, and inspire the next generation of scientists, we must build trust between the scientific community, the public and policy makers."¹⁶ The mission statements of scientific organizations express similar ideas. The American Institute of Biological Sciences says that it "works to ensure that the public, legislators, funders, and the community of biologists have access to and use information that *will guide them in making informed decisions* about matters that require biological knowledge."¹⁷

Second, the informed decision-making framework provides a unifying explanation for the assorted requirements typically found in codes of scientific ethics. Honesty and clarity will tend to promote informed decision-making for obvious reasons. Conformity to disciplinary norms will also usually do so, since having scientists in the same field using different methodologies can be confusing. Other norms of scientific ethics, such as those requiring disclosure of conflicts of interest, also support informed decision-making.

What about the norms which we earlier saw to be vague and underspecified? The informed decision-making framework justifies those norms, while at the same time suggesting particular interpretations of them. When it comes to ideas of openness, transparency, and completeness, the idea is relatively straightforward and unsurprising: a presentation of results is suitably transparent and complete if it includes information presented in all of the ways that are likely to prove materially relevant to a policy-maker's decision. Of course, such a principle can't be applied categorically, but must instead be balanced against other considerations.¹⁸ The informed decision-making framework, though, can suggest which ways of presenting information should be prioritized.

Next, consider objectivity and freedom from bias. As physicians know, helping patients to make informed decisions requires getting to know them — understanding their values, specific informational needs, and so forth — and then tailoring information to fit those values and needs. Similarly, a scientist seeking to promote informed decision-making should, ideally, tailor her presentation of information to

¹⁶ Quoted at <https://ethics.agu.org> (emphasis added)

¹⁷ <https://www.aibs.org/about-aibs/> (emphasis added)

¹⁸ See Keohane, Lane, and Oppenheimer's (2014) discussions of precision and audience relevance, both of which include aspects of completeness.

ensure that it is responsive to the specific values and needs of the policy-maker. If, for example, policy-makers in some society are particularly concerned about gender equality, scientists there can best promote informed decision-making by disaggregating certain results by gender and calling attention to areas with great discrepancies.

This focus on the values of the policy-maker (as opposed to the values of the scientist) means that two scientists with access to the same information (including the same information about the values of the policy-maker) preparing a presentation for the same policy-maker should present their results in roughly the same way. In other words, according to the informed decision-making framework, the way information is presented should depend on the content of that information as well as features of the person to whom it is being presented, but *not* on any particular features of the scientist. This matches a conception of scientific objectivity which has been discussed at length by historians and philosophers of science — what Reiss and Sprenger (2014) call “objectivity as freedom from personal biases”, Daston and Galison (2007) call “mechanical objectivity”, and Douglas (2004) calls “procedural objectivity”. Objective science, on this view, is science that isn’t influenced by the idiosyncrasies of individual researchers.¹⁹

Thus, the informed decision-making framework can both unify existing principles of scientific ethics, and add precision and clarity to principles that currently lack them. It can therefore potentially serve as an organizing principle for scientific ethics: identifying appropriate lower-level principles, suggesting interpretations of those principles, and helping us to navigate any conflicts that might arise among them.

Finally I come to a third consideration in favor of the informed decision-making framework. The analogy between clinicians and patients on the one hand and scientists and policy-makers on the other, is rather deep, encompassing nearly all of the features which have been used to defend informed consent requirements in medicine. In both cases, we have one party (the patient or policy-maker) who has the right to make a decision that calls for information possessed by another party (the doctor or scientist), where the second party is unable to fully convey her knowledge to the first party. As a result, the first party is in a position of vulnerability and has no realistic alternative but to trust the second. Given the many significant similarities between the cases, it seems reasonable to expect similar ethical standards to be

¹⁹ Boulicault (*unpublished*) labels this the “idiosyncrasy-free ideal” for science, in contrast to the more familiar value-free ideal. Boulicault and I discuss the idiosyncrasy-free ideal and compare different ways of implementing it in (Boulicault and Schroeder 2021).

appropriate.²⁰ To the extent that we find the requirement of informed consent compelling in the clinical setting, therefore, we should probably also find the informed decision-making framework appealing in the scientific setting — unless, of course, there is some special feature of the scientific case that renders it relevantly different. (I consider one potentially important difference in §VII.)

V. REFINING THE ANALOGY

Though none of the three considerations discussed in the previous section is decisive, I think that collectively they show that the informed decision-making framework offers a plausible starting point for thinking about how scientists ought to choose among alternate ways to present their results to policy-makers. To turn that general framework into a set of useful principles, however, requires much additional work. I leave the details of that for another occasion, but in this section I will show how the process might proceed — and how it can be jump-started using the existing literature in bioethics and political theory.

What would it mean to take the bioethical requirement on physicians to promote informed decision-making and apply it to scientists? In standard situations, physicians are told to tailor their presentation of information with the aim of helping patients to make decisions that reflect their own values. So, for example, if a patient is wearing a “meat is murder” t-shirt, her physician should highlight that a medication contains gelatin. But that same information probably need not be brought to the attention of a patient snacking on a ham sandwich. That said, physicians are not directed to simply cater to whatever preferences or goals a patient happens to assert at a given moment; they are encouraged, when possible, to seek out and be guided by a patient’s considered, informed values (Groll 2011). Suppose, for example, a patient says she doesn’t want a flu vaccine because the flu is no more serious than a cold. Or she says she doesn’t need information about pain management following a major surgery, because pain doesn’t bother her. Even if these patients are being sincere, physicians ought not simply accept the assertions and move on. In the former case, a physician ought to attempt to correct the patient’s false empirical belief. In the latter case, she ought to have a conversation with the patient, to be sure that she firmly means what she says — that this value isn’t simply a whim, likely to give way upon reflection.

²⁰ One apparent difference between the cases is the fiduciary role the physician often takes on vis-a-vis the patient. It is not clear, however, that that sort of relation is necessary to ground physicians’ obligations (Eyal 2011), and in any case many have argued that the support given to science by the public (via grants, but also via social recognition and esteem) grounds a similar obligation on behalf of scientists to work for the benefit of society (Shrader-Frechette 1994, 25; Elliott 2006).

Let us, then, apply these bioethical requirements to scientists as mechanically as possible. Doing so yields a principle like this:

First Try. *In normal situations,²¹ scientists have a prima facie duty to present information to policy-makers in a way that promotes informed decision-making. This means presenting and highlighting information that is relevant and important in light of the considered and informed values and goals of the policy-maker.²²*

First Try isn't a plausible principle to govern scientists' communications with policy-makers. In some cases it fails to give scientists any clear guidance, while in other cases it gives guidance that is ethically suspect. Let's try to refine it.

Refinement #1: Moving From Ethics to Politics²³

The most obvious problem with First Try is that it doesn't respect the distinctly political character of policy decisions. Patients are typically making decisions that are theirs: they have the right to (within certain limits) make whatever decision they like, and they aren't obligated to justify that decision to others. This is reflected in the bioethical requirement's exclusive focus on the values of the patient. Policy decisions, however, aren't individualistic in the same sense. Legislative bodies and

²¹ For now, I leave this undefined. It is meant to rule out exceptional cases in which other considerations override the importance of facilitating informed decision-making. Examples might include emergencies (in which scientists don't have time to present significant amounts of information), situations in which an adversarial relationship is explicitly sought or expected, and cases where a scientist explicitly announces she is acting as an advocate (e.g. when writing a commentary or editorial). I also set aside the question of what a scientist should do when replying to a report clearly prepared as a work of advocacy. The question of whether one should follow a set of norms being violated by one's interlocutor requires more space than I can give it here.

²² It is important to note the difference between this, and the claim, common in the literature on evidence-based policy, that policy-makers are much more likely to act on scientific research that is tailored to the decisions they face (Rose *et al.* 2020). That literature is largely making the *empirical* claim that research tailored to policy is in fact more likely to get noticed and used. I am proposing the *normative* claim that scientists ought to tailor the way they present their information. These are distinct claims, since there are plenty of situations where scientists might not want policy-makers to act on their research, or on specific findings they've reached. (This might be especially common in situations where a scientist's values and goals differ from policy-makers'.) In addition, the notion of "tailoring" and "relevance" used in the evidence-based policy literature is quite different from what I am proposing. I thank an anonymous reviewer for encouraging me to clarify this point.

²³ For the general importance of this distinction and its relevance for work on the value-laden aspects of science, see Schroeder (2020).

regulatory committees often make decisions as groups. In such cases, it is incumbent on each policy-maker to be able to explain her point of view to her co-decision-makers and to make some effort to understand and respond to their points of view. Policy-makers must also understand things from the perspective of the public, both because they act on behalf of the public, and because the public has a right to provide input into policy decisions. For all of these reasons, informed decision-making in a political context requires that a policy-maker have not just the information that speaks to her own values and goals, but also the information that speaks to the values and goals that motivate other policy-makers and the public.

That, then, is the first respect in which First Try needs to be modified: the reference to the values of the policy-maker needs to be broadened, so that information is presented and highlighted that is relevant and important according to the considered and informed values of other policy-makers and the public. (For simplicity's sake, I will assume that the values of policy-makers align with the values of the public. What to do when that isn't the case is a challenging question I will briefly comment on below.)

Without further qualification, though, this suggestion is too ambitious. The GBD data set, for example, could be presented in countless ways. In a large, pluralistic society, catering to the positions of every policy-maker and member of the public would require that GBD scientists present their results in thousands of different ways. This would be impractical and counterproductive. We need, therefore, a way to determine which (or whose) values scientists ought to prioritize when presenting their results — both when deciding what information to present, and in deciding which presentations to give pride of place (appearing, for example, in an abstract or executive summary, rather than being buried in the body of a long paper, in an online appendix, or accessible via a configurable data visualization tool). When it is not feasible to tailor the presentation of information to all perspectives in a society, it seems reasonable, as a first approximation, to favor the values that are more commonly held among the public and policy-makers.²⁴ This will enable a larger fraction of the public to meaningfully engage in debate and dialogue concerning the relevant policy decisions, and it will enable policy-makers to understand the perspectives and arguments of a larger group. It does seem right to say that, all else equal, a policy-maker who understands the concerns of a wider range of her constituents makes a more informed decision. Work in democratic theory highlighting problems with majoritarianism can help us to refine this initial idea. An egalitarian foundation for democracy, for example, may justify giving extra weight to the values of those whose voices have been marginalized or excluded (Schroeder *forthcoming*).

²⁴ Several scholars have argued that when scientists face key value-laden decisions in their research, they should defer to the public in something like this manner. See e.g. Brown (2009); De Melo-Martín and Intemann (2018: 125-6); Douglas (2005); Intemann (2015); Lusk (2020); Schroeder (*forthcoming*).

Refinement #2: Handling Substantively Objectionable Values

The previous refinement was driven by a somewhat abstract concern that First Try failed to reflect the political nature of policy decisions. There are many other cases where First Try is problematic for more concrete reasons, because it delivers guidance that seems suspect. In such cases, it often isn't hard to find parallel problems afflicting simplistic applications of an informed decision-making standard in bioethics. This suggests a promising recipe for revising First Try by piggy-backing on the work of bioethicists: for any case where First Try gives scientists intuitively questionable guidance, first construct a clinical case that as far as possible matches it. Second, ask how bioethicists have handled that clinical case. Third, by reflecting on the similarities and differences between the scientific and clinical cases, see whether or how the clinical solution can be adapted to provide guidance to scientists.

Let me illustrate this method by considering a case where First Try offers unacceptable guidance. Suppose an epidemiologist is presenting data to a group of policy-makers, a significant number of whom are racist. The epidemiologist could present information in ways that would help those policy-makers make decisions that furthered their (racist) goals in an informed way. He could, for example, partition geographical regions based on the racial makeup of populations, or prominently flag health conditions that are correlated with race. But it seems obvious that the epidemiologist should not cater to the policy-makers' racist values in these ways, so there must be a problem with First Try.²⁵ Let's ask, then, what would count as a comparable case in the clinic. We can easily imagine scenarios where a patient's morally unacceptable goals — infecting a sexual partner with HIV, say — would be furthered by medical information a physician could provide. This type of case has not received any attention in the bioethical literature, but a set of related cases has: cases in which a patient requests a procedure (e.g., physician-assisted death) that a physician deems morally wrong. The dominant approach to potential "conscientious refusals" says that when the requested procedure isn't especially problematic, physicians must either perform it or assist the patient in finding another physician who will. When the requested procedure crosses a certain line, however, physicians may refuse to assist in any way. The tricky part, of course, comes in determining how to draw the line, a point on which bioethicists differ.²⁶

In the scientific case, a similar approach seems plausible. Scientists should generally present information relevant to the values of policy-makers, even if they

²⁵ Of course, there are plenty of situations where it would be perfectly appropriate and indeed desirable for an epidemiologist to present data in ways that make race salient — for example, to help policy-makers identify racial disparities in health outcomes. I mean to be considering a case where these redeeming features are not present.

²⁶ Proposals include appealing to the ethical views of the profession at large (Blustein 1993), a substantive ethical standard (Davis 2004), or a legal standard (Brock 2008).

disagree with those values. But in especially egregious cases, scientists need not cater to the morally unacceptable values held by policy-makers. The challenge, as in the clinical case, comes in determining what counts as an “egregious” case. Fortunately, work in political philosophy suggests a way forward here. If, as the informed decision-making framework suggests, we think of scientists as facilitating policy-making when they communicate with policy-makers, then the problem they face here is connected to the more general issue of distinguishing substantive values that are legitimate bases for public decision-making, from those that are not.²⁷ Intuitively, for example, if the majority values jazz more highly than opera, that would be a good reason for the government to subsidize a jazz festival rather than an opera festival. An opera-loving economist who intentionally presented statistics in a way designed to make the opera festival look more appealing would be undermining a legitimate public goal. But if the majority values the welfare of its white citizens more highly than the welfare of its black citizens, that would not justify the government in implementing racist policies. A scientist who refused to assist in this pursuit would not be undermining any legitimate public interest, because racist interests are by their nature politically illegitimate.

Political philosophers and theorists have written a fair amount about which values are, due to their substance, illegitimate in the political sphere. That literature can therefore be used to refine First Try. I can’t go into the details of that work here, except to note that when it comes to the case of racist policy-makers, many different theorists have specifically picked out anti-egalitarian values as paradigm examples of values that are politically illegitimate.²⁸ This suggests that racist and sexist values might be ones that we can provisionally mark as examples of values that scientists ought not cater to, even if held by the majority.

Further Refinements

I have suggested two refinements to First Try. Putting them together yields:

Second Try. *In normal situations, scientists have a prima facie duty to present information to policy-makers in a way that promotes informed decision-making. This means presenting and highlighting information that is relevant and important in light of the considered and informed values and*

²⁷ I consider here only values or goals that, due to their *content*, are politically unacceptable. There are other reasons a policy-maker’s values might be politically unacceptable: they might conflict with the values of the public; they may have been formed in unacceptable ways; etc. A fully worked out version of the informed decision-making framework would need to consider each of these cases.

²⁸ See Nussbaum (2011, 29, 38); Rawls (2005, 243n32); Christiano (2008, 269); Gutmann and Thompson (1996, 2-3, 73-79). I discuss this issue in more detail in an unpublished manuscript, “The Limits of Democratizing Science: When Scientists Should Ignore the Public.”

goals held by policy-makers and the public, so long as those values and goals are politically legitimate. If it is not feasible to accommodate all views, preference should be given to the values and goals more commonly held.

As its name suggests, Second Try is not a final principle. It needs much more refinement before it could serve as an adequate foundation from which to derive concrete guidelines for scientists. It does not, for example, give clear direction in cases where the values of policy-makers diverge from the values of the public. (Here, work in political theory on the nature of representation will be important.) It does not give guidance in cases where there is no clear fact of the matter about what views people would hold if they were to carefully reflect on some issue. (Here, both empirical and normative work on deliberative democracy may be relevant.) It does not identify precisely which values are politically legitimate vs. illegitimate. It does not offer guidance on how to handle situations where multiple policy-makers will be relying on the same information to make different decisions with different informational needs.²⁹ These, along with many additional issues, must be addressed before Second Try can be turned into a satisfying and useful principle. But I hope the discussion in this section has shown that there are promising ways of approaching this task, and that it can be expedited by making use of existing work in bioethics and political theory.

VI. PUTTING IT TO USE: FOUR CASE STUDIES

Whatever its abstract merits, the informed decision-making framework will only be of practical use if it can offer substantive guidance to scientists that goes beyond existing recommendations. It is fair to be skeptical that it can. As we saw earlier, many scientists and scientific organizations claim to endorse something like

²⁹ I suspect that this type of case will pose serious challenges for *any* account of how scientists ought to present information to policy-makers. After all, if different policy-makers are facing different decisions with different informational needs, how could any presentation of information be suitable for all of them? The obvious and clearly most desirable solution would be to prepare separate reports for each group of policy-makers. But in cases where, for whatever reason, that is impossible, the informed decision-making framework could potentially use democratic mechanisms like the ones mentioned earlier to decide whose informational needs to prioritize. Even more complex would be a case where the way information is presented will influence how policy-makers frame problems and so what types of decisions they consider (e.g., one mode of presentation might lead policy-makers to perceive some problem as an economic issue, while a different presentation might lead them to perceive the same problem as an environmental issue). I don't know the best way to revise Second Try to account for such cases — though I note they have analogues in political contexts outside of science, which might provide a path to a solution. I thank an anonymous referee for raising these issues.

the informed decision-making framework, and so it is reasonable to wonder whether whatever guidance the framework could provide has already been built into standard professional practices and norms. This, however, is not the case. Although nuanced application of the informed decision-making framework will have to wait until a more refined version has been produced, even the crude version I presented in the previous section has bite. In this section I will demonstrate that through four brief case studies. In each example, the informed decision-making framework offers advice that goes beyond standard codes of scientific ethics and conflicts with standard scientific practices. This shows that, right or wrong, the informed decision-making framework represents a substantive and revisionary proposal.³⁰

Case #1: Absolute vs. Relative Risk

Risks can be and commonly are reported in either relative (“doubles the risk”) or absolute (“increases risk by 0.01”) terms. Many scientists prefer to report risk in relative terms for a variety of reasons: it can be easier to understand, may be more memorable, and may help in drawing attention to important issues.³¹ Some epidemiologists and ethicists, however, have expressed concerns about relative risk, questioning its relevance to decision-making. If I tell you that some behavior doubles your risk of an adverse outcome, there isn’t much you can (rationally) do with that information. It matters quite a lot whether it increases your risk from 0.2 to 0.4 — a huge change! — or from 0.0001 to 0.0002 — virtually nothing. This result has been formalized by Sprenger and Stegenga (2017), who prove that given standard assumptions in decision theory, relative risk is typically irrelevant to rational decision-making concerning treatment or policy options, while absolute risk differences are relevant.

There may be, then, a number of benefits to reporting risk in relative terms: doing so may make it more likely that audiences form true beliefs (e.g., because relative risks are easier to understand and more memorable), and may also lead to better outcomes (e.g., because it startles people into making decisions that are, in fact, good for them). These virtues — educating the public and promoting good outcomes — seem like things that scientists should be seeking. Indeed, it wouldn’t be surprising for scientists to announce those aims: “We presented risk in relative terms because research shows that such statistics are more readily picked up by the public, and we

³⁰ To be clear, I am not claiming that the recommendations I offer here are novel. In the first three case studies, the scientific practices I question have been challenged by other scholars (though the issues remain controversial). The point is that the informed decision-making framework provides clear ground for questioning existing practices that are common and widely accepted - thus showing that existing scientific codes of ethics and professional practices have not internalized the informed decision-making framework.

³¹ For a concrete example, see Skovlund *et al.* (2016), which reported that certain types of hormonal birth control “doubled” the risk of depression in teens, and the popular response to it.

think this is a critical issue the public needs to know about.” But, according to the informed decision-making framework, those goals should be secondary to promoting informed decision-making. If relative risk is not relevant to rational decision-making, then the informed decision-making framework will direct scientists to present risk in absolute terms.

Case #2: IPCC, Sea Level Rise, and Radical Uncertainty

In a 2014 paper, Keohane, Lane, and Oppenheimer discuss a presentation problem faced by the Intergovernmental Panel on Climate Change (IPCC) in 2007. I agree with their conclusion and the reasoning in support of it. I want to discuss the case, though, because I think the informed decision-making framework plausibly lies behind their analysis, providing a unifying explanation for several of the principles they identify, and perhaps offering a simpler route to their conclusion.

Here is the case. IPCC scientists in Working Group I were attempting to estimate sea level in 2099 under a variety of different scenarios. Of the factors that contribute to sea level rise, several were understood reasonably well: the thermal expansion of sea water, the melting of mountain glaciers, and the melting of ice sheets on Greenland and Antarctica. But at the time, scientists had no models to predict a fourth factor: the sliding of ice sheets in Greenland and Antarctica into the sea (“dynamical changes in ice flow”). Accordingly, scientists chose to present their estimate of the combined impact of the first three factors, while noting that the fourth factor had been excluded from their assessment:

Table SPM.3. Projected global average surface warming and sea level rise at the end of the 21st century. {10.5, 10.6, Table 10.7}

Case	Temperature Change (°C at 2090-2099 relative to 1980-1999) ^a		Sea Level Rise (m at 2090-2099 relative to 1980-1999)
	Best estimate	Likely range	Model-based range excluding future rapid dynamical changes in ice flow
Constant Year 2000 concentrations ^b	0.6	0.3 – 0.9	NA
B1 scenario	1.8	1.1 – 2.9	0.18 – 0.38
A1T scenario	2.4	1.4 – 3.8	0.20 – 0.45
B2 scenario	2.4	1.4 – 3.8	0.20 – 0.43
A1B scenario	2.8	1.7 – 4.4	0.21 – 0.48
A2 scenario	3.4	2.0 – 5.4	0.23 – 0.51
A1FI scenario	4.0	2.4 – 6.4	0.26 – 0.59

Table notes:

^a These estimates are assessed from a hierarchy of models that encompass a simple climate model, several Earth System Models of Intermediate Complexity and a large number of Atmosphere-Ocean General Circulation Models (AOGCMs).

^b Year 2000 constant composition is derived from AOGCMs only.

The problem with this choice, as Keohane, Lane, and Oppenheimer explain, is that the fourth factor could be huge — potentially more significant than the other three combined. Nevertheless, it was “almost [inevitable]...that some policy-makers, out of

confusion or desperation, would use the numbers given” (346). Thus, the choice by Working Group I to present their results in this way predictably led to “the inhibition of effective planning by coastal communities” (347) — in other words, to uninformed decision-making.

Here is one way of seeing the problem. The chart was presented in the “Summary for Policymakers,” thus identifying its intended audience. For nearly all planning purposes — e.g., to build sea walls, or to determine how far inland to relocate population centers or infrastructure — policy-makers care about the total sea level rise; they have no independent interest in the source of the rise.³² That means that if in some scenario scientists believe there is a reasonable chance of *no* significant increase in ice flow, then the lower number presented in each range is potentially of policy interest, since it gives a lower bound on potential sea level rise. But the upper end of each estimate is almost wholly irrelevant to policy-making. The chart essentially says that in scenario B1, future sea level rise is “0.18-0.38m, plus a contribution from ice flow which could range from 0 to several meters.” The 0.38m is of no use for policy-making. Thus, the problem with the chart is that it presents information irrelevant for policy-making in a venue intended for policy-makers — precisely what the informed decision-making framework counsels against.

What, then, should the IPCC scientists have done? I agree with Keohane, Lane, and Oppenheimer that the best route would have been to provide their best guesses concerning potential future ice flow, with an indication that these were subjective and highly uncertain. But if, for whatever reason, that option was rejected, it would have been an improvement to remove the upper bound, replacing “0.18-0.38” with “at least 0.18” or “more than 0.18”. This conflicts with the standard expectation that scientists presents results completely and precisely. But, at least according to the informed decision-making framework, completeness and precision are not of independent value in communication with policy-makers; they are of value only insofar as they promote informed decision-making. In this case, completeness and precision promote uninformed decision-making and therefore are not virtues.³³

Case #3: Distribution-Sensitivity in QALYs

³² The audience is clearly crucial here: many *scientists* have good reason to care about the different sources of increase. Of course, we can imagine the rare policy-maker who would care about the source — perhaps one considering geo-engineering proposals that could differentially affect different sources of sea level rise. But I take it that such policy-makers are not a major audience of the IPCC Summary for Policymakers.

³³ For a similar view, according to which standard norms of scientific communication are largely of instrumental value and therefore potentially subject to exceptions, see John (2018).

There is widespread agreement that when it comes to health policy, distribution matters.³⁴ Our goal should not simply be to maximize total or average population health; we should prefer a more equal distribution of health, even if that comes at some cost to the total or average. For decades, health economists have discussed how economic measures, such as quality-adjusted life years (QALYs), could be adjusted to reflect egalitarian values. To date, however, it remains vanishingly rare to see a major health economic study that incorporates a preference for equality into QALYs³⁵ — despite the fact that such measures are commonly adjusted to reflect other ethical values (Schroeder 2017b). Why? As Temkin (1996), Sen (1973), and others have shown, inequality is complex. There are many different senses in which a distribution can be more or less equal, and many of these senses are plausibly of moral importance. Further, the intuitions which are typically taken to support egalitarianism can also support distinct views such as prioritarianism and sufficientarianism. As a result, no single way of quantifying egalitarian values has gained general acceptance. Since economists have not known how to capture egalitarian values, they have refrained from doing so.

The informed decision-making framework, however, suggests that this has been a mistake. Suppose you are a policy-maker who agrees that the distribution of health (and not merely its sum total) matters. In accordance with the economic mainstream, you are presented with cost-effectiveness analyses of various programs which are distribution-insensitive. How should you go about making your decision? A natural thought — and the one implicitly recommended by many economic studies — is to begin with the cost-effectiveness data you are given, and then to adjust it to reflect your own egalitarian values. Unfortunately, this usually can't be done, at least by policy-makers. To introduce distribution-sensitivity to a measure, one typically needs access to the disaggregated data, or at least to an estimate of what the disaggregated data would look like in the relevant respects (Arnesen and Kapiriri 2004). In most cases, policy-makers are not in a position to do this. That means that the egalitarian policy-maker given distribution-insensitive cost-effectiveness analyses is often faced with a choice: make an informed policy decision that reflects distribution-insensitive values, or largely set aside the data and attempt to make a decision that reflects egalitarian values.

Suppose, then, that egalitarians of various stripes can agree that some particular way of quantitatively adjusting for inequality is better than distribution-neutrality.³⁶ If

³⁴ The discussion in this sub-section is largely drawn from Schroeder (2019).

³⁵ The studies which do so are typically billed as investigations of inequality. The only major, general purpose study I know of whose results adjust for inequality is the WHO's World Health Report 2000.

³⁶ Something like this task was undertaken by the World Health Organization's Consultative Group on Equity and Universal Health Coverage, which settled on a (non-absolute) prioritarian approach (WHO 2014).

so, then given the consensus that the distribution of health matters, economists can better promote informed decision-making by presenting distribution-sensitive results alongside or instead of distribution-neutral results when reporting cost-effectiveness analyses and other policy-relevant measures. As in the IPCC case above, ignorance (in this case about exactly what dimensions of inequality are relevant to health policy) should not prevent economists from attempting to quantify inequality.

Case #4: GBD and Cancer Classification

Finally, let's return to the case with which I began this paper. The puzzle, recall, was that in the Global Burden of Disease Study's ranking of the top global health problems, cancers were ranked separately by type, which consequently sent each cancer far down the list. At the same time, other apparently heterogeneous conditions were lumped together into broad categories such as road injuries and neonatal preterm birth complications. This sent each of those up the ranking list. Since a high placement on the ranking list increases visibility for a cause, bringing with it attendant global health funding, these choices matter. So what should the GBD team have done?

Here is the only explanation that Murray and colleagues give describing the thought process behind their rankings:

[W]e have also identified a ranking list with 176 causes selected to distinguish and cluster disorders that might have programmatic or public-health significance. We aggregated detailed causes within the broader categories of maternal disorders, diarrhoeal diseases, lower respiratory infections, stroke, and road injury for this reason. (Murray *et al.* 2012, 2201)

This explanation fits well with the informed decision-making framework. Although a category like "road injuries" is pathologically heterogeneous, there are policy measures (speed limits, mandatory safety equipment in motor vehicles, road repairs) which can prevent a wide range of road injuries. The same is true for neonatal preterm birth complications and diarrheal diseases. The current thinking on cancer, however, is that we are not likely to develop screening, prevention, or treatment programs for cancers as a whole, at least in the near future. Instead, promising avenues of research and effective treatments target specific types of cancer.

If, then, there are many policy measures which can reduce the impact of road injuries, birth complications, and diarrheal diseases as a whole, then it is valuable for policy-makers to know the health loss attributable to those broadly-defined categories. It can inform their decisions about whether to improve road surfaces, hire skilled birth attendants, or increase funding for oral rehydration therapy. But if there are no major screening or treatment initiatives that fight cancer generally, then knowing the health loss attributable to cancer as a whole does not promote informed decision-making, at

least for most important policy purposes. Although cancers exhibit a kind of pathological homogeneity, they are largely heterogeneous from a policy perspective. When allocating funding for research, treatment, or screening programs, what policy-makers need to know are the health losses attributable to specific types of cancer, since those are the things they can directly intervene on.

Despite the fact, then, that policy-makers may have strategic reasons to prefer aggregated cancer statistics — aggregated statistics, for example, may be more striking and therefore helpful in securing funding for medical research or public support for health initiatives — the informed decision-making framework endorses presenting cancer statistics separately by site, as the GBD does, as opposed to grouping them together, as the U.S. National Vital Statistics Report does. This, of course, does not mean the GBD’s approach is *optimal*. Other presentations (perhaps one that grouped together all smoking-related cancers) could be even better. To determine that, we’d need to gather information about policy-makers’ values and what policy options are available to them. But it strikes me as significant that, even without collecting such data, the crude version of the informed decision-making framework presented here can at least tell scientists what *not* to do — in this case, ruling out the very common epidemiological practice of presenting cancers as a single category.

VII. AN OBJECTION?

The last section presented four cases in which the informed decision-making framework yields recommendations which I find plausible, despite going beyond existing principles of scientific ethics and conflicting with standard scientific practices. But there is another type of scenario where the informed decision-making framework offers guidance that strikes me as much more controversial.³⁷ Although, as noted earlier, many scientists think that their primary role in policy-making is to provide information, other scientists aim to use their research to effect change in society, including changes in society’s values. Consider the following passage from a pair of conservation biologists:

Conservation biology is inescapably normative. Advocacy for the preservation of biodiversity is part of the scientific practice of conservation biology. If...[the journal] *Conservation Biology* direct[s] the discipline toward an “objective, value-free” approach, then [it does] not educate and transform society... To pretend that the acquisition of “positive knowledge” alone will avert mass extinctions is misguided. (Barry and Oelschlaeger 1996)

³⁷ Much of the material in this section is drawn from Schroeder (2017a), supplemented with arguments from Schroeder (*forthcoming*).

This kind of perspective — essentially an endorsement of the sort of advocacy permitted by the laissez-faire model discussed earlier — seems common in certain scientific fields. I suspect, for example, that it is shared by many scientists researching economic inequality or sexual violence. Such scientists often hope to present their results in ways that will promote the outcomes they favor — for example, to reduce economic inequality. The informed decision-making framework, however, rejects such an aim, when presenting results to policy-makers who do not share those goals. Further, some scientists hope to use their results to change society's values — for example, to convince people that certain types of behavior are very serious wrongs. The informed decision-making approach rejects this, as well. So long as the values of policy-makers and the public lie within the range of politically legitimate values, the informed decision-making approach directs scientists to present results in a way that promotes informed decision-making in light of those values. That could mean giving more weight or more extensive discussion to the economic benefits of a development project, compared to its ecological costs. It may mean defining sexual assault in a more restrictive way than the scientist would prefer. It may mean including luxury goods alongside basic necessities in an economic price index. Is it really fair to ask these things of scientists, especially scientists who may have gone into their field in order to push back against such positions?

I agree that it seems unfair to place these demands on scientists, and that this signals a real concern. The problem isn't simply that this is a restriction on advocacy, since many occupations unproblematically include such restrictions. (There is nothing troubling about Coca-Cola, for example, barring its salespeople from advocating for Pepsi products while on the job.) The problem here is the particular type of advocacy that is being prevented. The right to *political* advocacy is, appropriately, regarded as an especially important one, one we should be very hesitant to infringe upon. Nevertheless, I think that this is a cost of the informed decision-making framework that we should be willing to bear. There are a range of situations in which we impose significant restrictions on the political advocacy rights of those in important social positions, including judges, military officers, and lawyers. So it doesn't seem in principle problematic to restrict scientists' rights in this way if there is an important public good served by doing so.³⁸

³⁸ It is important to remember that the informed decision-making framework is meant only to constrain scientists' advocacy when speaking *qua* scientist. And, as mentioned early in the paper, I leave it open how broadly the ethical norms discussed here ought to apply, beyond contexts where scientists are directly addressing policy-makers. This means scientists will still have plenty of avenues to vocally advocate for their preferred positions — e.g. when participating in political rallies, writing newspaper op-eds, and perhaps more generally when they clarify that they are speaking as concerned citizens. The existence of these alternative avenues for expression goes some way to weakening the force of this concern, as an anonymous reviewer emphasized to me.

What, then, is that public good? Adopting the informed decision-making framework can enhance the ability of the public to exercise its right of self-governance in a meaningful way. As we saw at the outset, the importance of science for policy-making raises a serious concern for democracy, because those with the authority to make certain decisions aren't the people who have the knowledge needed to make those decisions. In clinical settings, we solve the parallel problem by imposing a professional obligation on clinicians: they are ethically bound to present information in a way tailored to the patient's values and goals. It is not a perfect solution, but it is a significant improvement over a baseline where clinicians are permitted to share information with an eye towards their own interests.

The same is true when it comes to scientists and policy-makers. In order to make decisions that effectively further the public's goals and reflect the public's values, policy-makers need the information relevant to achieving those pursuits. If the public wants to minimize racial disparities in education, policy-makers need data presented in ways that foreground such differences — something that can be affected by the way populations are partitioned in data analyses, the start- and end-points of time series, the use of averages, and so forth. If the public is particularly concerned about certain consequences of pollution, then those consequences need to be presented prominently and separately, and not lumped together with many other effects where they are likely to be overlooked. The informed decision-making framework directs scientists to provide information in these ways — to choose statistical representations, significance tests, classification schemes, and so forth that provide policy-makers with the information they need to make informed decisions — thus putting the public in a position to effectively achieve its goals. The *laissez-faire* model, by contrast, allows scientists to present results in ways that may fail to include, or at least obscure, information relevant to the public's values and goals. And, given the complex and technical nature of much scientific work, policy-makers and the public will often be unaware of what they are missing.

This, in turn, suggests a second, indirect benefit to adopting the informed decision-making framework: adopting it has the potential to increase the trust that the public and policy-makers have (or at least *should* have) in scientists. Under the *laissez-faire* model, scientists are permitted to present information in ways that further their own goals, or the goals of their funding sources. Since the public and policy-makers may not be in a position to detect this, a certain level of distrust towards scientists therefore seems warranted. If, however, the informed decision-making framework were adopted and effectively enforced as a principle of scientific ethics, those grounds for suspicion would be lessened.

VIII. CONCLUSION

Scientists exert a significant influence over the policy-making process through the choices they make about how to present their results. The GBD team likely steered millions of dollars away from cancer research and treatment and towards other causes. The IPCC's presentation of sea level rise probably led coastal communities to underestimate future sea level changes. Health economists' use of distribution-insensitive calculations has led many egalitarian policy-makers to make policy choices that give little weight to reducing inequalities. In none of these cases did scientists do anything dishonest. There wasn't any noticeable lack of clarity or transparency. What they did was fully consistent with accepted disciplinary practices. In short, they didn't violate existing standards of scientific ethics.

Many scholars who have noted this seem to have simply accepted it, acknowledging scientists' influence and recognizing them as a significant, unelected force in political decision-making. Though such an analysis may accurately capture the *status quo*, I don't think we need to resign ourselves to such an arrangement. I have suggested that the informed decision-making approach offers a way of arriving at ethical principles that can guide scientists in making such choices. By presenting results in a way designed to assist policy-makers in making informed decisions that reflect the policy-makers' (and the public's) values — and thus taking the scientist's values out of the equation — scientists can promote important democratic ideals and also provide a foundation for public trust in science, one that does not pretend that science is a value-free pursuit.

Though the idea behind the informed decision-making approach is intuitive, I have argued that even in the relatively unrefined version presented here, adopting it would require significant changes in certain scientific practices. It would require an even greater change to many scientists' conception of their ethical responsibilities, since to be most effective the informed decision-making framework would need to be adopted and enforced by the scientific community as an important principle of scientific ethics. But — and this is one of the virtues of the approach — it would not require any significant changes to the structure of government or society at large. This is a standard that the scientific community can implement itself.

Much work remains to be done to turn the general framework suggested here into a set of principles and guidelines that are of practical use. In particular, it will often be challenging for scientists to determine what policy-makers and the public value (though I think less challenging than some fear, especially if the task is taken up by large scientific societies, rather than individual research groups). But the familiarity of the informed consent standard from clinical medicine, the ability to jump-start the project through existing work in bioethics and political theory, and the fact that even the crude framework suggested here can be used to criticize existing scientific practices, all suggest that this is a manageable task.

Acknowledgements

The core of this paper was written in 2017-18, when I was a Laurance S. Rockefeller Visiting Faculty Fellow at Princeton's University Center for Human Values, which provided an amazingly stimulating environment for my research. I thank audiences at Princeton, NYU, and UC San Diego, as well as my students at Claremont McKenna College for helpful feedback. Conversations with Marion Boulicault, Kevin Elliott, Nir Eyal, Marc Fleurbaey, Blake Francis, Johann Frick, Dale Jamieson, Melissa Lane, Amy Sepinwall, Anna Stiliz, and Daniel Wikler were extremely valuable. Several anonymous reviewers offered insightful suggestions, which improved the paper a great deal. Some of the preliminary research for this paper was supported by a grant from the Claremont McKenna College Center for Innovation and Entrepreneurship.

REFERENCES

- American Chemical Society. 2015. "Ethical Guidelines to Publication of Chemical Research." Available at <https://pubs.acs.org/userimages/ContentEditor/1218054468605/ethics.pdf>.
- American Geophysical Union. 2017. "AGU Scientific Integrity and Professional Ethics." Available at https://www.agu.org/-/media/Files/Learn-About-AGU/AGU_Scientific_Integrity_and_Professional_Ethics_Policy_document.pdf.
- Arnesen, Trude, and Lydia Kapiriri. "Can the value choices in DALYs influence global priority-setting?" *Health Policy* 70: 137-149.
- Barry, Dwight and Max Oelschlaeger. 1996. "A Science for Survival: Values and Conservation Biology." *Conservation Biology* 10: 905-11.
- Benjamin, Daniel, *et al.* 2018. "Redefine statistical significance." *Nature Human Behavior* 2: 6-10.
- Blustein, J. 1993. "Doing What the Patient Orders: Maintaining Integrity in the Doctor-Patient Relationship." *Bioethics* 7: 289-314.
- Boulicault, Marion. Unpublished. "A Tale of Two Ideals: Values and Idiosyncrasy in Science."
- Boulicault, Marion and S. Andrew Schroeder. 2021. "Public Trust in Science: Exploring the Idiosyncrasy-Free Ideal." In *Social Trust*, edited by Kevin Vallier and Michael Weber, 102-121. New York: Routledge.
- Brock, Dan. 2008. "Conscientious refusal by physicians and pharmacists: who is obligated to do what, and why?" *Theoretical Medicine and Bioethics* 29: 187-200.
- Brown, Mark. 2009. *Science In Democracy: Expertise, Institutions, and Representations*. Cambridge, MA: MIT Press.
- Bullock, Merry and Sangeeta Panicker. 2003. "Ethics for All: Differences Across Scientific Society Codes." *Science and Engineering Ethics* 9: 159-170.
- Christiano, Thomas. 2008. *The Constitution of Equality: Democratic Authority and Its Limits*. Oxford: Oxford University Press.
- Daston, Lorraine and Peter Galison. 2007. *Objectivity*. Cambridge, MA: MIT Press.
- Davis, J.K. 2004. "Conscientious Refusal and a Doctor's Right to Quit." *Journal of Medicine and Philosophy* 29: 75-91.
- De Melo-Martín, Inmaculada and Kristen Intemann. 2018. *The Fight Against Doubt: How to Bridge the Gap Between Scientists and the Public*. Oxford: Oxford University Press.
- Dewey, John. 1927. *The Public and Its Problems*. New York: Swallow.
- Douglas, Heather. 2004. "The Irreducible Complexity of Objectivity." *Synthese* 138: 453-473.
- Douglas, Heather. 2005. "Inserting the Public into Science." In *Democratization of Expertise? Exploring Novel Forms of Scientific Advice in Political Decision-Making*, edited by Sabine Maasen and Peter Weingart, 153-170. Dordrecht: Springer.

- Douglas, Heather. 2009. *Science, Policy, and the Value-Free Ideal*. Pittsburgh: University of Pittsburgh Press.
- Dubash, Navroz, Marc Fleurbaey, and Sivan Kartha. 2014. "Political implications of data presentation." *Science* 4 July 2014: 36-37.
- Edenhofer, Ottmar and Martin Kowarsch. 2015. "Cartography of pathways: A new model for environmental policy assessments." *Environmental Science & Policy* 51: 56-64.
- Edenhofer, Ottmar and Jan Minx. 2014. "Mapmakers and navigators, facts and values." *Science* 4 July 2014: 37-38.
- Elliott, Kevin C. 2006. "An ethics of expertise based on informed consent." *Science and Engineering Ethics* 12: 637-61.
- Elliott, Kevin C. 2011. *Is a Little Pollution Good for You? Incorporating Societal Values in Environmental Research*. Oxford: Oxford University Press.
- Elliott, Kevin C. 2020. "A Taxonomy of Transparency in Science," *Canadian Journal of Philosophy*. DOI:10.1017/can.2020.21
- Elliott, Kevin C. *Forthcoming*. "The Value-Ladenness of Transparency in Science: Lessons From Lyme Disease," *Studies in History and Philosophy of Science*. DOI: 10.1016/j.shpsa.2021.03.008
- Eyal, Nir. 2011. "Informed Consent." In *The Stanford Encyclopedia of Philosophy (Fall 2012 Edition)*, edited by Edward N. Zalta
- Fischer, Frank. 2009. *Democracy & Expertise: Reorienting Policy Inquiry*. Oxford: Oxford University Press.
- Groll, Daniel. 2011. "What Health Care Providers Know: A Taxonomy of Clinical Disagreements." *Hastings Center Report* 41.
- Gutmann, Amy. and Dennis Thompson. 1996. *Democracy and Disagreement*. Cambridge, MA: Harvard University Press.
- Hay, Simon I., Amanuel Alemu Abajobir, Kalkidan Hassen Abate *et al.* 2017. "Global, regional, and national disability-adjusted life-years (DALYs) for 333 diseases and injuries and healthy life expectancy (HALE) for 195 countries and territories, 1990–2016: a systematic analysis for the Global Burden of Disease Study 2016." *Lancet* 390: 1260-1344.
- Heron, Melonie. 2016. "Deaths: Leading causes for 2014." *National vital statistics reports; vol 65 no 5*. National Center for Health Statistics.
- Intemann, Kristen. 2015. "Distinguishing between Legitimate and Illegitimate Values in Climate Modeling." *European Journal for Philosophy of Science* 5: 217-232.
- Jasanoff, Sheila. 1990. *The Fifth Branch: Science Advisors as Policymakers*. Cambridge, MA: Harvard University Press.
- John, Stephen. 2018. "Epistemic trust and the ethics of science communication: against transparency, openness, sincerity and honesty." *Social Epistemology* 32:75-87.
- John, Stephen. 2019. "Science, truth and dictatorship: Wishful thinking or wishful speaking?" *Studies in History and Philosophy of Science* 78: 64-72.
- Keohane, Robert O., Melissa Lane, and Michael Oppenheimer. 2014. "The ethics of scientific communication under uncertainty." *Politics, Philosophy & Economics* 13: 343-368.
- Kitcher, Philip. 2011. *Science in a Democratic Society*. Amherst, NY: Prometheus Books.
- Lloyd, Elisabeth A. and Vanessa J. Schweizer. 2014. "Objectivity and a comparison of methodological scenario approaches for climate change research." *Synthese* 191: 2049-2088.
- Lusk, Gregory. 2020. "Political Legitimacy in the Democratic View: The Case of Climate Services." *Philosophy of Science* 87: 991-1002.
- Martin, Mike and Roland Schinzinger. 2010. *Introduction to Engineering Ethics (2nd ed.)*. Boston: McGraw-Hill.
- Mastrandrea, Michael D., Christopher B. Field, Thomas F. Stocker, *et al.* 2010. "Guidance note for lead authors of the IPCC fifth assessment report on consistent treatment of uncertainties." Technical report, Intergovernmental Panel on Climate Change (IPCC).
- McKaughan Daniel J. and Kevin C. Elliott. 2013. "Backtracking and the ethics of framing: lessons from voles and vasopressin." *Accountability in Research* 20, 206–226.
- McKaughan Daniel J. and Kevin C. Elliott. 2018. "Just the facts or expert opinion? The backtracking approach to socially responsible science communication." In *Ethics and Practice in Science Communication*, edited by Susanna Priest, Jean Goodwin and Michael F. Dahlstrom, 197-213. Chicago: University of Chicago Press.

- Murray, Christopher J.L., Theo Vos, Rafael Lozano, *et al.* 2012. "Disability-adjusted life years (DALYs) for 291 diseases and injuries in 21 regions, 1990–2010: a systematic analysis for the Global Burden of Disease Study 2010." *Lancet* 380: 2197-2223.
- Murray, Christopher. 1996. "Rethinking DALYs." In *The Global Burden of Disease*, edited by Christopher J.L. Murray and Alan Lopez, 1-89. World Health Organization.
- NAS-NAE-IOM (National Academy of Sciences, National Academy of Engineering, and Institute of Medicine). 1992. *Responsible Science: Ensuring the Integrity of the Research Process*. Washington, DC: National Academy Press.
- NAS-NAE-IOM. 2017. *Fostering Integrity in Research*. Washington, DC: National Academy Press.
- Nisbet, Matthew and Chris Mooney. 2007. "Framing Science." *Science* 316: 56.
- Nussbaum, Martha. 2011. "Perfectionist Liberalism and Political Liberalism." *Philosophy and Public Affairs* 39: 3-45
- Pielke, Jr., Roger. 2007. *The Honest Broker*. Cambridge: Cambridge University Press.
- Reiss, Julian and Jan Sprenger. 2014. "Scientific Objectivity." In *The Stanford Encyclopedia of Philosophy* (Winter 2017 edition), edited by Edward N. Zalta. <<https://plato.stanford.edu/archives/win2017/entries/scientific-objectivity/>>
- Resnick, Brian. 2017. "What a nerdy debate about p-values shows about science — and how to fix it," *Vox.com*, available at <<https://www.vox.com/science-and-health/2017/7/31/16021654/p-values-statistical-significance-redefine-0005>>.
- Resnik, David. 2001. "Ethical Dilemmas in Communicating Medical Information to the Public." *Health Policy* 55: 129-49.
- Rawls, John. 2005. *Political Liberalism (extended edition)*. New York: Columbia University Press.
- Rose, David, Caroline Kenny, Abbi Hobbs, and Chris Tyler. 2020. "Improving the use of evidence in legislatures: the case of the UK Parliament." *Evidence and Policy* 16: 619-638.
- Schroeder, S. Andrew. 2017a. "Using Democratic Values in Science: An Objection and (Partial) Response." *Philosophy of Science* 84: 1044-1054.
- Schroeder, S. Andrew. 2017b. "Value Choices in Summary Measures of Population Health." *Public Health Ethics* 10: 176-187.
- Schroeder, S. Andrew. 2019. "Which Values Should We Build Into Economic Measures?" *Economics and Philosophy* 35: 521-536.
- Schroeder, S. Andrew. 2020. "Thinking about Values in Science: Ethical versus Political Approaches," *Canadian Journal of Philosophy*. DOI: 10.1017/can.2020.41
- Schroeder, S. Andrew. *Forthcoming*. "Democratic Values: A Better Foundation for Public Trust in Science." *British Journal for Philosophy of Science*. DOI: 10.1093/bjps/axz023
- Sen, Amartya. 1973. *On Economic Inequality*. Oxford: Oxford University Press.
- Shamoo, Adil E. and David B. Resnik. 2015. *Responsible Conduct of Research (3rd ed)*. Oxford: Oxford University Press.
- Shrader-Frechette, Kristin. 1994. *Ethics of Scientific Research*. London: Rowman and Littlefield.
- Singapore Statement on Research Integrity. 2010. Developed as part of the 2nd World Congress on Research Integrity. Available at <https://wcrif.org/statement>.
- Skovlund, Charlotte Wessel, Lina Steinrud Mørch, Lars Vedel Kessing, *et al.* 2016. "Association of Hormonal Contraception With Depression," *JAMA Psychiatry* 73: 1154-1162.
- Smith, Katherine. 2013. *Beyond Evidence-Based Policy in Public Health*. London: Palgrave Macmillan.
- Sprenger, Jan and Jacob Stegenga. 2017. "Three Arguments for Absolute Outcome Measures." *Philosophy of Science* 84: 840-52.
- Temkin, Larry. 1996. *Inequality*. Oxford: Oxford University Press.
- Turner, Stephen. 2003. *Liberal Democracy 3.0: Civil Society in an Age of Experts*. London: SAGE Publications.
- Victor, David, Reyer Gerlagh, and Giovanni Baiocchi. 2014. "Getting serious about categorizing countries." *Science* 4 July 2014: 34-36.
- World Health Organization (WHO). 2000. *The World Health Report 2000: Health Systems: Improving Performance*. Geneva: World Health Organization.
- World Health Organization (WHO). 2014. *Making Fair Choices on the Path to Universal Health Coverage*. Geneva: World Health Organization.