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Persson, Johannes

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VETENSKAP OCH BEPRÖVAD ERFARENHET SCIENCE AND PROVEN EXPERIENCE





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Foreword

"We will follow the science", Joe Biden, president-elect, said at a meeting in November. A president committed to science (and maybe also proven experience)! What else can you wish for? Sadly, it isn't as easy as it sounds – there is a small hitch. What if there is no science to follow, or if the science we have points in many directions and with a trembling hand? The hallmark of science is that it helps us to manage uncertainty, but also that it is itself marred with doubt. The present pandemic is a prime example.

It is not only the quality and quantity of the scientific evidence and proven experience that can raise problems. Five years from now we will celebrate the centenary of the birth of rational decision making theory. Essentially, the theory tells us that in any given decision situation the perfectly rational decision maker should choose the alternative with maximal expected utility. And if this imagined figure, the ideal agent, does it, so should we. The problem is that more often than not the science and proven experience do not allow us to express our knowledge in terms of the unique numerical uncertainty the theory requires. Furthermore, we might not - at least, with the precision the theory demands - be able to express our preferences and values. What do we do then?

Theories have been developed to handle decisions being made when the uncertainties are uncertain and the values are unstable. The problem is that, then, for purely mathematical reasons, we can no longer use the classical decision rule: Maximization is no longer an option. Again, theories have been developed to overcome this problem, to make the theory more realistic. These new theories do a far better job of representing human uncertainty and preferences. But this isn't enough, for each suggests a different decision maxim, generating apothegms that can give conflicting recommendations in one and the same choice situation or no recommendation at all. And there is no meta-theory that can help us resolve the problem.

Covid-19 has taught us, if we didn't know it before, that science and proven experience deals in uncertain, imprecise *materia*. Those obliged to follow the trembling hand of science and proven experience with no decision rules to guide them have an unenviable task. Which decision rule will Joe Biden, or his team of epidemiologists, use? Which rule, or rules, has the Public Health Agency of Sweden chosen to use? Do they know? Will they let us know? And if so, will they provide a well thought-out moral argument for their choice?

Lack of science and proven experience is not merely an epistemic problem. It can be a serious moral issue. Knowledge gaps can erode trust; create injustice; lead to more

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harm than good; make us do things that have no effect, wasting both our time and money; lead to unwarranted priority settings; and paralyze decision making. Covid-19 has laid bare other types of moral problem as well.

Since March we have seen a horde of scientists telling us how to manage the pandemic. Not just experts in the field, but also, for example, economists and statisticians. Some of them tell us that if we had just followed their advice, looked carefully at their models, made use of the scientific evidence or proven experience they have, the total number of deaths would have been far lower than it is today. We can say "dabblers" and shrug our shoulders and decide not to listen to them. But that will not do. Many are well-known, highly regarded scientists within their fields of expertise. A complication, of course, is that they are sometimes talking about matters that lie outside their fields of competence - although some, it is true, are not. But the problem with some of them has been that they seem to overstate their own findings. Scientific findings can be too narrow, and they are not always directly applicable to real world problems.

In Sweden, we have seen that what these experts say in the news media is not always in line with the recommendations given by, for example, the Public Health Agency. This is confusing, of course, and impacts upon our decision making unhelpfully. In November 2020, The Royal Swedish Academy of Sciences's expert group on Covid-19 published a report in which they recommended wearing face masks. They referred

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to current scientific evidence but without offering any substantial discussion of the uncertainties involved. The guidance was not in direct conflict with what were then the current recommendations of Public Health Agency, but equally it was not fully congruent with them. Those of us who, a couple of weeks before The Royal Swedish Academy of Sciences's report was published, read a systematic review article on face masks in the *Lancet* are now more bewildered than we were before, and we do not really know what we should do to follow the science. In whom should we trust? Scientists can create as much spin as politicians.

Science has shown that what we – you and I – need in situations like this are unbiased facts. Politicians, it is argued, are not the best communicators when facts matter. It has been said that politicians lead "by things they can spin". Perhaps, but there are exceptions. The theme of the fifth volume in this series was science, proven experience and politics. In that volume three well-known Swedish politicians stressed how important both science and proven experience are in good political decision making, trustworthy political communication and policy development.

During this pandemic we have seen what may be a new phenomenon – *scientists* trying to lead by things they can spin. (I have in mind biased, narrow selection of science and proven experience.) What should be done about this? Can anything be done at all? ALLEA, All European Academies, has published The European Code of Conduct for Research

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Integrity. It seems there is a need to supplement this code with a code on the communication of science and proven experience. I am not suggesting we should limit freedom of speech. Noam Chomsky has said that "the smart way to keep people passive and obedient is to strictly limit the spectrum of acceptable opinion, but allow very lively debate within that spectrum - even encourage the more critical and dissident views. That gives people the sense that there's free thinking going on, while all the time the presuppositions of the system are being reinforced by the limits put on the range of the debate". Yes, we should not limit the spectrum. But if science communication leads to citizens becoming lost in evidence, we have a serious problem, not least if our lives are at stake. If we do not understand why we are being asked to do something, we will probably not do it. And understanding why means seeing the bigger picture, as clear or dim as it may be. It is not enough to be shown minute details of a fantastically complex evidentiary map, or to be handed a completely different map.

This is the final volume in this series, a book that brings the program to an end. I would therefore like to take the opportunity to express my gratitude to all of you – to everyone who has contributed to these eleven volumes. In addition to them, the VBE program today has well over 150 publications, and several more are in the pipeline. A list of the publications can be found at the end of this volume. Periodically, we will update it on our webpage: vbe.lu.se.

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To my VBE colleagues – thank you for six fantastic years – thank you very much indeed.*

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Information about the VBE-program can be found at vbe.lu.se.

Covid-19 risk perceptions and reported protective behaviors in the United States

WÄNDI BRUINE DE BRUIN

As Covid-19 began to spread across the world in March 2020, people were confronted by a novel virus. With emerging diseases like Covid-19, objective risk information is typically scarce, characterized by uncertainty, and subject to change. In the public discourse, it was discussed whether or not the case-fatality rate for Covid-19 was comparable to that of seasonal influenza (De Ridder, 2020; National Public Radio, 2020; World Health Organization, 2020). In the absence of pharmaceutical interventions, mass adoption of protective behaviors such as handwashing and social distancing is usually recommended to limit the spread of emerging infectious diseases (Aledort, Lurie, Wasserman, & Bozzette, 2007; Bruine de Bruin, Fischhoff, Brilliant, & Caruso, 2006). Although the science and experience of Covid-19 were still developing, people were faced with important decisions about whether the risks were high enough to implement these protective behaviors.

To examine how people in the US were responding to the emerging infectious disease, my colleagues at the University of Southern California and I conducted a national survey of US residents through the nationally representative Understanding America Study (Kapteyn et al., 2020). The Understanding America Study is an internet panel that was launched in 2014. At present, it includes about 9,000 US adults who complete, on average, about two online surveys per month, on a wide variety of topics. Members of the panel were selected to be representative of the non-institutionalized population of the United States (Alattar, Messel, & Rogofsky, 2018). National representativeness was achieved in the following ways. First, invitations to participate were sent to a random selection of US addresses. Second, sampling probabilities were adjusted to ensure that members of underrepresented populations were included. Third, recruited individuals were provided with a tablet and broadband Internet if needed. Address-recruited online panels tend to be more successful than opt-in online panels in achieving national representativeness (Tourangeau, Conrad, & Couper, 2013) and delivering high-quality data (Kennedy et al., 2020).

Covid-19 risk perceptions

Our participants answered two risk perception questions: (a) "On a scale from 0 to 100%, what is the chance that you

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will get the coronavirus in the next three months?" and (b) "If you do get infected with the coronavirus, what is the chance you will die from it?" Both risk perceptions were assessed on a visual linear scale ranging from 0 to 100% (Bruine de Bruin & Carman, 2018). Across all participants, median risk perceptions were 10% for (a) and 5% for (b) (Bruine de Bruin & Bennett, 2020). However, participants disagreed markedly about these risks – perhaps reflecting the limited information available to them. For both risks, the participants used the entire range from 0 to 100%. But a majority of the responses fell towards the lower end of the scale: Addressing (a), 30% of participants thought the risk of infection in the next three months was in the range of 0–2%, and addressing (b), 40% thought the risk of dying if infected was in the range of 0-2%.

During the period the survey was online (10–31 March), the news about Covid-19 was rapidly changing. On 10 March, the first day that the survey was online, the national weekly average of newly recorded Covid-19 cases per day was 123 (Centers for Disease Control and Prevention, 2020a). By 13 March, when half of the participants had completed the survey, it had nearly doubled to 241 (Centers for Disease Control and Prevention, 2020a). In an attempt to curb the rapid spread of Covid-19, on 13 March the US government announced a national emergency and a ban on travelers entering the country from Europe, and several US states closed schools and banned large gatherings (White House,

2020a; White House, 2020b; Yeung et al., 2020). Yet, by 31 March, the last day of the survey, the number of new cases of Covid-19 had increased to 18,807 (Centers for Disease Control and Prevention, 2020a).

Perhaps as a result of this information, perceptions of the chances of getting Covid-19 were higher among the 50% of participants who completed the survey before 13 March than among the 50% who completed the survey later (henceforth early vs. late responders). Specifically, the median perceived risk of getting Covid-19 in the next three months was 5% in early responders and 10% in late responders (Bruine de Bruin & Bennett, 2020). Figure 1A shows the distribution of responses provided by the early and late responders. It can be seen that the percentage of individuals reporting a 0-2%chance of getting Covid-19 in the next three months was 34% among early responders and 25% among late responders. Both the early and the late responders also seemed to select the 50% responses disproportionally. This is common in risk perception surveys and may reflect uncertainty about what the risk is (Fischhoff & Bruine de Bruin, 1999; Bruine de Bruin et al., 2000). Indeed, 50% responses are more likely than other risk perception response to be explained as "I actually have no idea about the chances" and "No one can know the chances" (Bruine de Bruin & Carman, 2012).

The median perception of the risk of dying if infected with Covid-19 was 5% among both early and late responders, perhaps because there had been no reports of changing case-

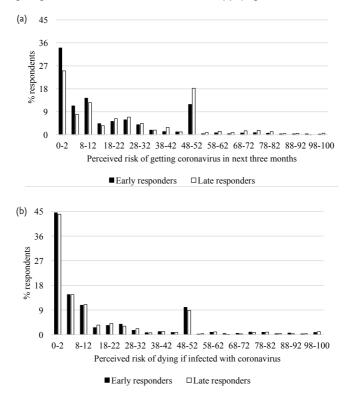
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fatality rates during March. Figure 1B shows little to no change in the response distribution here. For example, the percentage of responses in the 0-2% range was 45% among early responders and 44% among late responders.

Because the day of survey completion was not randomly assigned, it is of course possible that the participants who answered earlier differed in significant ways from those who answered later – and this could explain their differing perceptions of becoming infected with Covid-19. However, the results held when we accounted for differences between respondents in terms of age, gender, race/ethnicity, college education, household income, and living in California, Massachusetts, New Jersey, New York, and Washington (the US states worst hit by the pandemic at the time) (Bruine de Bruin & Bennett, 2020).

Initial reports of protective behaviors

In the survey, participants also reported on the behaviors they adopted to protect against Covid-19. Specifically, they were asked: "Which of the following have you done in the last seven days to keep yourself safe from coronavirus in addition to what you normally do? (yes/no)". Response options referred to behaviors recommended by the Centers for Disease Control and Prevention (2020b), including (1) "washed hands with soap or used hand sanitizer several times per day", (2) "avoided public spaces, gatherings, or crowds", Figure 1: Distributions of participants' perceptions of the risk of (a) getting coronavirus in the next three months and (b) dying if infected.



Note: Early responders completed the survey 10–12 March, and late responders completed it 13–31 March, 2020.

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(3) "avoided contact with people who could be high-risk", and (4) "canceled or postponed air travel for work" and "canceled or postponed air travel for pleasure" (for which responses were combined). In all, 90% of participants reported handwashing, 58% avoiding high-risk individuals, 57% avoiding crowds, and 37% canceling or postponing travel.

Here, as with the risk perceptions, early responders and late responders differed. Early responders were less likely than late responders to report handwashing (86% to 93%), avoidance of public spaces or crowds (43% to 71%), avoidance of high-risk individuals (46% to 71%), and canceling or postponing travel (24% to 49%). Again, the differences between early and late responders remained when we accounted for respondent characteristics such as age, gender, race/ethnicity, college education, household income, and living in one of the US states that was worst hit by the pandemic at the time, including California, Massachusetts, New Jersey, New York, and Washington (Bruine de Bruin & Bennett, 2020).

Relationship between risk perceptions and protective behaviors

Participants' reported protective behaviors were related to their perceptions of the risk of becoming infected (Bruine de Bruin & Bennett, 2020). Figure 2A shows that reported hand washing was 84% in participants who perceived a 0-2% risk

of infection to 97% in participants who perceived a 98–100% of becoming infected. In the same groups, reported avoidance of public spaces or crowds rose from 46% to 81%, reported avoidance of high-risk individuals rose from 53% to 82%, and reported cancellation of travel increased from 18% to 57%. It is likely that the relationship between risk perceptions and reported protective behaviors was less pronounced where higher risk perceptions were concerned, because here we had fewer observations (Figure 1A).

These relationships between perceptions of the risk of infection and protective behaviors held in both the early and late responders, though they were somewhat stronger among the latter (Bruine de Bruin & Bennett, 2020). Although the data were correlational, one interpretation of this finding is that the late responders were more willing to act on their beliefs.

The participants' reported protective behaviors were less strongly associated with their perceptions of the risk of dying if they were infected than with their perceptions of the risk of getting Covid-19 (Bruine de Bruin & Bennett, 2020). It is possible that the perceived risk of infection here had a stronger relationship with protective behaviors than perceived risk of dying if infected because Covid-19 was believed to have severe outcomes other than death, including serious illness and self-quarantine. In a study conducted during the H1N1 epidemic, it was similarly found that perceived risk of mortality

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following infection with intentions to be vaccinated (Gidengil, Parker, & Zikmund-Fisher, 2011).

Conclusion

In March 2020, Covid-19 was an emerging risk. Scientific understanding as well as proven experience of the disease was still developing. Perhaps as a result, the participants in our survey exhibited wide disagreement in their perceptions of the risk of becoming infected with Covid-19 and in their perceptions of the risk of dying from it if they were to become infected. Our findings suggest that people may have already been acting on their risk perceptions in mid- to late-March 2020. Protective behaviors, such as hand washing and social distancing, were more likely to have been adopted by participants who perceived greater risk of infection, and the likelihood increased as perceptions of this risk increased over time. Indeed, as the available information started to point to the seriousness of the disease, perceptions of the risk of becoming infected rose, along with the likelihood of reporting associated protective behaviors.

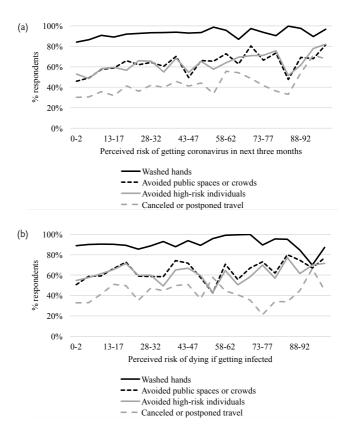
Perceptions of the risk of mortality following infection were less strongly associated with protective behaviors. As noted above, this may be because infection with Covid-19 was perceived as a sufficiently negative experience to motivate the adoption of protective behaviors.

The limitations of the present study include the fact that

its findings were correlational, precluding causal conclusions, and the fact that the protective behaviors were self-reported and therefore may not have accurately reflected the participants' actual behaviors.

Still, the reported findings have potential implications for our understanding of the public perception of risks associated with an emergent, potentially fatal disease, and communication of those risks by governments and health authorities. Our findings suggest that perceptions of risk, willingness to act, and their relationship increased as the threat became more clear over time. Indeed, research on psychological distance has suggested that people may be more willing to act if risks are presented as happening in the "here and now" rather than possibly emerging in the future (Trope & Liberman, 2010). Previous expert panels on pandemic infectious disease have therefore suggested that surveillance of cases and deaths is central in the pandemic response (Aledort et al., 2007; Bruine de Bruin et al., 2006). To promote protective behaviors, public communication may need to address, not just the risks, but also other factors that have been deemed relevant to behavior change. These include people's perceptions of the likelihood of infecting others, social norms, their ability to adopt protective behaviors bearing any ensuing costs, and their need to follow policymakers' recommendations and stay-at-home orders (Fischhoff, 2013; Rogers & Prentice-Dunn 1997; Rosenstock, 1974).

Figure 2: Relationship of reported protective behaviors with perceptions of (a) contracting coronavirus in the next three months and (b) dying if infected.



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Evidence-based policymaking under exceptional circumstances

JOHAN BRÄNNMARK

Like evidence-based medicine, evidence-based policymaking typically operates under what one might called a *presumption of non-intervention*. In other words, the burden of proof for interventions is balanced so that we need evidence that a policy is effective and beneficial before enacting it, and it is not enough merely that there is no evidence that it is ineffective or harmful. This means, in practice, that the ideal of evidence-based policymaking will underpin an approach to politics oriented primarily towards gradual and incremental reform of our societies rather than radical and comprehensive transformation of them. It also means that the ideal encourages restraint in the political arena, where the demand on politicians, whenever there is a societal problem crying out for a solution, is otherwise typically to *do something now*.

Of course, the expectation that politicians will *act now* tends to become especially pressing in times of crisis, and the recent Covid-19 pandemic has provided a wealth of

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examples of governments across the world adopting a variety of drastic measures even when the evidence for their effectiveness, or suitability in a reasonable overall cost-benefit balance, is arguably far from solid. But then perhaps the presumption of non-intervention should be questioned, at least under such circumstances? Under normal circumstances we can be relatively certain that not introducing new policies will simply lead, for the most part, to more of the same, which at least gives us predictability. Yet under exceptional circumstances this is no longer true. Indeed, Greenhalgh et al. (2020) suggest that "in the face of a pandemic the search for perfect evidence may be the enemy of good policy. As with parachutes for jumping out of aeroplanes, it is time to act without waiting for randomized controlled trial evidence."

The question of how to live by the ideal of evidence-based policymaking even under exceptional circumstances cannot, of course, be fully resolved here. In what follows, we will look, first, at some of the reasons why a presumption of non-intervention is judged to be reasonable, and then at how one might still want to shift the balance of different kinds of evidence, or reasoning, when conditions are exceptional.

Reasons for a presumption of non-intervention

Why treat non-intervention as the default? To begin with, one might note that human morality in general tends to favor

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inaction: More precisely, the duty to not harm others is generally considered stronger, or at least stricter, than the duty to help others. In medicine, for example, this asymmetry is built into Hippocratic medical ethics (even if the maxim *First, do no harm!* is not literally part of the original Hippocratic oath). Contemporary bioethical frameworks often emphasize the difference between duties of non-maleficence and those of beneficence (e.g. Beauchamp & Childress 2019). A consequence of this idea is that a missed opportunity to help is typically not considered to be as bad as a seized opportunity that leads to harm, an asymmetry which arguably makes it reasonable to balance the burden of proof in line with a presumption of non-interference. Additionally, in a contemporary (and highly institutionalized) healthcare context, there are important reasons of cost efficiency to consider. It is just a plain fact that we do not have sufficient resources to provide all the healthcare which, technically, we are capable of providing. For every intervention we do provide, there will typically be some other intervention, or interventions, that we are unable to provide. Accordingly, it becomes important to ensure that we deploy our resources well. And if we have strong reason to think that intervention 1 is effective and only weak reason for believing that intervention 2 is effective, it certainly seem sensible, ceteris paribus, to prioritize intervention 1. It should be noted that this kind of assessment is always comparative, so in principle it opens up the possibility of spending our resources in *the least bad*

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way. However, in actual practice new interventions will always need to have resources shifted towards to them from existing types of intervention, so there being a certain threshold that evidence for the new intervention needs to pass seems reasonable.

When we turn from medicine to policymaking, and consider what evidence-basing might involve there, things become more complicated. To begin with, randomized controlled trials are often not possible simply because we cannot control the relevant environments well enough, or create experimental settings that are a close enough semblance of reality for us to be able to generalize from them to real-life circumstances. But perhaps an even greater challenge has to do with the interventions themselves. There is what one might call a problem of multiple implementability. When we debate policy options, we often consider the alternatives in skeletal form, types of policies rather than particular concrete tokens. However, in putting policies into practice there will always be an enormous amount of detail making up the exact character of the concrete implementation. Some of the details must be filled in on the political and administrative side, and will depend on the institutional mechanisms available for implementing the policies in question, but many of them will be filled in by the behavior of the general public. Of course, some of these issues arise with medical interventions as well, especially with non-pharmacological ones, but in a policy context they really are quite substantial. For instance,

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while a physician may occasionally struggle to communicate with a patient (the risk here being that the patient will not follow relevant advice or instructions), he or she does at least often have the benefit of direct physician-patient contact. The path from policy-maker to individual citizen is considerably more complex, making it much harder to ensure that the policy that is actually put into practice is really the policy that was intended.

The complexity of policy interventions provides an additional reason to take non-intervention as the default. Successful implementation of policies, more or less as they were intended to be implemented, depends both on managing the institutional framework through which the policies will be put into practice, and being able to communicate with the general public and convince them to modify their behavior in accordance with the new policies. The introduction of new policies will thus always involve competing for attention and effort, both in the relevant organizations on which successful implementation depends and among the general public whose behavior is typically the ultimate target of the interventions. This means that not only do we have to be careful how we utilize the available attention and effort at any given point in time, but we also need to be careful about how we tend the capacity for attending to and putting effort into adapting to new policies - too many new policies implemented too rapidly, one after another, could lead to what might be called intervention fatigue. There is accordingly a limited space of

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opportunity for implementing new policies as intended, and we need to be sure that we use that space well. At the very least, this means we should be careful not to implement too many things at the same time. But we also need to keep in mind that to simply try things out now, without confidence in them as meaningful interventions, is to gamble with, and perhaps fritter away, the available attention and effort that will be there for future policy interventions.

Making policy interventions under exceptional circumstances

How much does the fact that circumstances are exceptional change the overall picture painted above? Before addressing this question, we need to note that some of the demands presently being made about modifying the way we think about hierarchies of evidence when faced with something like Covid-19 actually involve arguments that have already been made in connection with policymaking under normal circumstances. Partly on the basis of an older debate about the nature of causality, with difference-making accounts competing with mechanistic accounts, some authors have, for instance, suggested that we can distinguish between *statistical* and *mechanistic* evidence (Russo & Williamson 2007), where the former is evidence for an intervention making a certain difference while the latter is about *how* it makes that difference. Grüne-Yanoff (2016) even argues that unless policy is

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based not just on statistical evidence but also mechanistic evidence, it cannot really count as evidence-based. The main reason is precisely that without a mechanistic understanding of the how and not just the that of previous policy interventions that have been successful, we will not be able to understand and control the details involved in implementing the policy in a new context. Reservations about this might be reasonable. Perhaps the relevant distinction here should not be drawn in terms of different types of evidence, since we often have a mechanistic understanding of things partly based in statistical evidence (Marchionni & Reijula 2019). What seems clear, however, is that in considering particular policy interventions we often have to balance the more direct evidence for their effectiveness with a general understanding of how our societies work, in particular general knowledge about how things work coming from basic research.

There is no room here to go into the weeds of this particular debate. However, let us grant that we should understand evidence-based policymaking as something that always involves a significant element of mechanistic reasoning (ideally still science-based) in order to deal with at least two issues: the fact that there is often a relative lack of evidence from randomized controlled trials, and the problem of multiple implementability. The question then remains: Should the threshold of support, whether statistical or mechanistic, for particular policy interventions be lowered under exceptional circumstances? There seems little reason ever to do

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things blindly, so in practice what this question boils down to is arguably this: To what extent can mechanistic reasoning play a larger role in the design of suitable policy interventions? Should we be more willing to accept interventions that should, or at least could, work in theory, even though the statistical evidence for them working in practice, and especially under the circumstances under consideration, is scant? While this is not the place to consider the balance of support in favor of that particular policy, the mandating or recommending of the use of face masks to slow the spread of Covid-19 (which is what Greenhalgh et al. are considering when making the analogy with parachutes) seems to be a clear case where in theory widespread use of face masks should be able to promote the desired goal, but where the evidence for it actually doing so in practice might not be as solid as we would ideally want.

Now, if we look at some of the reasons touched on above for the presumption of non-intervention, they do seem weaker under exceptional circumstances. To begin with, the underlying asymmetry in which our negative duties are more strongly emphasized is often already seen as, above all, making sense under normal circumstances. Even a theorist like Nozick (1974, p. 29n), who in general argues for the absolute status of our negative rights, opens up for certain exceptions in extreme circumstances (although it should be said that his notion of "catastrophic moral horror" is probably meant to have very limited applicability). Whether the

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more practical concerns that point us towards non-intervention as the default are also lessened under exceptional circumstance is a more complex matter. However, at the very least it seems reasonable to think that, in terms of the economy of attention and effort, where policymakers need a certain level of buy-in from organizations and the general public for effective implementation, a larger willingness to put in both the attention and the effort can probably be expected. On the other hand, to the extent that those exceptional circumstances last for a considerable time, it will remain important not to draw on that pool of available attention and effort in ways that undermine future uses of it. This also means that one factor that needs to be considered, in any given country where one is contemplating a particular policy option, is the degree to which there is already a reasonable level of public support for, and acceptance of, the intervention under consideration; or alternatively, if there is little or no support, whether it could likely be secured through feasible pedagogical efforts. If the answers here are negative, implementation is likely to be flawed and contested, and might undermine future efforts to address the issues at hand. While the presumption of non-intervention is arguably weaker under exceptional circumstances, there is accordingly still some reason for why it should remain in play.

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Addressing inequities in pandemic policies

BARUCH FISCHHOFF

The Covid-19 pandemic has produced shortages of many things, ranging from mundane necessities to vital medicines and equipment. Anticipating such dire situations, ethicists have proposed various schemes for rationing limited supplies. One common term for these schemes is "crisis standards of care," as distinct from "usual standards of care".¹ The ethical principles guiding these standards preclude inequitable allocation of resources. Sometimes, those principles clash. For example, a scheme could either treat all lives as equal or all life-years as equal. The second principle values younger people more than the first, because more life-years are lost if they die. Reasonable people have argued both ways.

Schemes that avoid creating inequities may still perpetuate them. Consider a scheme that assigns higher priority to

^{1.} National Academies of Sciences, Engineering, and Medicine. Rapid Expert Consultation on Crisis Standards of Care for the COVID-19 Pandemic. Washington, DC: The National Academies Press, 2020. https://doi.org/10.17226/25765

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people who are more likely to benefit from treatment. It would give lower priority to individuals whose health was compromised by historical inequities (e.g. in access to healthcare) or whose ability to benefit is compromised by current ones (e.g. in living conditions, workplace protection, or food security). Righting wrongs means shifting resources from individuals who would otherwise have received them, the scheme bounded by the program's direct effects.

That conflict faced the US National Academies Committee on Equitable Allocation of Covid-19 Vaccine. Commissioned by the heads of the National Institutes of Health and the Centers for Disease Control and Prevention, it was explicitly charged with answering the question, "What criteria should be used in setting priorities for equitable allocation of vaccine?" It was tasked, further with explaining how the application of those criteria "would take into account factors such as

- · Health disparities and other health access issues
- Individuals at higher risk (e.g. elderly, people with underlying health conditions)
- Occupations at higher risk (e.g. healthcare workers, essential industries, meat packing plants, military)
- Populations at higher risk (e.g. racial and ethnic groups, incarcerated individuals, residents of nursing homes, individuals who are homeless)

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- · Geographic distribution of active virus spread
- Countries/populations involved in clinical trials".²

As documented in the committee's report, the US has large racial and ethnic inequities in health, healthcare, food security, occupational protection and housing, among other things. If the committee addressed them directly by giving greater priority to groups subject to structural discrimination, it would send a strong signal regarding the unacceptability of that legacy. However, it would also assign lower priority to otherwise equal individuals who were not members of those groups, and ethically speaking that would, in effect, hold them responsible for the inequities. On the other hand, politically speaking, it would visibly position the vaccine program within current social tensions.

The committee elected instead to base its recommended priorities on four risk-based criteria that reflected its six "foundational principles".³ Three of those principles were ethical: Maximum benefit, equal concern, and mitigation of health equities". Three were procedural, requiring processes to be fair, transparent, and evidence-based. Equity was addressed indirectly in the choice of risk-based criteria and

^{2.} National Academies of Sciences, Engineering, and Medicine. Framework for Equitable Allocation of COVID-19 Vaccine. Washington, DC: The National Academies Press, 2020. https://doi.org/10.17226/25917, pp. 1–2.

^{3.} Ibid. p. S-5/6.

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directly in chapters devoted to reducing potential barriers to realization of the recommended priorities. Those barriers included limits in the distribution system, lack of trustworthy information about the performance of the vaccine and allocation program, and distrust of the institutions involved.

The four risk-based criteria were (in brief):

- The risk of contracting the disease
- The risk of serious health consequences, should someone fall ill
- The risk of negative societal impact, should someone fall ill
- The risk of someone transmitting the disease

Structural inequities have made each of these risks greater, on average, for members of disadvantaged groups than they are for members of more privileged ones. Such people are more likely to work, live, travel and shop in ways that increase their risk of catching and transmitting the virus. They are also more likely to have had their current health and future treatment compromised by limited access to healthcare, making severe consequences more likely if they catch the disease.

The report defined "negative societal impact" as "the extent that societal function and other individuals' lives and livelihood depend on [individuals] and would be imperiled if they fell ill".⁴ By prizing people on whom many others de-

^{4.} Ibid. p. S-7.

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pend, that definition assigns higher priority to individuals working in service jobs and living in congregated settings. Generally speaking, both circumstances are more common among people who are less well-off and less powerful. Within workplaces, the report places equal value on all those needed to keep it running (e.g. valuing cleaners and surgeons in hospitals equally).

According to the report, "The committee recognizes that its proposed framework must not only be equitable, but also be perceived as equitable by audiences who are socioeconomically, culturally and educationally diverse, and who have distinct historical experiences with the health system".⁵ By this standard, the report's recommendations might satisfy people who care only about the options. All that they might need to know is that the report's priorities do not perpetuate historical inequities. In fact, those patterns are reversed. The roles that historically disadvantaged individuals play in society afford them higher priority for these scarce resources.

These outcomes alone might not satisfy people who want more overt repudiation of historical inequities. Indeed, such people might even be willing to imperil the outcomes, by drawing political attention to the allocation framework, in order to ensure that equity is perceived by all. However, that confrontation might not be avoidable. Once the allocation

^{5.} Ibid. p. 3-3.

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program begins to remove structural barriers to its implementation, the changes may quickly become apparent to those who have benefited from them.

Counting in the time of Covid-19

The Covid-19 pandemic has led to an intense focus on numbers. People follow the latest statistics of infected, hospitalized and dead closely to get a sense of how the pandemic is evolving. Policymakers use population-adjusted rates to inform and motivate policy measures which are themselves often expressed in numbers, such as how many persons are allowed to congregate, how far from home people may travel, and how many days people need to self-isolate after being exposed to contagion. Advanced epidemiological expressions previously known only to experts, such as "R₀" and "R_e" (the basic and the effective reproduction rates), have become subjects of heated public debate. In many countries, opinions about how to fight Covid-19 are polarized. It is increasingly contested how numbers should be interpreted and which numbers should count.

Quantified information is essential to developing and communicating science and proven experience, but it in-

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volves potential pitfalls, and these also need to be discussed. The counting related to Covid-19 shows the practical usefulness of numerical reasoning; quantification makes it possible to capture the spread of disease, to compare countries, to identify risk groups, to evaluate treatments, and to test vaccine candidates, among other crucial things. At the same time, it actualizes problematic aspects of quantification that are familiar from recent social science research, such as the false precision of numbers and their constitutive or performative capacities (Espeland and Stevens, 2008; Levay et al., 2020). What is more, the upscaled use of numbers in the public domain raises new questions, such as whether the public debates over epidemiological figures make the wider public more aware of their limitations and contingencies.

Numbers convey a sense of neutrality and precision that is not always warranted. This is clearly the case when it comes to tracking Covid-19. The only thing that is certain about the regularly reported statistics on infected individuals in each country or region is that the actual number is higher, since many contract the disease without being tested. The percentage of all performed tests that are positive, the positivity rate, might be a better indicator of disease spread, but it too depends on the availability of testing. National death tolls are continuously adjusted and put into new context following the discovery of under- or overreporting. For example, Spain was underreporting deaths in nursing homes, and this was noticed when national statistics were compared with regional

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reports and with regular death rates in previous years. Half a year into the pandemic, Public Health England reduced the official total death toll by more than 5,000 when it sharpened the criteria and started to count only those who had died up to 28 days after testing positive.

Despite such uncertainties, the regular public announcements of coronavirus cases and deaths have taken on a ritual character in several countries – something similar happened to the US daily casualty reports during the Vietnam war. Covid-19 is thus accorded a national significance that other preventable causes of death are not.

To make sense of numbers, we normally need to relate them to other numbers. But it is not clear which numbers on Covid-19 to focus on, and which numbers to relate them to, especially when comparing countries in order to evaluate policies. Should the number of cases be related to the same kind of number in other countries at the same point in time or at a similar stage of epidemiological spread? Is it perhaps cities or regions that should be compared rather than countries, considering the large variations within countries? Should other relevant outcomes also be considered, such as rates of depression, spousal abuse or missed cancer treatments, given the potentially severe consequences of widely used interventions that confine people in their homes?

When policy measures such as lockdowns, school closures and mask wearing are debated, questions of what numbers to focus on and what to compare them with become politi-

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cally charged and may be weaponized. And when experts disagree – as is often the case when scientific knowledge is evolving – it is even more difficult for policy makers and constituencies to reach common, well-founded conclusions.

Under prevailing conditions of uncertainty, many decision makers commit themselves to following preselected metrics when imposing or easing restrictions. They tie themselves to the numerical mast, as it were, in order to navigate a straight course, much like Ulysses. The German authorities have concentrated on whether the effective reproductive rate, R_{e_i} is above or below 1, which indicates whether the outbreak is progressing or subsiding. Some countries require quarantine for people traveling from countries or regions with a 14-day number of Covid-19 cases per 100,000 inhabitants above a certain threshold. The effect can be confusing, as it was when the capital of Norway at one point exceeded the maximum incidence rate the country applied to incoming travelers.

Numbers are also judged against decision makers' ambitions. In early August 2020, four confirmed Covid-19 cases from an unknown source in Auckland were enough for the New Zealand government to immediately reimpose national recommendations and a strict lockdown of the entire city. New Zealand has a so-called elimination strategy, which aims at stopping the disease entirely from spreading within the country, and the four cases appeared after a successful streak of more than 100 days without signs of local transmission. In Sweden, an oft-cited example of the contrasting suppression

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strategy of minimizing the incidence and consequences of the disease, four new local cases would hardly even have been discernible at the time.

Another reason why numbers are not the neutral conduits of objective facts they are often taken to be is that when quantified information is used to depict and influence social systems, the conscious actors who make up such systems – that is, people like you and me – pay attention to, and often adjust, how they act and think. Since human beings are inevitably reflexive, quantification has performative and even constitutive effects in society. From the history of census taking, it is clear that the need to count creates a need for categories, and that once they are introduced, the categories are formative (Hacking, 1982). Quantification brings about change to that which is quantified and sometimes even brings it into existence (Espeland and Stevens, 2008).

When it comes to the Covid-19 pandemic, people affected respond not just to formal policy measures but also to the disease statistics that inform them, which incidentally adds to the difficulties of evaluating and predicting the effect of measures. Moreover, epidemiological numbers are basically how we know anything at all about this global epidemic. Without the numbers and charts, even victims would encounter Covid-19 as a potentially deadly disease, not as a pandemic, just as people who have lost their job need statistics to know anything about unemployment, beyond their own personal experience.

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Policy makers may also be sensitive to the continuous publication of comparative numbers of cases and deaths, often in "league tables" that supposedly reveal how successful the different countries' strategies have been. The problematic effects of public rankings are well known from higher education, driving schools to care increasingly about the quantitative indicators rather than the actual educational quality they are meant to indicate (Espeland and Stevens, 2020). The effects may be weaker when several rankings are available and open to competing interpretations, which seems to be the case with the ongoing pandemic. Still, politicians and opinion makers do not appear insensitive to existing epidemiological rankings. For example, a Swedish economist called for national policy measures to be at least superficially adapted to what most other countries do, regardless of their proven effectiveness, in order to improve the country's national reputation.

It is striking that some of the most impactful numbers related to Covid-19 are projected calculations based on epidemiological modelling rather than results of actual surveillance. In particular, a disease model report released by Imperial College in mid-March 2020 (Ferguson et al., 2020) caused much alarm and reaction. Published on an institutional website without peer review, it predicted 2.2 million deaths in the US and 510,000 deaths in the UK. The report recommended firm lockdowns as the only viable strategy until a vaccine became available, which was predicted to take

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18 months or more. It did so without discussing the proven public health strategy of testing and contact tracing and without considering the social, economic and political implications of shutting down whole societies. Along with harrowing images from overwhelmed hospitals in northern Italy, the report prompted coercive national lockdowns around the world, including in countries such as India, where many of the poor earn their living day-by-day, outside of home. The immensity of the Covid-19 numbers overshadowed, it appears, other possible threats to life and livelihood. Horizons shifted, politicians were pressured to take a more offensive approach and a chain of events was set off that radicalized pandemic responses worldwide (Caduff, 2020).

As the pandemic rolls on, counting remains central to the communications of experts and the decision-making of officials, but their messages are increasingly questioned. Alongside public protests calling for lessened or more precisely targeted restrictions, debates rage among public intellectuals and commentators over the effectiveness and drawbacks of public health interventions such as school closures and mask mandates. Numbers and calculations are constantly brandished and criticized on both sides of these arguments. Heated disputes that would normally be confined to scholarly journals and conferences are playing out in the open, away from the ivory towers.

Under current conditions, we must ask whether it really is possible for attentive onlookers to maintain a naïve belief in

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the objectivity and precision of numbers. Is it not more likely that the general audience will become increasingly aware that the figures, charts and tables depicting Covid-19 are not neutral, one-to-one reflections of reality but pieces of selected, crafted information that need to be interpreted with caution? If so, the pandemic will not just exemplify the social dynamics of quantification but actually modify it. In the best case, counting in the time of Covid-19 will constitute a mass education program on the power and limits of numerical reasoning by prompting the general citizenry to reflect on what is behind the epidemiological numbers, how they are calculated and how they should be understood. Hopefully, this will stimulate healthy skepticism rather than sloppy denialism toward quantified information - with regard to Covid-19 as well as other burning issues of common interest.

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On the relation between experience, personal experience, and proven experience

JOHANNES PERSSON

There is no desire more natural than that of knowledge. We try all ways that can lead us to it; where reason is wanting, we therein employ experience,

Per varios usus artem experientia fecit, Exemplo monstrante viam,

["By various trials experience created art, example shewing the way."]—Manilius, i. 59.

... which is a means much more weak and cheap; but truth is so great a thing that we ought not to disdain any mediation that will guide us to it. (Montaigne 1588)

Our understanding of the concept of experience tends to oscillate between something that is had (and sometimes shared) and something that is made. Sancho Panza, it has been said, illustrates the first sense and Don Quixote the second (Eriksson 2020). Both are important in this context.

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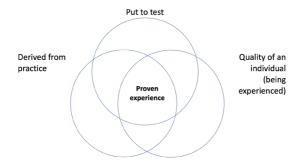
Together they secure, on the one hand, the cumulative potential and revisability of experience-generated knowledge, and on the other, the idea that experience is also a quality of the individual – the quality of being experienced. The point of departure in this note will be the relation between personal experience and proven experience. To many readers, the second of these may be unfamiliar. But it is a concept that has been of importance in Sweden for a very long time, particularly in medicine. Already in 1733, the promotion act to medical doctor at Uppsala University contained the following promise:

Jag lovar heligt [...] att vid utlärande av läkekonsten icke utan orsak avvika från de gamla läkarnas föreskrifter eller från av nya och högst ansedda läkares läror och av vunnen och under lång tid prövad erfarenhet framsprungna metoder, och att även följa samma metoder vid botande av sjukdomar: att icke använda okända och farliga läkemedel utan blott dem, som jag förstår mest bidraga till de sjukas botande. (Juramentum medicorum 1733, as reported in von Stapelmohr 1950, 2469)

Since then much has happened, and the concept of proven experience might have changed slightly. Today all healthcare personnel in Sweden are obliged to provide care that is consonant with science and proven experience (*vetenskap och beprövad erfarenhet*). However, there has never, as far as we know, been an attempt to define the concept in medicine, nor has this been done in the other healthcare professions. A

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survey we conducted recently suggests that physicians and nurses conceive of proven experience as a matter of interventions (etc.) being *tested* and *practice-derived*, and that an individual or team can be an individual/team of proven experience, i.e. have the quality of *being experienced*. In fact, this multi-dimensional but relatively sparse model explains the responses in the survey surprisingly well.



With these structural similarities in mind, it makes sense to think of proven experience as being ontologically related to experience. The two are not totally different, but relevantly similar things. And they both have the dual nature exemplified by Sancho Panza and Don Quixote. Proven experience is had and can be shared, but it is also a quality of the individual that emerges in those who make experiences. This makes it important to try to relate two kinds of experience that we talk about in decision-making contexts within the profes-

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sions. First, and from a Swedish perspective, *proven experience* is an extremely important notion. Second, internationally, and particularly in evidence-based healthcare discourse, *personal experience* is often highlighted (sometimes in conjunction with clinical expertise).

What is the relation between personal experience and proven experience? It seems to me that proven experience entails personal experience. There must be at least one (personal) experience of X for there to be proven experience of X (see Persson 2019). However, the (personal) experience of X need not be actual. This can already be concluded from the 1733 promise. The newly graduated physicians promised to follow proven experience – experience which was not their (personal) experience, but someone else's. In another example, it might happen that an individual makes an experience at a point in time, and that this experience is later replaced by another, but that the first rather than the second becomes proven experience.

In this short note, I would like to use the example of William Withering to probe this relationship.

The drug digitalis was used in practice long before there were any systematic scientific proofs of its effectiveness. Indeed the scientific world condemned digitalis, which was being used as a remedy for a wide variety of illnesses, and it was removed from the London Pharmacopoeia in the 1740s (Somberg et al. 1985). Herbalists continued to use it, however. The Foxglove (*Digitalis purpurea*) is abundant in the

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Midlands, England. In the eighteenth-century, William Withering, a physician with botanical interests living in Birmingham, decided to systematically study the clinical effects of powdered extracts of the plant in patients with dropsy. By using doses of only one grain (twice daily) coupled with opium, Withering was able to moderate most of the toxicity in the extracts. The therapeutic success rate he obtained was remarkably high (Somberg et al. 1985); and in fact it was later suggested that many of the cases where no improvement was found, such as those with pulmonary tuberculosis, did not involve diseases amenable to treatment with digitalis anyway. After Withering's work, clinical use caught on rapidly, but the utility of digitalis was often limited by the limited pharmacological skills of physicians. Still in 1835, a prize of 500 francs was offered by La Société de Pharmacie de Paris for the best answer to the question "Does there exist in Digitalis purpurea, one or more proximate principles to which the medical properties of this plant may be attributed?". In 1940, Cattell and Gold had demonstrated the inotropic effects of digitalis in the right ventricular papillary muscle in cats, and since then it has remained an important tool in the therapeutic management of patients with congestive heart failure (Somberg et al. 1985).

The writing of history is a difficult thing, and I will not assume that what I have just said about Withering and the use of digitalis is true in every detail. Instead I wish to use it as an interesting story that might highlight aspects of the

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relationships we are interested in. So, what does this story tell us about experience, personal experience, and proven experience?

First, digitalis had been used by herbalists – often in combination with other medicinal plants – for a very long time, and well before we had systematic knowledge of its specific effects. Irish monks cultivated it from early on. Its early use in Germany is also documented. And so on.

Thus, there were definitely experiences of its medicinal use before Withering. Some of these were merely personal, but many were also shared and documented. So, there was personal experience and possibly proven experience related to the medicinal use of Foxglove extracts before Withering. And of course the reason why Withering decided to conduct experiments on the effects of digitalis had something to do with these earlier experiences.

However, Withering mainly built on previous experiences – in the sense that he wanted to test these experiences under controlled conditions. He was therefore deeply involved in the generation of proven experience in one of its three main dimensions: *Testing*. In his work, he also contributed to proven experience's other two main dimensions. His impressive results in a clinical setting over the course of nine years increased *practice-derived knowledge* of digitalis' medicinal use enormously, and perhaps not least importantly, it ensured that Withering was considerably experienced – a man of *proven* experience.

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Which, then, is the experience that proven experience entails? I would argue that it might be none of the experiences pre-Withering. What is entailed is that there is at least one experience, but also that the experience must have a content relevant to what Withering is trying to monitor and must have been had under the appropriate conditions. And this is the second aspect in which Withering differs from the herbalists. He is involved in a different epistemic project. He is interested in a subset of the experienced effects of foxglove. For instance, in *An Account of the Foxglove and Some of Its Medical Uses: With Practical Remarks on Dropsy and Other Diseases*, Withering himself says that he was inspired by an old family recipe for the cure of dropsy:

This medicine was composed of twenty or more different herbs; but it was not very difficult for one conversant in these subjects, to perceive, that the active herb could be no other than the Foxglove.

It seems that the difference between whatever experience one has of using that mix and an experience of the medical use of digitalis is enough to exclude these herbalist experiences as instances of the proven experience built by Withering. Thus, as long as we are interested in the *content* of proven experience – in proven experience as *evidence* (and in the Swedish context, requiring both science and proven experience, it is very natural to refer to this as the evidentiary or compensatory role of proven experience: Persson et al. 2019) – it is only

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possible to have proven experience of X if there are sufficiently similar personal experiences of X. (This is why proven experience might be lacking when we are tackling a new virus, even if we have encountered many viruses before). On the other hand, it may arguable be that experiences like those from using an old family recipe can build one's (and could have built Withering's) personal experience. If this is true, it is important to distinguish between proven and personal experience in this case. The herbalist experiences are a material used for the purpose of hypothesis generation in the case of proven experience, but also part of the content of personal experience of Withering and others. That concludes the first observation.

The second observation is that, plainly, personal experience may build proven experience in the-quality-of-an-individual sense (i.e. the sense in which one might be someone of proven experience) even when it does not issue in proven experience in the compensatory or evidentiary sense. An experienced herbalist could be better equipped than a newly graduated physician to implement Withering's proven experience. Similarly, a physician who has dealt with dangerous viruses before could have proven experience (the quality) making her eminently suitable to manage a risky situation involving a new virus.

The third observation concerns the uptake of Withering's newly established proven experience. Medical use of the foxglove increased significantly as a result of Withering's findEXPERIENCE, PERSONAL EXPERIENCE, AND PROVEN EXPERIENCE | 63

ings. The method was proven, and thus came to be used. The results that followed, however, were mixed. Withering writes:

The use of the Foxglove is getting abroad and it is better the world should derive some information, however imperfect, from my experience, than that the lives of men should be hazarded by its unguarded exhibition, or that a medicine of so much efficacy should be condemned and rejected as dangerous and unmanageable.

What kind of experience was it that Withering now tried to communicate? I would argue that it was proven experience again, but this time proven experience with an epistemic role other than that of being evidentiary (compensatory) or a quality of someone. This time it was urgent to share a different message – a message about the *implementation* of knowledge of the type latent in proven experience.

Problems of implementation have been discussed at length in connection with evidence-based medicine. In the discussions, clinical expertise (and proven experience) have often been seen as the necessary remedy.

But here we see that proven experience also generates problems of implementation. It does not travel, or translate, easily into new contexts – nor to new users. Withering's case highlights users. It is almost as if the message is that, when it is traveling, proven experience (as compensatory knowledge) needs not only proven experience (as implementation

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knowledge), but also to be used by professionals of proven experience (those with the quality of being experienced) to travel well.

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Epistemic vices, critical and zetetic

FREDRIK STJERNBERG

I spent a good part of this morning counting the number of books on the top-left shelf in the bookcase in my study (47), then adding up the pages (in total, 14 476), then computing the average (308) and the median (286) numbers of pages in the books. Now I had acquired some information I didn't have before. After lunch, I rechecked. After all, I might have made a mistake somewhere. Nope, everything fine. Now I knew something more – I could be pretty good at some simple, straightforward counting tasks. I also discovered that the whole process could be excruciatingly boring. But still, knowledge was acquired.

Was this a morning well spent, from an epistemological point of view? Pretty clearly, the answer is *no*. But I had been taking care to do things properly. I was well rested. I counted carefully, kept a clean record of what I had been doing, rechecked. Many of the things we usually think of as epistemic *virtues* were at play here. Still, I think we should see the whole

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exercise as time wasted, from the point of view of someone looking for knowledge. I did get new knowledge, but the triviality of it should bother us. Some knowledge is pointless, and no matter how carefully we go about acquiring it, we could have done better doing something else. And "could have done better" does not necessarily even mean that we could have come to know a less trivial assortment of facts – I could have done better by taking some early steps to solving more pressing problems, even if during the morning I didn't add any new facts to my inventory of things believed.

Simple cases like the above one come in conflict with many things people have said about knowledge, from Plato and onwards. Knowledge is good or valuable, epistemic virtues (like being careful, having an open mind, and others) make the acquisition of knowledge possible, or at least more likely. But knowledge need not be a good thing without qualification. This much is perhaps obvious, once we start thinking about it, but the consequences are perhaps not as obvious.

Epistemology is often described as an attempt to answer the question "What is knowledge?", but this makes the discipline sound like a dry exercise in logic-chopping (which it occasionally has been). Epistemology can profitably be seen as answering a slightly different question, namely "What beliefs should I have?" I think this latter question is more central. When is my evidence good enough to warrant a knowledge claim? Which beliefs should be discarded? How

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should I react if someone challenges my beliefs, even my deeply held beliefs? Only some beliefs pass muster. These are the well-founded beliefs. And now there is room to talk about epistemic virtues: Something is an epistemic virtue if it helps us to acquire well-founded beliefs.

Where there is virtue there is vice. Epistemic vices are habits, or perhaps ways of thinking, that get in the way of our successfully having the beliefs we should have, the wellfounded ones. In a recent book, Quassim Cassam writes that epistemic vices are

systematically harmful ways of thinking, attitudes, or character traits ... Epistemic vices get in the way of knowledge. They obstruct the gaining, keeping, and sharing of knowledge (Cassam 2019: viii).

This may not be intended as a full definition of *epistemic vice* (Cassam makes things clearer later in the book), but it is clear enough to start working with. This formulation covers the essential aspects of epistemic vice, enough to discuss the problem that is of interest in this paper.

The problem I want to highlight concerns a certain poverty of this conception of epistemic vice. There are reasons to differentiate the epistemic vices further. One reason is that skepticism here might be labelled an epistemic vice. After all, the consistent sceptic will have the kind of attitude towards acquiring knowledge that makes it too difficult to know things. Perhaps the sceptic places excessively high demands

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on knowledge. But this accusation looks like a facile dismissal of skepticism.

Another reason is that the above conception of epistemic vice focuses too much on using epistemic virtues to handle the beliefs we happen to already have. This is a worthwhile task, but it is not all there is to epistemology.

We should draw a distinction between two kinds of epistemic vice (and, correspondingly, two kinds of epistemic virtue). If we formulate the epistemological problem in terms of the questions "What kind of beliefs should I have?", we will see that this question can, and should, be handled in two ways, and distinctive epistemic vices are connected with each way. They differ.

The first way is a *critical* task: Given all the things I find myself believing, all the things I find in my belief box, which beliefs should I throw out, and which should I keep? This is what is usually done in epistemology. Descartes starts out with an inventory of all the things he happens to believe, and he then tries to sort them into those that should be thrown out and those to be kept. Precious little remains. This critical result is then used for further housekeeping: In future, only accept those new beliefs that pass critical muster.

The second way is what I would like to call a *zetetic* task (after the Greek word for "searching"; see Friedman forthcoming). This is the task of inquiry, the task of arriving at new knowledge. The zetetic vices are vices of inquiry, vices that are at play in a slightly different setting where the question is:

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"How should I go about looking for new truths?" This task covers two issues, or sets of issues. The first is: *What new beliefs should I be looking for*? The second is: *How should I go about doing this*?

Our preoccupation with the critical aspects of epistemology rests on a picture of how knowledge is acquired that is understandable, but wrong. In this picture, we can simply sit down, and look through an enormous quantity of beliefs, and throw out some. Acquiring new beliefs is never a problem, on this picture, because beliefs come to us at all times and in various ways. Acquiring beliefs is simple, weeding out bad beliefs is the true task of epistemology.

The claim that the acquisition of beliefs is simple means, for instance, that their procurement is cost-free. But new beliefs have *opportunity costs*, as economists call it: they are always acquired at the expense of some other beliefs that could have been acquired. Instead of counting the books on my shelf, I could have acquired some other information.' There is a good chance that this other information would have been a better acquisition. In this respect, counting the books on my shelf is an example of an epistemic vice at work. Economists like to say that there is no such thing as a free lunch. Epistemologists would do well to remember that there is no such thing as free knowledge.

Sorting through my existing beliefs is not, and cannot be,

^{1.} Echoes of Simon (1955) here.

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all there is to epistemology. It is a central starting point and has taken up much of the interest in epistemology, but it should be enhanced with an aim to inquire, to pursue inquiry. This is the zetetic project of looking for new knowledge. These two epistemic projects, the critical and the zetetic, are obviously related. Without the critical aspect, morsels of misinformation would be allowed into our system of beliefs; without the zetetic aspect, our well of things believed would soon run dry. Not only are the projects related, they are occasionally conflated. It is easy to start believing that the critical aspect is all we need. But this way of thinking is itself an epistemic vice.

Imagine that the critical task has been fulfilled, that I know which of my existing beliefs should be held on to. For the sake of discussion, let us just assume that this has been achieved within some classical foundationalist empiricist epistemology. Certain beliefs are okay because they can be traced back to immediate sense experience. Others are thrown out. What should the agent do once the ill-founded beliefs are purged? The doxastic remainder will surely not amount to all that can be known about the world. New beliefs will be needed, but where is the agent to go looking for them? How much effort should he or she spend acquiring new beliefs? The critical project of weeding out "bad" beliefs doesn't say anything about this.

Consider two different cases where zetetic vices seem to be at play, even while the critical virtues are in place. First, the

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case of low-hanging fruit. When I am in a critical mode, only accepting into my belief box things that are readily assured to be true looks like a good proposal. This will mean that I should go for the safe bets: *Only accept things that are easily verified*. But continuing to amass easily verified truths will quickly lead to a certain poverty of beliefs. Counting the books on the top-right shelf in my study is beginning to look like a good project. Without some kind of criterion for assessing the value of the things believed, just amassing more things believed will always be better, as long as they satisfy the critical standards.

Second, constant rechecking of already accepted beliefs. After a while, such rechecking will amount to a kind of epistemological pathology. But from a critical point of view, it is not easy to say what's wrong with constant rechecking. Safer is better, and mistakes about accepted beliefs are clearly possible.

We need to augment the usual epistemic virtues and vices with zetetic virtues and vices. Precisely how these two sets of virtues ought to be weighed against each other can be understood as an optimization problem. Is it better to have dull but safe beliefs, or beliefs that are interesting but not as safe?

The virtues of proven experience

This set of problems is also a live issue in the context of the present volume, and within the program in which it is

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appearing – the relations between science and proven experience. The critical virtues and vices relate to the scrutiny of various kinds of evidence we have; the zetetic virtues relate to the way we think about the acquisition of new evidence. Science is the search for truth. Science, as it is often described, excels in its critical virtues. Most courses in methodology teach students how to scrutinize, or validate, putative findings. But, in effect, science as practiced also involves tacit reliance on the zetetic virtues. These virtues are not to be understood and formulated from within a purely scientific perspective. Singling out certain truths as interesting, and worthy of examination, is part of what scientists do, in their practical day-to-day work. This is part of their proven experience. Without it, science would be much less powerful. The proven experience of scientists shows them a way forward.

Zetetic virtues and vices

As I said above, zetetic virtues and vices are connected with the acquisition of new beliefs. Too much emphasis on critical virtues and vices will hinder the acquisition of new beliefs, and so some attitudes towards the critical virtues can actually be detrimental. Note here that it is not the virtues themselves that do the damage – it is the attitude towards them. It is okay to be epistemically cautious, with all that that involves, but it is not okay to think that this is all that can be said about knowledge.

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It would be easy to propose an overriding zetetic virtue: That of being disposed to *aim for interesting truths*, with its obvious corresponding vice: *Staying with uninteresting truths*. But this will clearly not work by itself. How should we measure which beliefs are "interesting", and once we have a suitable measure, how would that interact with the safety of the knowledge acquired? By this I mean, how should we compare safe knowledge about something that is pretty interesting with less well founded beliefs about something that is a bit more interesting? I think we will have to take small steps here if we are to get anywhere. One option is to look at the usual assortment of ordinary epistemic vices and see if these can be used to understand zetetic virtues and vices, but this is a topic for future work.

Right now, I can only concur with Jane Friedman, when she writes: "We have good reason to take the zetetic turn".

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An attempt to distinguish science and proven experience

One thing we have learned in this research program is that vetenskap och beprövad erfarenhet (VBE) – "science and proven experience" – is understood in many different ways. Proven experience is seen to range from mere collective accepted practice to the property, belonging to an individual, of being "proven" in their profession. In between, moreover, lies something emanating from practice but severely tested, or something severely tested in the practice (Persson and Wahlberg, 2015). In general terms, we can perhaps characterize proven experience as what you have when you entertain a firmly held belief in the effectiveness of a certain treatment.

Theoretical studies have dug into the relationship between evidence-based medicine (EBM) and VBE, and asked what the "and" in science and proven experience might actually mean (Persson et al., 2018). One thing we have not said much about is how to understand what the distinction between science and proven experience is. This text is an attempt to deal with this question.

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The distinction could be one of methodology – that there is a method that is typically scientific, and that proven experience is achieved through means other than this scientific method. Alternatively, it could be one pertaining to the kinds of question that one wants to find an answer to – science perhaps deals in "why"-questions, while proven experience is about establishing *that* something works, that a treatment is effective, and so on. I will in the following try to say something about these ways of understanding the science and proven experience distinction, but I start with an example.

ARDS, TPE, Covid-19 – an example

In an editorial in the journal *Critical Care* earlier this year (Keith et al., 2020), Philip Keith and his colleagues suggested that therapeutic plasma exchange (TPE) could be used in the treatment of fulminant Covid-19. In early spring 2020 the pandemic was in its infancy with 100 000 people infected and 3300 dead worldwide, but the urgency of finding effective treatments was of course acutely known.

Fulminant Covid-19 can cause several critical states. Keith and his colleagues mention "sepsis, acute respiratory distress syndrome (ARDS), and/or multiple organ failure which are not unique to coronavirus" (Keith et al., 2020).

The case for TPE in fulminant Covid-19 is made in several steps. First, some success in treating patients with plasma

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from those who had survived the illness had been reported from China, and plasma transfusions are not novel treatments so there is no obstacle to using it in that respect. Second, TPE is known to be effective against the mechanisms in play in many of the states that can obtain in fulminant Covid-19. Third, a randomized controlled study had shown "a tendency toward improved mortality" (Keith et al., 2020) when adult sepsis patients were treated with TPE, and the same tendency had been found in a meta-analysis. Fourth, TPE was used on three children in the 2009 influenza (H1N1) pandemic, all in situations not unlike that created by fulminant Covid-19, where mortality is high. They all recovered "after receiving rescue TPE".

The authors conducted a single-center retrospective study of the TPE treatment for sepsis where the patients required mechanical ventilator support, and this gave positive results, especially for patients whose sepsis was the result of pneumonia. They write: "Our practice has changed based on our experience, and we now often utilize TPE earlier in the clinical course of septic shock with [the multiple organ dysfunction syndrome] MODS and ARDS rather than as 'rescue therapy'." And further: "Anecdotally, the results have been remarkable but have not been reviewed or statistically analyzed." (Keith et al. 2020).

They conclude the editorial with the observation that TPE "shows promise" and remark that it would be worth doing randomized trials in order to "investigate further".

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There is of course a lot of science here, but also experience and some of it perhaps proven. We learn that TPE has been used as "rescue therapy" (because of results from a few studies that are not exactly relevant to the situation at hand); that it was then systematically evaluated in a small retrospective study; that the practice was modified on this basis (if I read them correctly), with TPE then being applied earlier in the sepsis process; and that, in order to be sure, randomized trials ought to be conducted.

So, is the experience proven, and if so, when did it become proven? And what in this example is science, and what is proven experience?

Scientific methodology as distinguishing feature

In the TPE case, the authors use the treatment in their practice and test its effectiveness in a single- retrospective study. So, they have the experience, and they have tested it by analyzing previous cases in their own hospital. It seems they have proven experience, then. They also see the need for randomized studies. It is not all that far-fetched, if this was in a Swedish setting, to see the need for randomized trials as that which is needed to arrive at VBE – to add science to the proven experience. The reason would in that case seem to be that a single- retrospective study is not science, while a randomized controlled study is. Both kinds of study try to answer the same question. Each evaluates a hypothesis that

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is present as a rather firm belief. Their methodologies differ, however. The randomized trial, which will handle problems with bias better than the retrospective study, is more scientific. Perhaps it can even be said to be science while the other is not.

Or we could accept that the retrospective study is actually science too, and that the proven experience was present already when it was conducted, so that the study issued in VBE. (Would we then say that the randomized study issued in even better VBE?) Perhaps it was some combination of the results from the H1N1 study on three children together with the practical application that made the experience proven? But even that small case series involved systematic handling of a set of observations, the comparison of outcomes with a baseline, proper handling of data, etc. All these are marks of a scientific methodology, albeit more vulnerable to bias than the retrospective study.

It is difficult to see how a clear distinction between science and proven experience can be drawn in terms of methodology if it is part of the concept of proven experience that something has been properly tested, since testing will typically involve systematic study of a phenomenon of some sort. (I realize it is possible that no such distinction is to be found.) And what is more, such a distinction, cast in terms of methodology, is not adding anything useful in comparison with the situation where we have only well-proven experience. The question is only whether the experience has been tested

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enough. Is a case study of three patients enough? Is a singleretrospective study adequate? Or do we require an RCT in addition? What kind of study suffices will depend on what it is possible to do, as well as on how obvious the effects at issue are.

The questions needing answers

In a loose sense, every systematic study of phenomena, every systematic search for new knowledge, can be called science. What the knowledge consists in can differ. It can be to know *that* there is a causal relation between two phenomena, on any given level of complexity, or it can be the search to say what that causal relation is (by screening off certain aspects of the phenomena in order to isolate the cause). In other words, to explain *why* the phenomena are related the way they are. Let us for now entertain the idea that what science is ultimately after is understanding – in conducting science we want to know *why*.

I take it that our interest in proven experience is an interest solely in knowing *that* some treatment is effective, or that the treatment causes the patient to be healthier than she would have been without it. Why the treatment causes the patient's health to improve is not the important thing here. To know that it works is enough.

The experience is a practical experience. Proven experience is learning, coming to know, by doing. But not only by doing

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- that would only be to pile up experiences, one on top of the other. Somehow this pile of experiences becomes a proven experience, a conclusion as to what these experiences, taken together, as a whole, tell us. How does that happen? In more than one way, presumably: From an unconsciously formed conviction, a firmly held belief, that the treatment is effective, or through conscious observation that a satisfactory proportion of patients do not come to see the doctor again (or perhaps something like the "remarkable" results reported in Keith et al. (2020)). Or the experience of the effects of the treatment can be systematically tested through a singlecenter retrospective study, or even a randomized trial. The result, in any of these cases, is proven experience in the sense that the those with the experience have used the treatment and, for some reason or other, come to form a strong belief that it is effective, become convinced that it works. How this belief is formed depends on how severe one requires the test to be (and on how obvious the effects are). One practitioner may settle for the look on the patients' faces when they leave the hospital. Others may challenge this and claim that experience of that kind is not proven after all. It takes a more rigorous kind of testing, they will argue, for it to be proven experience. Perhaps setting up a registry would work, or designing and running an observational study on one's patients, or even performing a randomized trial. Perhaps the way alternative medicine is viewed, in Sweden at least, could serve as an example here.

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But then, one might ask, what happened to science? Clinical research seems to have been all but disgualified. And, yes, so it has. In this picture science has retracted to the kind of activity that involves trying to sort out the inner(most) workings of things: Basic science, bench research. Perhaps, again, the whole meaning of VBE has been lost? Hospital legal teams will not need the "V", the science, to sort out whether or not there was malpractice, surely? What they will want to know is whether the treatment was safe enough, effective enough. Why it works and the way it works is not of much concern to the court. Well this is true I suppose. Nonetheless, in an indirect way science does enter the picture in here. Consider a new treatment that has not yet been introduced/accepted in ordinary practice. Here the basic science on which the treatment is founded can be an argument in favor of the reasonableness of using it.

It is even better, of course, if some randomized trial has been conducted with promising results. This trial will not perform the same function as it did in the proving of experience. Here, it is instead a test of the implementation of a scientific hypothesis, from micro level to macro level, cell to whole human. The study is a tool that can be used to test the experience of an intervention/treatment/action – to show whether it is as effective as we believe it to be (or not to be). Or it can be used to test whether a mechanism found through science can be expected to do the same

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work in a whole human body as it has been found to do in individual cells. Same kind of test, but for different purposes.

These are cases where there is either science or proven experience. What is the value of having both? With a treatment that is already in use, having a firm belief that it has shown to be effective, and a justification of that belief, seems to be all that is needed. But it this belief is certainly given substance when it is backed up with an argument as to why the treatment may actually work, as opposed to an argument showing that the treatment's effectiveness is robust. And the science here has another use: Having a grasp of the basic mechanisms at work makes it possible to extend the treatment to other areas of use. As Keith et al. (2020) report: The knowledge that TPE "uniquely offer[s] benefit on multiple levels by removing inflammatory cytokines, stabilizing endothelial membranes, and resetting the hypercoagulable state" is an argument in favor of using TPE on patients with Covid-19. The rather weak proven experience gleaned from the successful treatment of the three H1N1 patients further strengthens this belief, as does the added proven experience the authors themselves have of treating sepsis caused by pneumonia. But an important part of the justification for using TPE comes from the conviction that it works on the (many) mechanisms that are in play in fulminant Covid-19.

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Conclusion

Methodology offers a poor basis on which to draw a meaningful distinction between science and proven experience – partly perhaps because it is difficult to pin down what a scientific methodology actually is, but mostly because such methods are methods of obtaining or attaining *something*. It is that something – at least, to my mind – that could be different things in the two cases. In a court of law, the evaluation of evidence will look rather different depending on the issue being adjudicated: Is it a question of establishing whether a treatment that is actually used, and where there is practical experience, *should* be used, or is the question instead whether a treatment of which nobody has any real practical experience was used in an acceptable way in the case at hand?

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Vetenskap och beprövad erfarenhet – ett rättsligt begrepps innebörd och gränser

LENA WAHLBERG

Ett undflyende begrepp

För mig som rättsteoretiskt intresserad är begreppet *veten-skap och beprövad erfarenhet* närmast oemotståndligt. Begreppet opererar i skärningspunkten mellan rätten och andra discipliner. Trots att det spelar en central roll i flera rättsregler är dess rättsliga innebörd notoriskt svår att bestämma. En del rättsvetare har framhållit att det faktum att samma behandlingsmetod vid en tidpunkt kan anses förenlig och vid en annan stå i strid med vetenskap och beprövad erfarenhet visar att begreppet i hög grad är dynamiskt och att dess mening varierar över tid. Vissa menar att begreppet i själva verket är tomt på rättsligt innehåll och helt hämtar sin mening från andra professioners begreppsapparater.

Forskningsprogrammet om vetenskap och beprövad erfarenhet har förvisso gett insikter om begreppets innebörd och användning men också väckt nya frågor, bland annat om

dess räckvidd. I denna korta text kommer jag först att presentera några inblickar om begreppets innebörd som vunnits genom forskningsprogrammet, för att med utgångspunkt från dessa diskutera begreppets förklaringskraft och relevans för två i skrivande stund mycket aktuella frågor: det rättsliga utrymmet för läkarassisterat självmord och hanteringen av coronaviruset.

Inblickar från forskningsprogrammet

Det stod tidigt klart att uttrycket "överensstämmelse med vetenskap och beprövad erfarenhet" inte bara är vagt utan också mångtydigt. I en litteraturstudie av artiklar som publicerats i Läkartidningen räknade vi till inte mindre än sex betydelser bara hos "beprövad erfarenhet" (Persson och Wahlberg 2015). Senare undersökningar visade att mångtydigheten finns såväl hos medicinska och odontologiska professioner som i rättstillämpningen, och att den återfinns i konjunktionen "vetenskap och beprövad erfarenhet" (Wahlberg och Persson 2017, Wahlberg och Sahlin 2017, Wahlberg 2018a, Wahlberg 2018b, Wallin 2019, Sahlin et. al. 2020a). Ibland används uttrycken för att beteckna metoder som är vedertagna av professionen. Andra gånger används de för att beteckna metoder som har testats och vunnit stöd genom vetenskapliga studier eller praktisk tillämpning. Fler betydelser förekommer och ofta är det inte klart vilken som avses. Även om de olika betydelserna överlappar, kan de i enskilda

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fall leda till olika svar på frågan om en behandlingsmetod är förenlig med vetenskap och beprövad erfarenhet. Svaret beror då på hur den vi frågar förstår uttrycket.¹

I det rättsliga regelverket fungerar kravet på vetenskap och beprövad erfarenhet inte bara som en allmän standard för medicinsk vård och behandling, utan som förutsättning för patienters och vårdanställdas rättigheter och skyldigheter. I den mån kravets innebörd är oklar, är det också oklart hur långt dessa rättigheter och skyldigheter sträcker sig. I vår forskning har vi sett hur avsaknaden av en tydlig begreppsbildning försvårat både en effektiv överföring av information mellan rättslig och medicinsk expertis och en ändamålsenlig lagtolkning av kravets innebörd. (Wahlberg och Persson 2017; Wahlberg och Sahlin 2017; Wahlberg 2018 a; Sahlin et al. 2020 a). Enligt vår uppfattning är det självklart att det rättsliga kravet på vetenskap och beprövad erfarenhet måste förstås i ljuset av de relevanta rättsreglernas ändamål och behovet av rättslig förutsebarhet. Vi håller alltså inte med dem som menar att begreppet vetenskap och beprövad erfarenhet är tomt på rättsligt innehåll och helt hämtar sin mening från andra discipliner (Wahlberg och Persson 2017, Wahlberg och Sahlin 2017). Däremot tror vi att det även från ett rättsligt perspektiv är viktigt att kravet på vetenskap och

Att en behandlingsmetods förenlighet med vetenskap och beprövad erfarenhet även växlar från en tidpunkt till en annan behöver däremot inte vara ett tecken på att begreppsinnehållet förändrats utan kan helt enkelt bero på att olika behandlingsmetoders utbredning och stöd varierar över tid.

beprövad erfarenhet ges en innebörd som är acceptabel och meningsfull för den medicinska professionen. (Wallin et al. 2020) (Sahlin et al. 2020 b).

Vi har föreslagit att det rättsliga kravet på överensstämmelse med vetenskap och beprövad erfarenhet utläses som ett krav på evidens (Wahlberg och Sahlin 2017, Wahlberg 2018). I en behandlingssituation innebär denna tolkning att det ska finnas tillräcklig evidens för att behandlingens nytta för den enskilda patienten överväger den risk patienten utsätts för genom behandlingen, alltså för att behandlingen är effektiv och säker. Evidensen kan komma från vetenskapliga studier och/eller praktisk erfarenhet. Hur mycket evidens som krävs beror på vad som står på spel i det enskilda fallet, till exempel om behandlingen är irreversibel och vilka alternativ som står till buds (Wahlberg och Sahlin 2017, Wahlberg 2018a). I många fall kan det vara enkelt att konstatera att det finns tillräcklig evidens för ett visst behandlingsalternativ. När tillgången till vetenskapliga studier och praktisk erfarenhet är begränsad blir avgörandet svårare, och väcker i förlängningen principiella frågor om beslutsfattande under osäkerhet som liknar dem som diskuterats inom exempelvis den bevisrättsliga litteraturen om robusthet (se t.ex. Dahlman et al. 2015).

Det finns flera skäl för vår tolkning av kravet på vetenskap och beprövad erfarenhet. Till att börja med är den i linje med regleringens syfte att främja den enskilda patientens säkerhet och behandlingsmetodens effektivitet. Samtidigt upprätt-

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håller den gränsen mellan vård och forskning genom att - till skillnad från vad som är fallet i regelverket för forskning inte tillåta att den nya kunskap som kan vinnas genom att en metod används vägs in i bedömningen av om användningens förväntade nytta överväger risken (Wahlberg och Sahlin 2017). Vi tror dessutom att vår tolkning kan accepteras och är meningsfull för den medicinska professionen. Genom enkätstudier har vi sett att uppfattningen att beprövad erfarenhet inte bara är något man gör, utan också något som kan ge evidens, har starkt stöd inom såväl medicin som omvårdnad och odontologi (Sahlin et al. 2020a). Den tolkning vi föreslår ligger också nära Socialstyrelsens tillämpning av kravet på vetenskap och beprövad erfarenhet i framtagandet av generella riktlinjer, men avser i vårt fall balansen mellan risk och nytta för en enskild patient i en konkret behandlingssituation (Wahlberg 2018a). För vår tolkning talar dessutom att den i förhållandevis stor utsträckning kan användas för att förklara gränsen mellan tillåtna och otillåtna behandlingar. Till skillnad från tolkningar som innebär att endast vedertagna behandlingsmetoder kan vara förenliga med vetenskap och beprövad erfarenhet, tillåter vår tolkning att också nya behandlingsmetoder uppfyller detta krav, så länge det finns tillräcklig evidens för metodernas säkerhet och effektivitet. Vår tolkning kan också förklara varför det i enskilda fall kan vara tillåtet att använda icke-vedertagna metoder, utan att den därmed förutsätter att det då är frågan om nödsituationer i rättslig mening (Wahlberg och Sahlin 2017).

En viktig fråga i sammanhanget är vilket jobb vi egentligen vill att kravet på vetenskap och beprövad erfarenhet ska utföra i den rättsliga regleringen. Det är tydligt att kravet inte förmår förklara alla rättsliga gränser som det ibland använts för att markera. Ett exempel är rätten till ersättning för kostnader till följd av vård i andra länder inom EES, där en behandlings förenlighet med vetenskap och beprövad erfarenhet tidigare behandlades som en i princip tillräcklig förutsättning för rätten till ersättning, men som i Högsta förvaltningsdomstolens senare praxis kraftigt tonats ned till förmån för frågor om vilka behandlingar svensk hälso-och sjukvård faktiskt erbjuder och prioriterar (Wahlberg 2018a). Med den tolkning vi föreslår, där kravet på vetenskap och beprövad erfarenhet i den rättsliga regleringen av hälso- och sjukvård preciserats till att värna behandlingens säkerhet och effektivitet för den enskilda patienten, är det tydligt att kravet inte omfattar ekonomiska prioriteringar.² Om kravet på vetenskap och beprövad erfarenhet lämnas opreciserat kan det emellertid vara frestande att hänvisa till detta krav för att förklara fler rättsliga gränsdragningar än det i själva verket mäktar med.

I det följande kommer jag att kort diskutera vilken relevans kravet på vetenskap och beprövad erfarenhet (preciserat som ett krav på tillräcklig evidens) har för att förklara det rättsliga utrymmet för läkarassisterat självmord respektive smitt-

^{2.} En annan sak är att behandlingens förväntade nytta i sin tur får betydelse för frågan om kostnadseffektivitet.

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skyddsåtgärder med anledning av det nya coronaviruset. Diskussionen kommer att lyfta fram men inte slutgiltigt besvara två frågor om kravet på vetenskap och beprövad erfarenhet: frågan om i vad mån etiska överväganden hör hemma i detta krav och frågan om det finns situationer där vi har anledning att göra avkall på krav på evidens.

Etiska dimensioner i VBE? Exemplet Läkarassisterat självmord

En omdiskuterad fråga är om det bör vara tillåtet för läkare att skriva ut läkemedel som en patient själv kan ta för att begå självmord, s.k. läkarassisterat självmord. Eftersom självmord inte är kriminaliserat i svensk rätt är inte heller medhjälp till självmord straffbart. Likväl anses läkare inte ha rätt att förskriva läkemedel i syfte att en patient ska kunna ta sitt liv. Den läkare som ändå gör detta riskerar att förlora sin legitimation. Att förskrivningen är otillåten brukar förklaras med att den skulle strida mot vetenskap och beprövad erfarenhet (Socialstyrelsen 2011, 16;37). Förklaringen att förskrivningen strider mot vetenskap och beprövad erfarenhet handlar dock knappast om att det saknas evidens för att läkemedlet kommer att uppnå det avsedda syftet. I stället verkar den bygga på förutsättningen att kravet på vetenskap och beprövad erfarenhet har en etisk dimension som avgör vilka mål som är relevanta, med innebörden att en patients död inte kan kvalificera som nytta ens om den innebär lind-

ring, och att en läkare aldrig får ge en behandling i avsikt att döda sin patient.

Det kan tilläggas att debatten om läkarassisterat självmord inte är det enda sammanhang där kravet på vetenskap och beprövad erfarenhet används på ett sätt som antyder en etisk dimension. Ett annat exempel är Socialstyrelsens uttalande att kvinnlig omskärelse i alla former står i strid mot vetenskap och beprövad erfarenhet, i samband med införande av lagen (1982:316) med förbud mot könsstympning av kvinnor (prop. 1981/82: 172, 9). Inte minst uttalandets generella karaktär tyder på att skälet till att behandlingsmetoden ansågs stå i strid med vetenskap och beprövad erfarenhet inte handlade om brist på evidens, utan snarare om att det resultat som behandlingen eftersträvade inte ansågs acceptabelt (Wahlberg 2018b). En etisk dimension framskymtar också i våra enkätstudier till medicinska professioner, där betydligt fler instämmer i påståendet "Att det finns beprövad erfarenhet av en behandling inom hälso- och sjukvården betyder att den inte strider mot den medicinska etiken" än i exempelvis påståendet "Att det finns beprövad erfarenhet av en behandling inom hälso- och sjukvården betyder att en grupp experter inom hälso- och sjukvården tillsammans kommit fram till att den fungerar", trots att det senare påståendet syftade på så kallade konsensuskonferenser, vilket är Socialstyrelsens metod för att hämta in beprövad erfarenhet (Sahlin et al. 2020a och b).

För egen del tror jag dock att man bör vara försiktig med

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att belasta kravet på vetenskap och beprövad erfarenhet med etiska överväganden och därmed göra kravet onödigt opakt. Såväl rättssäkerhetshänsyn som hänsyn till rättens systematik talar i stället för att i möjligaste mål renodla kravet på vetenskap och beprövad erfarenhet som ett krav på evidens och hänföra etiska överväganden i övrigt till andra delar av regelverket. Det har framhållits att läkarassisterat självmord strider inte bara mot kravet på vetenskap och beprövad erfarenhet, utan också mot det närliggande kravet på att patienten ska ges god och sakkunnig hälso- och sjukvård (Socialstyrelsen 2011, 16), vilket öppnar för att se förbudet som en (möjlig) del av det rättsliga begreppet *hälso- och sjukvård*, i stället för att försöka härleda förbudet från det rättsliga kravet på överensstämmelse med *vetenskap och beprövad erfarenhet*.

Vad beträffar förbudet mot läkarassisterat självmord kan slutligen konstateras att oavsett var i den svenska regleringen detta förbud närmare bestämt anses finnas, verkar det behöva härledas från en tolkning av rättsliga begrepp vars innebörd är långtifrån huggen i sten. Uppfattningen om vad som ingår i vårdens uppgift varierar över tid. I debatten om läkarassisterat självmord hänvisas ofta till den passage i Hippokrates 2 500 år gamla läkared som lyder "Jag skall icke ge någon gift, även om jag blir ombedd, ej heller ordinera något sådant" (se t.ex. Hännestrand 2020). Den följande satsen i eden lyder emellertid "Ej heller ska jag ge någon kvinna fosterfördrivande medel" (SLS 2020) och är idag

uppenbart otidsenlig. Samtidigt är det ett faktum att läkarassisterat självmord idag är tillåtet i flera rättsordningar (se t.ex. Mattsson och Wahlberg 2020).

Gränser för ett evidensbaserat förhållningssätt? Exemplet Smittskydd i covid 19:s tid.

Enligt 1 kap. 4 § smittskyddslagen (2004:168) ska smittskyddsåtgärder bygga på vetenskap och beprövad erfarenhet. Det nya coronaviruset och sjukdomen covid-19 aktualiserar frågan om det finns gränser för hur långt detta krav kan och bör upprätthållas. Det kan knappast ha undgått någon att det förelegat mycket stor osäkerhet i fråga om hur det nya viruset fungerar och vilka strategier som är bäst lämpade för att motverka smittspridning. Är ett krav på vetenskap och beprövad erfarenhet alls meningsfullt i en situation där *något* måste göras men där bristen på kunskap och beprövade metoder är så påtaglig?

Svaret på frågan beror i varje fall delvis på hur vi tolkar kravet på vetenskap och beprövad erfarenhet. Tolkat som ett krav på vedertagen praxis blir det förstås svårt att uppfylla på ett meningsfullt sätt när hotet vi står inför är så nytt att vedertagna metoder för att bemöta det i hög grad saknas. En förståelse i termer av tillräcklig evidens verkar däremot fungera också i en sådan situation, åtminstone i viss utsträckning. Teoretiska modeller, analogier från bekanta virus och insikter vunna efter hand kan bidra med evidens för olika

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åtgärders nytta också när det saknas vedertagna metoder och direkt tillämpliga vetenskapliga studier. Samtidigt kommer förstås bristen på forskning och praktisk erfarenhet att hämma möjligheten att vidta effektiva åtgärder även när kravet på vetenskap och beprövad erfarenhet utläses som ett krav på tillräcklig evidens.

Sedan viruset på allvar spred sig i Sverige har många argumenterat för att regeringens och Folkhälsomyndighetens åtgärder för att hindra smittspridningen inte varit tillräckligt långtgående. Röster har höjts för att hanteringen av situationen kräver kraftfulla politiska ingripanden och inte bör överlåtas till expertmyndigheter, vilket kan uppfattas som ett uttryck för att kravet på vetenskap och beprövad erfarenhet i detta läge måste ge vika. Också från ett teoretiskt perspektiv finns de som argumenterar för att i situationer som präglas av stor kunskapsosäkerhet ersätta beslut baserade på expertkunskap med kunskapsinhämtning och politiska ordningsskapande åtgärder (Snowden och Boone 2007, Tetlock 2017).

Om detta leder till att vi ger upp kravet på evidens gör vi emellertid samtidigt avkall på ett krav på argument som styrker förhållandet mellan mål och medel och begränsar utrymmet för godtycke. Det i debatten ofta bortglömda men grundlagsstadgade förbudet mot onödigt långtgående politiska begränsningar i enskildas fri- och rättigheter (2 kap. regeringsformen) skulle bli uddlöst om det inte åtföljdes av ett krav på tillräcklig evidens för ingripandenas effektivitet. Ett krav på evidens tjänar därmed inte bara intresset av

effektivitet utan även intresset av rättssäkerhet. En annan sak är förstås att *målen* med de åtgärder som vidtas kan variera. Argumentet att målet i ett visst läge är att skapa lugn och ordning snarare än att begränsa smitta gör det dock inte mindre relevant att kräva evidens för att de åtgärder som vidtas främjar detta mål.

Det är inte heller självklart att ett stort utrymme för att vidta åtgärder utan tillräcklig evidens främjar kunskapssökandet. Från hälso- och sjukvården finns vittnesmål om hur åtgärder som under coronapandemin vidtagits utan stöd av tillräcklig evidens i själva verket hindrat genomförandet av systematiska studier och därmed inhämtandet av ny kunskap (Dominus 2020). För egen del tror jag mot denna bakgrund att kravet på vetenskap och beprövad erfarenhet i bemärkelsen evidens har en viktig funktion att fylla också när kunskapsläget är osäkert, även om, som berörts ovan, det i dessa situationer kan vara en större utmaning att avgöra när evidensen för en åtgärds effektivitet verkligen kan anses tillräcklig.

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Science and proven experience: Applying evidence or compensating for it?

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While working on this project we have found not only that there are different ways to understand proven experience (e.g. Persson & Wahlberg 2015; Wahlberg & Persson 2017; Wallin et al., 2020, Sahlin et al., 2020, Persson et al., in preparation), but also that proven experience has different uses. The two that are most prominent concern how scientifically grounded evidence is *applied* to a particular situation and how to make responsible choices when clear scientific evidence is *lacking* (Persson et al., 2019; Wallin, 2019; Persson et al., in preparation).

A typical example of the first role is the situation a medical practitioner faces when ethical and practical concerns have limited research on the group most often encountered in care settings: The frail elderly with co-morbidities. In dealing with such a patient, the practitioner must look at the available evidence and consider whether it is applicable to the

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situation at hand. Will the treatment interact with other treatments? How damaging are the possible side-effects for this age group? Will the patient be able to make any required behavioral changes?

A typical example of the second role is the situation medical practitioners face when research simply has not yet been done. Urinary incontinence, for instance, severely affects quality of life but there is precious little research on the most common treatments (urinary pads, toileting programs, pelvic floor training). Practitioners are left to look for other sources of knowledge (Wallin, Sahlin & Bruine de Bruin, 2018).

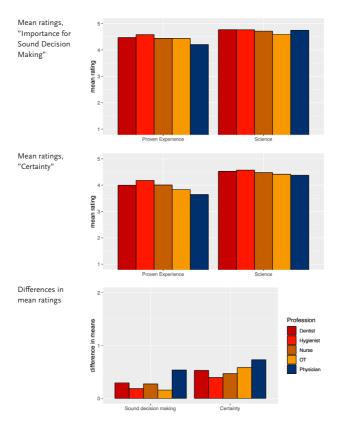
Across the medical professions there is variation in the quantity of relevant scientific evidence exists to inform clinical decision-making, and how readily available it is. Older professions, such as medicine, have access to a longer, and potentially more developed, line of research than younger ones, such as occupational therapy. The professions also differ in status. For example, more research funding is directed to medicine than to the other healthcare professions. Further differences exist within the professions. For example, consider the division between pharmaceutical and surgical interventions. On the one hand, pharmaceutical companies produce vast amounts of research, including large clinical trials for the most promising research. On the other hand, medical procedures that require specific skills, such as surgery, pose problems for randomized controlled

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studies. Equipoise is difficult when one procedure is more familiar than the alternative. Additionally, the learning curve for a novel, or non-preferred, procedure introduces error into the sampling process.

If the two roles of proven experience differ from one profession to the next, it is to be expected that the professionals themselves will also view proven experience differently. For instance, we might expect that professionals with less access to relevant scientific evidence (say, occupational therapists) will see proven experience as something that differs less from science than professionals with more access to scientific evidence (physicians) do.

In fact, that pattern is born out in our surveys of five healthcare professions: Physicians, nurses, occupational therapists, dental hygienists and dentists. In these surveys – with random samples of approximately 300 members of each profession – we asked participants to (among other things) rate proven experience and scientific evidence in terms of their importance for sound decision-making and their certainty (see Figure 1). All professions rate science more highly on those two characteristics than proven experience. In terms of their importance for sound decision-making, the largest disparity between the rating for science and the rating for proven experience was shown by the physicians, followed by the dentists, nurses, dental hygienists, and finally, occupational therapists. Similarly, where certainty was concerned, the largest disparity between the ratings was found in the Figure 1: Mean ratings, by profession. Each rating is on a 1-5 Likert scale, where 1 = "Not at all" (e.g. "Not at all systematic") and 5 = "Very". "Difference in mean ratings" refers to the difference between the mean rating of science and the mean rating of proven experience.



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physicians, followed this time by the occupational therapists, dentists, nurses, and dental hygienists. We also found that all professions see science and proven experience differing more in terms of certainty than they do in their importance for sound decision-making.

Access to scientific evidence within a profession will also change when a new affliction enters the stage. The current pandemic is a case in point. Writing in The New York Times, Susan Dominus (2020) describes the tensions between, on the one hand, physicians who are trying to help their Covid-19 patients and, on the other, physicians who are trying to help their Covid-19 patients *while* hoping to enroll them in clinical trials to build scientific evidence on treatments for Covid-19. The problem is, of course, that when the pandemic began, there were no treatment protocols, other than the default supportive care (e.g. supplemental oxygen) used for patients with non-Covid-related respiratory symptoms. Nevertheless, something had to be done in search of better treatments, and physicians around the world did their best both for their patients and for each other. Physicians in countries or regions with earlier peaks shared their experiences as best they could, and the profession extrapolated from its experience with other types of infections. Under normal circumstances neither anecdotal evidence nor reasoning from first principles would be considered good grounds for medical decisions (CEBM, 2009), but here there was little choice. Susan Dominus cites a pulmonary-critical-care doctor

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describing her thoughts at the time: "There's no proof that anything works! Everything is experimental!"

Interestingly, the article indicates that previous experiences shaped how positively physicians regarded possible interventions and treatment. The anti-inflammatory drug tocilizumab illustrates this. Infectious disease doctors tended to be skeptical about the drug because of its effects on the immune system, whereas hematologists, sometimes using it to ward off cytokine storms induced by cancer treatments, often suggested it. The groups had different experiences of the drug and its side-effects, and these differences were not just personal, but rather related to their specialties. One could argue that different kinds of proven experience of the drug and its effectiveness were operating here. These kinds of proven experience, however, were not directly tied to Covid-19, but rather connected with other types of affliction. When scientific evidence was lacking, proven experience became paramount and played a compensatory role. But in the shift between contexts (e.g. from cancer to Covid-19) proven experience lost the advantage it usually has of being generated close to relevant practice, which is fundamental to it (e.g. Persson et al. in preparation). Thus, when proven experience moves between contexts it can become more difficult to apply. It becomes less effective when the (possibly latent) factors determining its effectiveness change in the new context.

Two characteristics of useful knowledge are its systematicity and its reliability. Although science is the poster child for both

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virtues, proven experience can also possess them. It may be more reliable than science when it dodges certain issues of applicability (e.g. although there may be few randomized controlled studies on the frail elderly, there is certainly ample experience of them among physicians of the right specialties). It may also be systematic: When treatment results are documented and shared, some sort of systematic evaluation of the treatment's effectiveness can be provided. Problems tend to arise when the situation is so critical that calm evaluation is not possible – or is, at least, difficult to maintain. Dominus' article provides us with a good example here concerning the much-discussed drug *hydroxychloroquine*:

Typically, in clinical trials, after a patient is admitted to the hospital, a doctor or nurse, often affiliated with the research, talks to the patient about the possibility of enrolling in a clinical trial. But Libutti's team was finding that by the time a nurse could begin the conversation with the patient, that person had already been administered hydroxychloroquine — which meant the researchers could not get a baseline reading of that patient's viral load. Patient after patient was disqualified from the study. They had "been handed hydroxychloroquine along with their toothbrush and slippers when they got to the emergency room," Libutti told me. "They were giving it out like dinner mints."

One advantage of science over proven experience may lie in the fact that strict protocols govern its generation of evidence and results. Although proven experience can be systematic,

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that systematicity requires discipline and effort. Such effort is taken for granted in the generation of scientific evidence, but it is not as explicitly demanded for proven experience. Thus, one of the advantages of science over proven experience may be, not that the former *is* in itself very much more systematic, but rather that, unlike proven experience, science simply cannot be done without systematicity.

The results shown in Figure 1 suggest that the participants in our survey recognized that point, regardless of their profession. We conjectured that the largest differences were all seen among the physicians because medicine is the oldest of the professions included in the survey, and as a consequence of its age has accumulated the most scientific evidence. That would *necessarily* cause large differences only if proven experience, by its nature, cannot be as important, certain (and systematic) as science. One open question is whether the "best" proven experience eventually becomes part of the *scientific* literature – perhaps because its high-quality means that it has large effects that are easily observed in controlled studies (an example might be hand hygiene).

Returning to the current pandemic, the two groups of physicians described by Dominus might be characterized as follows: They differ in whether they hope to *gain* knowledge primarily through proven experience or instead prefer to engage in a systematic scientific approach in order to learn about (in)effective treatments. Both approaches have detractors, in as much as the first group risks using ineffective or

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dangerous interventions, and possibly delaying improvements in our understanding of Covid-19, while the second risks providing placebos to patients who might have benefited from treatment. Looking forward, it would be advantageous to know whether the two groups reflect different beliefs about the characteristics of science and of proven experience, or whether the difference in clinical decision-making is better explained by other things, such as moral outlooks or beliefs. Indeed, the pandemic has highlighted an aspect of our use of science and proven experience disregarded in our original study - intertemporal choice. Confronted with a novel coronavirus, providing placebos to some patients will lead to knowledge that will help future patients, but possibly at the cost of increased morbidity and mortality among the earlier patients. In fact, that is almost inevitably so, assuming we find treatments that work, since the controls in the associated studies will not have benefited from those treatments, at least initially. Given its ubiquity, we will need to consider how the pandemic has affected discussions within the healthcare professions about evidence. Otherwise, the next time we survey clinicians about the epistemology of their professions we may miss an important (and interesting) change in their beliefs.

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Contributory

All contributors are part of the VBE program

NILS-ERIC SAHLIN, Professor, Medical ethics, Lund University

WÄNDI BRUINE DE BRUIN, Provost Professor of Public Policy, Psychology, and Behavioral Science, University of Southern California

јонан вванимавк, Associate Professor in Ethics and Political Philosophy, Malmö University

BARRY DEWITT, Postdoctoral Research Scientist, Carnegie Mellon University

вакисн ғізснноғғ, Howard Heinz University Professor, Carnegie Mellon University

CHARLOTTA LEVAY, Associate Professor in Organizational studies, Lund University School of Economics and Management 110 | CONTRIBUTORY

JOHANNES PERSSON, Professor of Theoretical philosophy, Lund University

FREDRIK STJERNBERG, Professor of Philosophy, Linköping University

NIKLAS VAREMAN, Researcher, Medical ethics, Lund University

LENA WAHLBERG, Associate Professor in Jurisprudence, Lund University

ANNIKA WALLIN, Associate Professor of Cognitive Science, Lund University



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A selection of other publications and reports on VBE related topics and with the participation of VBE researchers

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VBE researchers

sten anttila, Formas јонан вганимагк, Malmö University WÄNDI BRUINE DE BRUIN, University of Southern California ALEXANDER DAVIS, Carnegie Mellon University BARRY DEWITT, Carnegie Mellon University BARUCH FISCHHOFF, Carnegie Mellon University CHARLOTTA LEVAY, LUND University BARBARA MCNEIL, Harvard University JOHANNES PERSSON, LUND University NILS-ERIC SAHLIN, Lund University ROBIN STENWALL, LUND University FREDRIK STJERNBERG, Linköping University NIKLAS VAREMAN, Lund University LENA WAHLBERG, Lund University ANNIKA WALLIN, Lund University



