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Evidence in Health Controversies

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Abstract: Health controversies involve the now-familiar complexities of polylogue: multiple positions, multiple players, and multiple places. A vexing issue that cuts across many health topics is what counts as evidence. Several different expert fields may each try to enforce their own evidence standards, and lay participants (whose well-being depends on any expert consensus that may form) often bring their own distinctive forms of evidence. This presentation examines disagreements over evidence within a series of case studies.

Keywords: Argument, black box, controversy, evidence, expertise, inference methods, health reasoning, polylogue, warranting device

1. Introduction

The term controversy is commonly used to refer to sustained differences of views in which various actors see difference of opinion as an obstacle or a threat to their own goals. Controversies always involve disagreement, but to be recognizable as a controversy, the disagreement must be sustained and (more importantly) consequential for at least a subset of actors. As Venturini (2010, p. 261) puts this, controversies "begin when actors discover that they cannot ignore each other and controversies end when actors manage to work out a solid compromise to live together." Controversies can die down (at least temporarily) even if important disagreements have not been resolved, so long as some arrangement makes it possible for all parties to ignore the disagreements and go on with their individual business. But unresolved disagreements can always bubble up again, or new disagreements can appear, bringing the controversy back to life.

Controversies give rise to arguments that may be simple at first but that become more complex as the participants elaborate their positions in response to all other positions that affect their own goals. Often, exactly what is controversial shifts over time, turning what seemed to be a controversy over one easily specified issue into a controversy over something quite different. These sequentially unfolding displays of reasoning are especially interesting objects for building argumentation theory not only because they generate many, many individual arguments but also because they so often put argumentation's natural normativity on display, as participants seek to enforce one or another conception of reasonableness on other participants (Jackson, 2019).

My particular focus in this essay will be health controversies. A health controversy is a sustained set of disagreements about a practical choice to be made regarding human health. Divergent views on these choices cannot simply be tolerated because the choices to be made have practical consequences. Health controversies generally develop into polylogues (Aakhus & Lewiński, 2017), involving multiple players, multiple positions the players may advance, and multiple places where one position can come into conflict with another. These controversies often involve two or three different expert communities as players, along with policy-makers,

policy-implementers, and ordinary people whose lives and well-being may depend on how component issues get resolved.

Various kinds of evidence (notably, scientific evidence concerning effects of medical treatments, factual claims extracted from public health data, and firsthand personal experience of patients) are obviously central to these controversies. Players with disparate interests and background may also bring disparate standards of evidence, and surprisingly often, health controversies involve serious and sustained disagreements over evidence. Except within homogeneous communities, no sort of evidence has automatic acceptability when offered as a premise in an argument. Disagreements over evidence, though quite common in health controversies, are often among the most frustrating to the participants themselves, who may find challenges to their own evidence as manifestly unreasonable. Generalizing across controversies I have studied in the past, I observe that disagreements over evidence can easily flow into argumentative dead ends (as when one side or another refuses to respond to criticism), but it is also possible for disagreements over evidence to create real opportunities for lasting resolutions of controversy.

In health controversies I have studied, arguments over evidence are extremely heterogeneous. They include (1) what to count as evidence or to deprecate as "non-evidence"; (2) what acknowledged evidence is evidence *for*; (3) how to resolve contradictions between one bit of evidence and another; (4) how new evidence may be generated; and (5) given that the generation of *new* evidence may be possible for only a subset of players, who should decide what evidence to generate. Materials selected for this essay come from three controversies: a very long-simmering and globally significant public resistance to vaccination (Jackson, 2015; Jackson & Lambert, 2016), a brief wave of public protest over AIDS drug trials in the 1980s (Brashers & Jackson, 1991), and a lingering debate over what should be taught in school sex education programs in the US (Jackson, 2007, 2008b). All of these have attracted notice from many other scholars, but in this essay, most of the data and prior analysis comes from my own studies.

For each case study, I begin with brief descriptions of the controversy, describing the circumstances giving rise to the controversy and the specific issues that involve disagreement over evidence. Then, key materials captured from the controversy are discussed in detail, and lessons from the case are briefly presented.

2. MMR vaccination controversy

Vaccination of very small children with the measles-mumps-rubella vaccine has been contentious for almost half-a-century. The practical question at the heart of this controversy is different for different players. For parents, the central question is whether they should have their children vaccinated. For policy-makers (including those responsible for public schooling), the central question is whether vaccination should be a requirement for attending school. For medical scientists, the central question is whether the MMR vaccine is safe and effective. For public health officials, the central question is how to achieve "herd immunity," with a subordinate question being what proportion of the population must be immunized in order to prevent epidemics of these diseases. There are other questions, too, such as who is responsible for vaccine injuries, that involve the pharmaceutical industry and other interests.

A common mistake in thinking about the controversy is to reduce it to a single question: does the MMR vaccine cause autism in previously healthy children? While this is one issue that continually surfaces in the controversy, it is not actually very central. People on the pro-

vaccination side are far more likely to bring up this topic than are people on the anti-vaccination side, with the result that too little attention is paid to people's actual arguments against vaccinating their children. The range of beliefs people actually have about vaccination—the reasons they may refuse vaccinations of all kinds—is explored by Gidengil et al. (2019) in a systematic review of studies that used open-ended questioning methods to discover "beliefs around childhood vaccination." When people talk to researchers about vaccination, they do externalize worry that vaccination may have adverse effects, but also express skepticism about the need for vaccination and distrust of the medical establishment. Refusal of or resistance to vaccination cannot reasonably be attributed to a specific belief that MMR vaccines cause autism, but this oversimplification surfaces constantly in the vaccination controversy.

What Gidengil et al. (2019) found in their systematic review of unstructured interviews and focus groups is even more evident in examination of what people say in their own conversations online. In actual interaction, people externalize all of the classes of beliefs identified in their review, but they also defend these beliefs with new reasoning, and they also regularly construct arguments against how their beliefs are misrepresented by elites.

Macroscope methods used in the study of argumentative polylogues allow researchers to locate and analyze *arguments* people spontaneously produce to try to convince others to their points of view on vaccination, focusing on points of disagreement (rather than isolated beliefs identified as obstacles from one point of view). Using Crimson Hexagon, a commercial tool for social media analytics, I searched 12 years of social media data for posts on MMR vaccine injury (query string: vaccine AND injury AND MMR), finding over 30,000 on various platforms. Crimson Hexagon automatically generates an analysis of topical content and the time trends in mentions of each topic ("topic waves"), as shown in Figure 1. The tallest topic wave represents the most common of the themes identified by the algorithm: "MMR vaccine and autism." But many of the individual posts are repeating the argument that MMR does not cause autism (with very few arguing that it does). Mention of a retracted *Lancet* article by Andrew Wakefield is a standard bit of background invoked in criticisms of "anti-vaxxers"; topic waves involving Wakefield rise and fall with the same peaks and valleys as the "MMR vaccine and autism" wave.

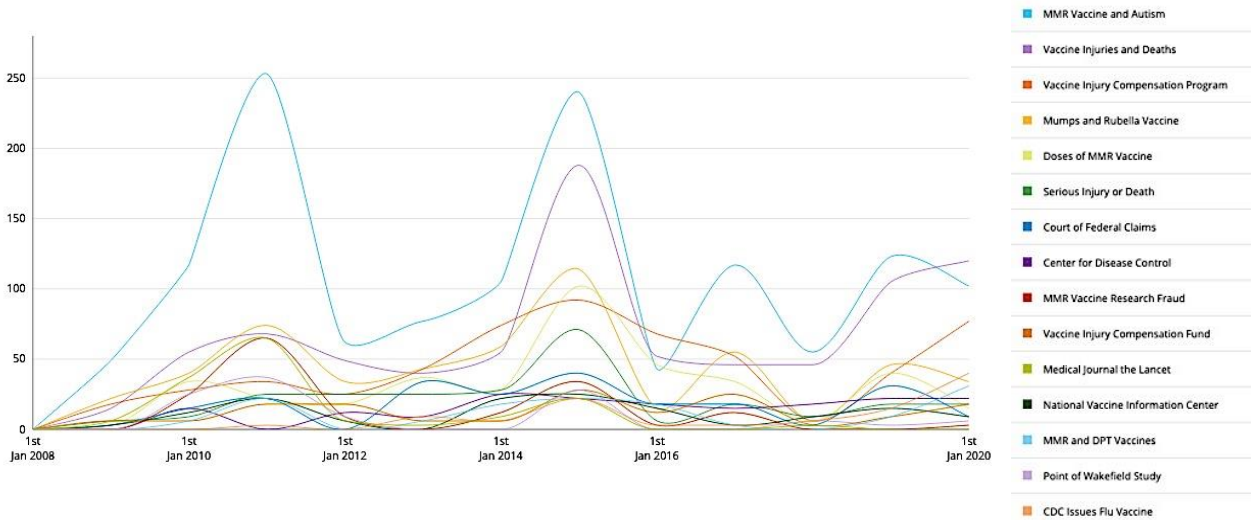

Figure 1. Social media trends in discussion of vaccine injuries; autism remains a common topic of discussion, but mostly because of repeated assertions that vaccines do not cause it.

The centrality of evidence to this controversy is very obvious, but it is far more complex than is normally supposed. On the scientific side, a vast literature has developed around trying to conclusively answer questions about vaccine safety and effectiveness, and regularly, government agencies attempt to evaluate the state of this literature and what conclusions can be drawn from it (Jackson & Lambert, 2015). Scientific papers and consensus reports are read by ordinary citizens and discussed in detail in social media conversations. Andrew Wakefield's infamous *Lancet* paper remains prominent in the discussion 10 years after its retraction because its shift from "evidence" to "non-evidence" of a connection between vaccination and autism so often appears (fallaciously) as evidence that autism is unrelated to vaccination. But the most interesting issue surrounding evidence in this controversy is the furor over what to make of *firsthand observational reports of vaccine injuries*—and it is this issue that led to the specific query I launched in Crimson Hexagon.

Adverse reactions to vaccines are not common, but their infrequent occurrence is openly acknowledged by the corporate, institutional, and clinical players involved in the controversy. Some of these adverse reactions are noted in experimental trials conducted prior to clinical use of a drug, and others are gleaned from post-approval surveillance systems such as the Vaccine Adverse Events Reporting System (VAERS). That vaccines will cause injury in a small percentage of administrations is known, acknowledged, and uncontested.

Firsthand observational reports of children harmed by MMR vaccination should surprise no one who is aware (as all medical professionals must be) that any vaccine may cause injury in a small percentage of cases. And yet, these reports have been given less and less credence over time, to the great wrath of those who had their children vaccinated and were the only firsthand witnesses to their children's reactions. From the medical establishment, the parents of children who (may) have been injured by vaccines *regularly* report that their observations are dismissed and discounted; for example, they may be assured that something bad that happened at about the same time as the vaccination was just coincidence, not an effect of the vaccination.

This is an argumentative dead-end from which no movement toward disagreement resolution can be expected. A parent who has witnessed firsthand a child's reaction to a shot cannot be talked out of this by being told that whatever happened to their child was coincidentally related to the shot. One of the 30,000 tweets retrieved in the Crimson Hexagon search put this well: "Everyone is pro-vaccination - until a flu shot paralyzes their friend or the MMR injures their child or the DTaP kills their granddaughter. Vaxxers are converted to antivaxxers not by Jenny McCarthy or Andrew Wakefield but by the horror of vaccine injury and death."

Social media are not to blame for people's beliefs about vaccination injury, but they do provide a very convenient place for noninstitutional players in any controversy to get themselves organized. Parents who have witnessed their children's adverse reactions to vaccines can share reports on a variety of platforms, and they soon learn that the dismissive reactions they receive from medical professionals are a *standard* reaction that amounts to denial that vaccinations *ever* cause injury. A cross-platform hashtag (#believemothers) has emerged in the past few years as a means of aggregating the experiences of parents who find themselves in this situation.

At the present state of this controversy, claiming to have witnessed vaccine injury draws ridicule, anger, and jeers—and yet it is important for all of us to know if there is some pattern of adverse events. Parental reports of adverse events following administration of a vaccine are regularly described as "anecdotal," meaning that they do not count as scientific evidence of a general pattern, and lately they have been treated as "misinformation" spread on social media.

But individually and collectively, they do count as evidence of something (*not* non-evidence of anything). Escaping the dead-end that has been reached along this path will require a breakthrough of some kind. For example, some progress might be made if doctors were to respond to such occurrences by entertaining the possibility that any one of them might be "one of those rare cases" and working with the parent to document the case for VAERS. In a polylogue, what happens at this most local level of interaction seeps out into all other places where people discuss vaccination; finding a way to see what these reports are evidence *for* is much more promising than continuing to insist that they are not evidence of anything.

3. AIDS drug trial protests

In the frantic early days of searching for drugs to prevent or cure AIDS, a movement formed within the patient population (people with HIV or AIDS) to demand change in the conduct of experiments designed to evaluate the safety and effectiveness of proposed treatments. Initially resisted by the research community, this movement became an exemplar for effective advocacy by those most affected by a disease. This controversy has the nature of expertise as an explicit theme. Activists repeatedly insisted "we are the experts," explicitly called out "expertism," and dared to challenge experts within the experts' own domain. Through sheer argumentative prowess, they showed that they could not be forced into deference.

A prolonged disagreement over evidence pitted AIDS activists against the medical research "establishment." As a point of entry to analysis, I have selected one historically significant document, a manifesto delivered to the Fifth International Conference on AIDS, held in Montreal in June 1989 (digitized copy at https://www.poz.com/pdfs/national-aids-treatment-research-agenda-1989.pdf). Titled "A National AIDS Treatment Research Agenda," and authored by the AIDS Coalition to Unleash Power (ACTUP), the document delivered a devastating critique of the AIDS drug development process in the US. The document did not and does not "stand alone": Before its delivery to the Montreal AIDS conference, much of the content had been worked up in countless earlier meetings between ACTUP and various public health officials.

In analyzing argumentative polylogues, Aakhus and Lewiński (2017) observe that the opposing players in a controversy engage around diverse sites of practical action. In the case of AIDS drug discovery, one such site of practical action is a kind of experiment in which patients are observed after being given experimental drugs under carefully controlled conditions—an arrangement known as a Randomized Clinical Trial, or RCT. The ACTUP document is mostly focused on this site (other sites of practical action being clinical care, drug manufacturing, and a variety of surrounding planning, funding, and regulatory activities).

RCT was (and still is) the core inferential machinery of the scientific community and their institutional and industrial partners; its abstract structure is shown diagrammatically in Figure 2. To the expert community of medical researchers, RCT is an inference tool or "warranting device" applied routinely to generate evidence (Jackson & Schneider, 2018; Schneider and Jackson, 2018, 2019). It is often described as the "gold standard" for causal inference, the top of the "evidence pyramid." But in many health controversies, RCT is a black box (Jackson, 2008a) as far as the public is concerned: an expert mechanism for generating facts that the public is not in a position to question.

In this controversy, the black box is opened and subjected to public critique (Brashers & Jackson, 1991). Of "12 principles for a new AIDS drug testing system" proposed in the ACTUP

document, 7 have to do with aspects of this warranting device: with the design and approval of protocols, with recruitment of research participants, with what should be allowable as a "control" condition in AIDS drug trials, with what to use as an outcome measure, and with what to do with evidence gathered under unblinded conditions (those where physician and/or patient know which drug they have been given). ACTUP did not object to the use of RCTs to generate evidence of drug effectiveness, but argued that modifications in clinical trial design would produce *better* evidence than what was being produced by standard implementations of RCT.

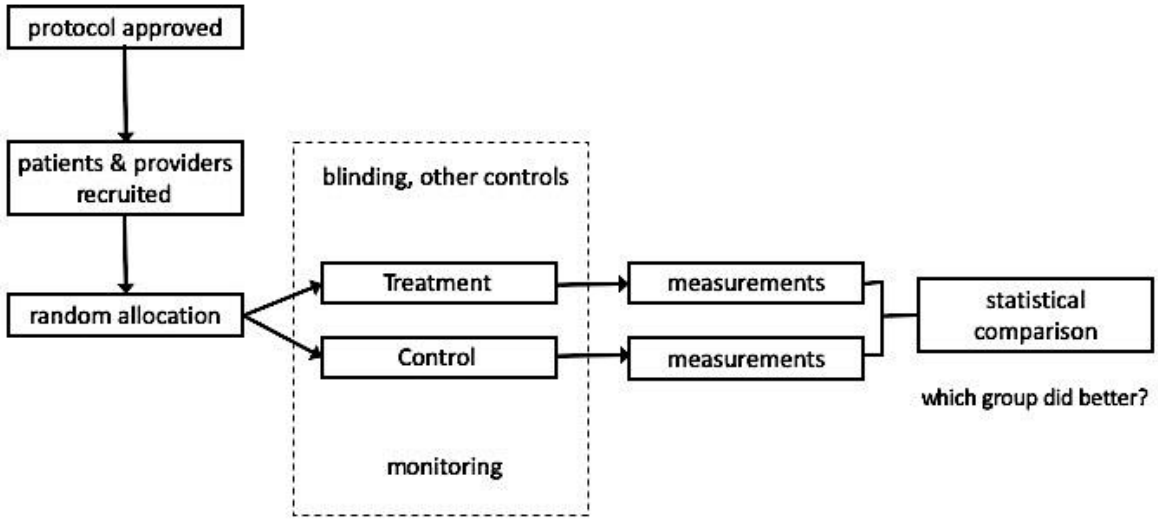

Figure 2. Design of an experiment to generate evidence of drug effectiveness; a "control" used as a point of comparison for the "treatment" may be a placebo or an existing alternative to the treatment being tested.

Early on, ACTUP had formed a group to study clinical trial design and how it was implemented in AIDS research, and through frequent interaction with medical researchers, they soon learned how scientists reasoned about design decisions at every step of the process. This allowed them to call out and attack specific beliefs held within the research community. For example, knowing that many scientists chose treatment vs placebo designs (instead of treatment vs treatment designs) for the supposed clarity of comparison they provide, ACTUP pointed out that patients enrolled in placebo-controlled experiments were often able to guess that they were being given worthless drugs, and those who believed they were being given placebos commonly sought drugs from other sources. From the document (with emphasis added):

> Placebo-controlled trials do not yield quick, clean data. Participants take drugs off trial, obscuring results. Target enrollment is frequently expanded to minimize data contamination from those who drop out or take concurrent medication.

And in case this attack on the actual value of the evidence obtained from these "contaminated" trials was unconvincing, ACTUP pointed out that AIDS patients have the power to kill a trial outright by refusing to enroll:

> No potential trial subject with even a vestigial instinct for self-preservation will join a placebo-controlled trial. If a standard treatment exists, new treatments can be compared to that. If no approved treatment exists, new treatments can be tested against each other.

Finally, ACTUP pointed out that treatment vs treatment comparisons were nearly always possible, and that they provided equal clarity of evidence to support real-world treatment decisions. Subsequently, "usual care" (not placebo) has become the default control condition in all medical research (and much social science research involving health interventions).

With analogous suggestions for patient recruitment and for alternative outcome measures, ACTUP advocated trials "designed for the real world," in language that has since become part of the case for much broader use of pragmatic trials (Schneider & Jackson, 2019). ACTUP also challenged the restrictiveness of the questions being asked by the scientific community (the nearly exclusive focus on the search for antiviral drugs, to the neglect of drugs suitable for treating the many "opportunistic infections" afflicting people with AIDS). Strictly speaking, these are not challenges to the quality of evidence being generated, but to the choice of *what* evidence to generate.

As recalled by Peter Staley in a June 2014 blog post (https://www.poz.com/blog/1989-act-up-aids-treatment-research-agenda), activists "pushed their way into the conference" and "wowed the researchers in attendance." Twenty-five years after that event he reflects, "We had not only demanded a seat at the table, we had earned it." This is the single most important element of the manifesto: insistence that every action affecting people living with AIDS or HIV should involve them as equal partners in decision-making—from writing rules for drug approval all the way to approving research protocols and to the eventual decision about approving a particular drug for use in clinical care. ACTUP argued that this is not just a matter of fairness but a *correction* of research practices that were failing to produce usable evidence of drug effectiveness.

4: Sex education and the politicization of science

A long-lasting controversy in the US centers on what teenagers should be taught about sex. Specific positions within this controversy have evolved greatly over a period of several decades. For some time the controversy focused on whether sex education should be taught as health instruction or as moral instruction: Should teenagers be taught how to avoid sexually transmitted diseases and unwanted pregnancies, or should they be taught that these consequences are the cost of immorality, avoidable through abstinence from sex outside of marriage? Over several decades, new players joined with concerns about whether sex education of both types implied that heterosexuality is normal and other sexual orientations abnormal. With rising public concern over broad patterns of sexual coercion, the controversy now seems to be reorganizing around a new take on whether sex education should involve moral instruction.

The complexity of argumentative polylogues is on full display in this controversy, with continual redefinition of the central disagreement as new issues open around the concerns of newly engaged players. Although this controversy is by no means settled, one of its most interesting moments occurred during the presidency of George W. Bush. The Bush administration used control over federal research and education spending to promote sex education aimed at promotion of sexual abstinence, to the exclusion of content relevant to public

health goals like controlling sexually transmitted diseases. The characterization of this as a "politicization of science" linked this controversy to several otherwise unrelated controversies.

In an earlier analysis (Jackson, 2008b), I examined a sequence of texts bearing on this controversy: a statement issued by the Union of Concerned Scientists charging the Bush Administration with distorting scientific work to align it with political ends; a statement responding to this charge, presented to the US Congress by John H. Marburger III (chief science advisor to President Bush); and a UCS rebuttal to Marburger's response. In brief, the UCS objected to the Bush administration's restriction of federal spending on sex education to "abstinence-only" curricula, when rigorous experimental research had repeatedly shown that such programs were ineffective in preventing STDs and unwanted pregnancies. The UCS charged that the Bush administration was undermining science by refusing to allow schools to use curricula that had been proven effective in achieving these goals. Marburger responded that, contrary to what UCS charged, the Bush administration was actively seeking science-based programs, but that it was funding the search for programs effective in promoting abstinence.

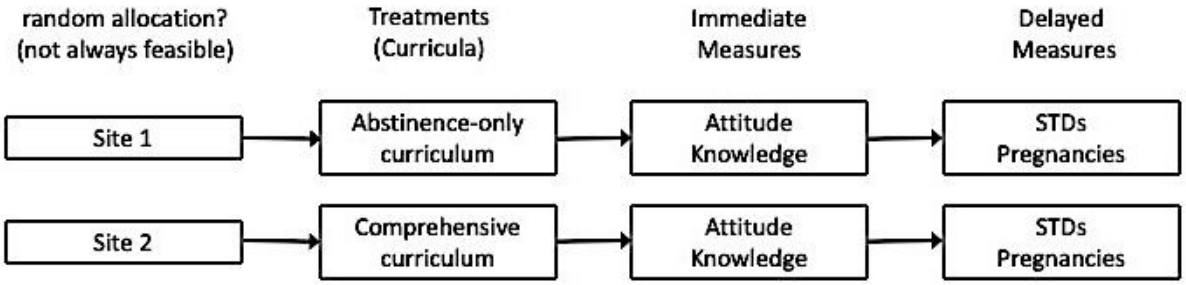

Figure 3. An experiment designed to evaluate the comparative effectiveness of two alternative approaches to school sex education; outcome measures are typically linked to measurable public health objectives that would be achieved (in theory) if either approach were effective.

Research on the effectiveness of sex education curricula uses methods similar to RCTs, with the important difference that randomization at an individual level is rarely possible. At best, different schools, or different classes within schools, can be randomly assigned to treatments, but even this is not always feasible. (This is a well-known threat to validity afflicting much educational research, but it will not concern us here.) Figure 3 shows a rather typical design, in which the dependent measures include both conventional measures of learning and health-related outcomes like reported STDs and reported pregnancies at some time delay from the end of the instructional program. Self-report measures related to abstinence are also sometimes included (e.g., questionnaire items about age of first sexual intercourse).

As in the AIDS drug case, experiments become a significant site of practical action, again involving disagreement on the outcomes used to define success and the "treatments" to be compared. Marburger's response to the UCS calls into question the choices the scientific community has made about these key features of sex education research. First, his argument treats sexual abstinence not as a means to control disease and pregnancy, but as the objective (or *an* objective) of sex education, while the research community tended to evaluate even abstinence-promoting curriculum as a means to other ends. While scientists are certainly best positioned to generate evidence of effectiveness, given a desired outcome, Marburger's point

was that the decision about what goals to pursue does not belong to science. From this point of view, the Bush administration simply set out a goal (to teach moral principles in sexual behavior) and allocated funding for scientific work on how to achieve it.

Second, Marburger strongly implied that the lack of successful abstinence-only curricula (even measured against public health goals) reflected a lack of serious effort by researchers to create curricula aimed at promoting abstinence. In educational research, where alternative curricula are treatments, the team conducting the research must find or devise the materials that instantiate a type of curriculum (e.g., "abstinence-only," "comprehensive," "sexual risk avoidance," etc.). In principle, the team should create the best instantiation they can for each of the contrasting types, but in practice, a team might or might not give equal creative effort to both instantiations. Is it possible that research teams fail to come up with effective strategies precisely because they do not believe in the possibility of persuading teenagers to abstain from sex? At the time of Marburger's statement, there was nothing really unreasonable in the suspicion that ineffective abstinence-only programs were products of self-fulfilling prophecy. Had Marburger been steeped in argumentation theory, he might have simply said that the scientific consensus was based on fallacious ad ignorantium reasoning: assuming that no effective abstinence-centered program can be found because an unmotivated (and even biased) search had not produced one.

Nor did Marburger concede any ground on public health goals that research had found ways to achieve without teaching abstinence. As he pointed out explicitly, public health goals would also be achieved if effective abstinence programs could be found. Lost in the UCS response is the value of finding a *single* effective abstinence program; the Bush administration was not concerned with showing that abstinence programs as a class are effective, but only with finding one approach that actually works well.

In short, Marburger defended the Bush administration as fully committed to science-based policy, but as exercising its rightful authority over setting goals for socially significant scientific research. Scientists control the resources necessary to generate scientific evidence, but if they also substitute their own goals for what most of the public wants to accomplish, they themselves become political actors. The Bush administration readily granted that educational programs should have scientific evidence of effectiveness but insisted that the broader society must have a voice in defining the effects to be achieved. To this day, though, I know of no program of abstinence-only sex education that has actually succeeded in getting teenagers to abstain.

5. Valuing disagreements over evidence

One regular feature of health controversies is that heterogeneous classes of participants tend to treat their own special forms of evidence as having privileged status. Often, opposing groups argue explicitly about what others' reasoning methods miss. So it is hardly surprising that in each of the three health controversies reviewed here, disagreements over evidence figure centrally.

In the vaccination controversy, the wave of anger over treating parent reports of vaccine injury as non-evidence is a reminder that in health controversies, evidence produced by experts is weighed by other players against forms of evidence *that experts themselves cannot produce*.

From the controversy over AIDS drug research, we learn that experts are not *uniquely* positioned to judge even their own expert forms of evidence and reasoning. Non-experts who know something is not right can, with effort, persuade experts that their assumptions about

evidence have been wrong, even while granting that they themselves are not in a position to take over the work of the experts. This latter point is important, because it has often been suggested that AIDS activists *became* experts; but they became interactional experts, not contributing experts, to borrow an important distinction from Collins and Evans (2007).

From the controversy over sex education, we learn that political actors can enforce a public role in decisions about what kinds of scientific evidence are useful in achieving policy goals, but they still cannot force facts to conform with their desires.

In what sense is public pushback positive in any of these cases? In the case of AIDS drug research, pushback from the patient community led to reform of clinical trial design that nearly everyone now recognizes as improvement. In the case of vaccine injuries, the judgment most commonly expressed is that reports of vaccine injuries are a dangerous form of misinformation; but as I have suggested, this is very problematic, and it offers no plausible path out of continued controversy. In the case of abstinence-only sex education, there were certainly better ways for the government to incentivize the search for new ideas, and there were also much better ways for the scientific community to respond; but one clear positive is the reminder that scientific communities should not use their control of the fact-finding apparatus to limit which of an array of policy options are given fair consideration.

Pushing back against expert conclusions and even against the inference devices that lead to these conclusions can have positive effects on the discourse as a whole. Even in the most dispiriting of the cases considered here (the vaccine injury case), those pushing back are looking to science and other forms of expertise for *answers*—clearly acknowledging society's dependence on expertise, even when experts seem intent on silencing them. And if we entertain even the slightest possibility that the medical establishment is missing a significant pattern in reports of vaccine injury, then the current trend toward treating them as non-evidence (as really *nothing* worth investigating) is badly in need of course correction.

6. Closing thoughts

The 2020 coronavirus pandemic has brought unprecedented journalistic attention to society's dependence on experts' work products. The world's struggle to control the pandemic has massively elevated the visibility of the science that provides evidence for the spread of the disease and for choice of methods to manage it. In the US, daily drama surrounds President Trump's extraordinarily fickle attitude toward the experts on whom he (and all of us) depend, generating masses of opinion journalism that directly addresses the importance of letting experts speak their truth.

The topic of this talk was chosen long before these events began to unfold, and my conclusions turn out to be awkwardly timed. One practical implication of what I have to say is that a certain amount of public push-back against expert communities is a healthy part of deliberative discourse, not a sign of derangement. Expert communities that cannot be questioned from the outside are in fact very dangerous. And expert communities are strengthened, not undermined, by public efforts to engage with them *over evidence*. But I cannot make this moderate point at this immoderate moment without also saying that broad, sustained attacks on the overall trustworthiness of science are neither healthy nor helpful. There is particular danger when someone who has no expertise tries push experts aside or allows them in only when convenient.

Pushing back is different from pushing aside, and the events of the past months have helped me to see this difference far more clearly. However, it is still too early (at least for me) to write about that, but I have been gathering data for future analysis.

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