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# Experts and Anecdotes

## The Role of “Anecdotal Evidence” in Public Scientific Controversies

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“Anecdotal evidence” has become a central point of contention in two recent controversies over science and technology (We follow Nelkin (1992, 10) in referring to our cases as controversies over science and technology.) in the United Kingdom and a contact point between individuals, expert institutions, and policy decisions. We argue that the term is central to the management of the boundary between experts and nonexperts, with consequences for ideas of public engagement and participation. This article reports on two separate pieces of qualitative social research into recent UK public risk controversies with the aim of unfolding the processes by which anecdotal evidence comes to be defined. We do not define anecdotal evidence as an epistemic category that exists prior to the public controversies themselves; rather, we aim to show how the term is constructed and contested by expert and nonexpert actors. We find that anecdotal evidence comes to be accepted (albeit in different ways) by the main actors as an epistemic category, yet that it is multidimensional, open to interpretation as subjective reports, as an indicator of expert ignorance, as a source of novel hypotheses and as a set of political claims for recognition and inclusion. We conclude that the flexibility of anecdotal evidence at the boundary between science and its publics can offer opportunities for participation and engagement, as well as exclusion and alienation.

**Keywords:** *anecdote; expertise; lay knowledge; risk; MMR; mobile phones*

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## Introduction

Public claims of symptoms associated with mobile phone use and a developmental disorder in children that their parents believed had been triggered by the measles, mumps, and rubella (MMR) vaccine have brought the meaning of individual experience and the epistemic status of anecdotal evidence to the center of two recent controversies. "Anecdotal evidence" in these cases became a term that served as a focus for doubts and suspicions about the very existence of the syndromes in question, as well as their possible environmental risk factors. This article explores the ways that anecdotal evidence is talked about, rather than treating it as an objectively defined unit of data to be analyzed. To begin with a definition, no matter how broad or narrow, would not only require taking a position on the epistemic status of anecdotal evidence, but it would also obscure its flexibility and thus its usefulness as a focus for analyzing work at the boundary between science and its publics. Our aim is to describe the social processes by which the category of "anecdotal evidence" comes to be constructed and contested by following anecdotes through two recent controversies over science and technology.

Our analysis of the term "anecdotal evidence" is informed by the concepts of boundary work, lay knowledge, and expertise, so we will explore the relations between them before we trace the contestation of "anecdotal evidence" in our case studies. The categories of "expert" and "lay"<sup>1</sup> draw on a distinction between what is internal and external to science, and a central argument in science and technology studies maintains that this distinction is best viewed as a product not of transcendent characteristics or methods, but of "contingent circumstances and strategic behavior" (Guston 2001). A central concern has been to explore the processes of constructing and maintaining the boundary between science and nonscience. This "boundary work" (Gieryn 1983, 782), Gieryn argues, is performed by scientists in their scientific practice, yet by introducing the notion of socially maintained boundaries, the range of actors who contribute to the construction of these boundaries is opened up to include nonscientists. As Gieryn later put it, "[b]oundary-work occurs as people contend for, legitimate, or challenge the cognitive authority of science" (Gieryn 1995, 405). The sociology of science thus brings into focus those people who are exercising "local critiques" as well as those scientists concerned with maintaining the boundary. Activists and social movements have exercised such local critiques in several emblematic case studies of expert and lay knowledge in public controversies over science and technology (see Brown 1995;

Tesh 2000; Brown et al. 2004). The concept of boundary work has been usefully extended to the analysis of the boundary between scientific and political tasks in advisory and regulatory organizations (Jasanoff 1990; Guston 2001). Jasanoff in particular uses the concept to explain the ways in which various actors may be given, or denied, a legitimate voice in the substance of regulatory debates. In this connection, we can think of the term “anecdotal evidence” as a focus of definitional work and, in our cases, political contestation, at the boundary between science and its publics.

Controversies over science and technology can be said to reveal a tension between the scientific search for universal, generalizable knowledge, and more localized forms of understanding, which are rooted in individual experience (Irwin 1995; Irwin and Michael 2003; Wynne 2005). Anecdotes and anecdotal evidence are clearly individual, and thus lend themselves to reconstruction in terms of “subjective” versus “objective” modes of thought. Touraine has argued that the success of modernity lay in its alienation of the subject, the separation of the ordinary person from the instruments of rationality (Touraine 1995, 219). Ulrich Beck has presented a similar analysis: “Experience—understood as the individual’s sensory understanding of the world—is the orphan child of the scientized world” (Beck 1995, 15). In seeking generalizable knowledge, the known takes precedence over the knower, and the subject is left out of the picture (Couch and Kroll-Smith 1997). Lay knowledge, however, must not be understood in terms of individual experience alone. The analysis of responses to environmental problems in particular has revealed the influence of complex social networks as well as everyday experiences on local understandings of those problems (Irwin, Simmons, and Walker 1999).

One way in which lay knowledge can contest the boundaries of scientific knowledge is through the social framing of risk. Lay knowledge here refers to local knowledge of the particular social constitution of the risk situation, concerning which risk analyses implicitly extend their claims. The object of knowledge, the risk situation, is extended beyond the laboratory out into the environment (Tesh 2000). Following this extension of the risk situation, it is clear that lay people can have knowledge of the risk situation that is valid and useful to the analysis of risk, even though it does not necessarily deny the substantive “expert” claims to knowledge in a narrow sense. Social framing can include assumptions about the behavior of people in the risk situation. A good example is the risk analysis of the herbicide 2,4,5-T, which, according to Wynne’s critique, was dependent on some highly unrealistic assumptions regarding the conditions of its storage and use (Wynne 1992, 285). One of the aspects of lay knowledge to emerge from

this example is the knowledge of specific, local conditions, including social conditions, that are not, and indeed cannot be accounted for in general assessments of risk based on "typical" circumstances. The key point here is that knowledge of these particular social conditions must come from the people most intimately involved.

The sense of lay knowledge as local knowledge of a physical and social situation can be extended into the domain of scientific practice itself, the construction and execution of experiments. Feminist work in science studies has contributed greatly to the recognition of embodied knowledge about health and risk, or, in Donna Haraway's term, "situated knowledges" (Haraway 1991), which are produced by lay people on the basis of their location in society. There have been a number of sociological studies describing lay beliefs about sickness and health in terms of individual experiences (Williams and Wood 1986; Calnan 1987). Research into "lay knowledge" has demonstrated that lay people have knowledge of their own bodies (Arksey 1994; Busby, Williams, and Rogers 1997), they have knowledge of how their bodies react to medication (Monaghan 1999), and they have knowledge of the situation in which they live (Popay et al. 1998). "This contribution to knowledge making," wrote Epstein in the conclusion to his study of activism and acquired immunodeficiency syndrome (AIDS) research, "is, in the most direct sense, enabled by the activists' own vantage point: They (or the research subjects they represent) are implicated within the experimental apparatus—they are part of the experiment" (Epstein 1996, 337). Such lay knowledge enables activists to contribute to scientific debates about the design and execution of clinical trials. As with Wynne's example, this sense of lay knowledge is complementary to "expert" scientific knowledge. Again, by virtue of conceiving the experiment beyond the controlled environment of laboratory, the social situation becomes the site of lay knowledge, an expertise that arises from direct experience of the situation at hand.

Such "local" and "embodied" knowledge is often set within a context of expert ignorance. Brown (1990) developed the concept of "popular" or "lay" epidemiology to analyze cases of expert and lay conflict over risk in which nonexperts highlight individualities or susceptibilities that are ignored in expert efforts at population-based models of public health. "Popular epidemiology" describes "a process in which lay persons gather statistics and other information and also direct and marshal the knowledge and resources of experts in order to understand the epidemiology of disease" (Brown 1990, 78). The central feature of popular epidemiology is that lay people direct attention to anomalies, particular cases, and possible

susceptibilities in subpopulations, and drive research and advocate certain types of research design. Such arguments are not just about existing bodies of knowledge; they are also about future patterns of knowledge production.

From the other side of the expert-public boundary, “anecdotal evidence” is a term whose meaning and jurisdiction has largely been defined in opposition to expertise. Lay knowledge arguments from the narrative tradition of social science and medical anthropology actually sharpen the divergence between scientific and patient understandings of illness, disease, and risk. Narrative studies of how nonexperts realize their condition serve, along with popular epidemiology, to strengthen the distinction between certified experts and nonexperts. A recent analysis of a contested illness, Multiple Chemical Sensitivity, addresses many of these concerns within the narrative tradition of medical anthropology and sociology of the body (Kroll-Smith and Floyd 1997). This book illustrates the construction of self-identity and embodied practical knowledge around an illness (or body of illnesses) that has scant expert recognition. But, because it focuses on the lay understandings of illness, the study does not address categories such as “anecdotal evidence,” traditionally constructed by expertise. In this article, we aim to develop such thinking by looking at the expert construction of anecdotal evidence. This allows us to consider the underlying tension and renegotiation of identities that takes place when evidence is classed as “anecdotal.”

We have followed anecdotal evidence through two recent UK public scientific controversies: Over risks to health from mobile phones and the MMR vaccine. The case studies were developed independently by the authors. Yet, they exemplify the same problem of the negotiation and accommodation of the individual within expert scientific regulatory and governmental structures, and suggest contrasting ways of constructing and handling the concerns of increasingly active, articulate, and politically engaged “citizen scientists.” We therefore maintain that these two cases can provide an instructive comparison of the ways in which evidence that comes to be known as “anecdotal” interacts with expertise. The case studies will show the emergence of nonexpert claims, and then detail the ways in which those claims were ignored, rejected, welcomed, or altered in their encounters with official experts, focusing on the contribution of expert and nonexpert actors to the negotiation of the meaning and status of anecdotal evidence.

The mobile phones study (conducted by the second author) is based on documentary research and interviews with scientists and advisory scientists who contributed to public discussion about the health risks of mobile

phones. The research covers the period up to 2003. Interviews focused on expert constructions of scientific uncertainties and "the public" and included questions about the nature, source and desired role of "anecdotal evidence" in a public scientific controversy. In the MMR case study, the author focused on the scientific claims made by MMR-critical activists and their interaction with official experts in the period up to and including 1998. This second case draws on analysis of policy documents, Internet and printed campaign literature, and a small number of interviews with activists and government experts.<sup>2</sup> This case study shows the development of parents' initial claims and their subsequent contestation in encounters with experts, exemplified by a report from an expert group convened by the Committee on Safety of Medicines (CSM) early in 1998 to review the claims made by the MMR-critical activists.

## **Anecdotal Evidence and Mobile Phone Risks**

The public controversy around mobile phone risks was borne from something that we might call an anecdote. The first suggestion of harm from a mobile phone which received global attention was a single story of a man in America who decided to sue a mobile phone company in 1992, blaming his wife's brain tumor on her exposure to mobile phone radiation. The publicity granted to David Reynard's story caused a large dip in the stock market value of American mobile phone manufacturers. In 1995, a federal judge had ruled that the evidence submitted in the Reynard case was not "scientifically valid,"<sup>3</sup> but by this time, the controversy was well under way, and was about to cross the Atlantic, where it began to excite UK newspapers in 1996 (Burgess 2004).

Newspaper reports warning of mobile phone risks tended to focus on new studies which revealed worrying effects, supported by stories of individuals who attributed their symptoms (from sleep loss, through epileptic seizures, to brain tumors) to their mobile phone use. Such stories typically juxtaposed this news against reassurances from scientists or industry representatives that the overwhelming weight of scientific evidence supported the regulatory position that current exposure guidelines prevented any risk to health.

As has been described elsewhere (Stilgoe 2005, 2007), the late 1990s saw a surge in the number of enquiries to industry and, in particular, to the National Radiological Protection Board (NRPB), expressing concern about

the health effects of mobile phones. These tended to be met with the response that there existed a well-supported, science-based set of guidelines in place to protect against the known hazard (overheating) of exposure to electromagnetic fields (EMFs). In many cases, these concerns were supported by symptoms experienced by mobile phone use or long-term proximity to mobile phone base stations. The NRPB, knowing that such symptoms should not have occurred at exposures below guideline levels, offered reassurance that all mobile phone technology complied with its guidelines (Stilgoe 2005).

The NRPB considered itself a scientific organization, charged with formulating advice based on the best-available scientific evidence. It therefore saw such “anecdotal evidence” as outside its remit, possibly even in direct opposition to its work. When asked about what the term meant to him, one of the NRPB’s scientific advisors replied:

“That’s why you have science. It’s to avoid anecdotes. It may be sensible in sociology, but if you want to know whether X causes Y, the fact you can find a person who has X and Y isn’t evidence.” (Interview transcript, No.5)

This construction of anecdotal evidence sits well as an example of boundary work (Gieryn 1983), used to define what science is, or rather what science is not. Science is not subjective, it is not individual, it is not localized to a particular health scare, and it is not presented by nonscientists.

However, it is interesting to note that this boundary around monolithic, consensual science was not shored up only by experts. Aggrieved nonexperts similarly used a strong construction of science and its rejection of “anecdotal evidence” to highlight what they saw as the many failings of the regulatory orthodoxy. The NRPB represented the public face of scientific risk assessment, and they rapidly acquired a reputation among interest groups and members of the public for arrogance in their framing of the issue as a scientific one with a well-established evidence base and a set of relevant questions. Much of the antipathy directed toward the NRPB originated from those whose symptoms, knowledge claims or concerns had been rejected. With the start of public controversy over mobile phone risks, public engagement was defined, at least in part, by the negotiation of the role of anecdotal evidence.

Some of the people who had associated their symptoms with mobile phone use gathered under the umbrella term “electrosensitivity,”<sup>4</sup> a supposed hypersensitivity to weak EMFs. As with other recent contested illnesses (Gulf War syndrome, chronic fatigue syndrome, etc.), scientists

and sufferers disagree over the etiology of symptoms and the relative importance of population studies and individual cases. But the continued scientific rejection of this illness was seen by many sufferers as evidence of the obstinacy of organizations such as the NRPB in investigating areas of scientific ignorance. In 1999, the House of Commons Science and Technology Select Committee conducted the first public UK investigation into the provision of scientific advice on mobile phone risks. By this time, the NRPB's reputation for its narrow framing of the issue had crystallized among concerned members of the public. One advocate of research into electrosensitivity presented a memo to the Select Committee in which she summarized the sentiments that many groups felt over the past behavior of the NRPB:

"The NRPB has failed miserably to recognise this condition when setting standards for exposure. Their position that there is "no scientific evidence" to back up the existence of Electrical Sensitivity is untenable due to the fact that they and other scientific bodies have not set up any kind of relevant research program."<sup>5</sup>

One NRPB scientist, discussing a recent confrontation with a vociferous group of people who claimed to be electrosensitive, explained the problem of addressing such concerns while remaining "science-based":

"We accept the symptoms are real, we believe that they are real, and then we say well, scientifically, we cannot help you, we can't do legislation, we can't write guidance based upon what is largely, or totally, anecdotal evidence, a few individuals here and there." (Interview transcript, No. 32)

The NRPB's boundary work could not accommodate anecdotal evidence within its construction of "science," so anecdotal evidence became "politics." But the people whose symptoms were being ignored were making epistemological as well as political claims. They claimed to know about (their own) novel symptoms in a way that was overlooked by orthodox science. People experiencing such symptoms were able to find greater comfort by aligning themselves with unorthodox knowledge. Manufacturers of protective mobile phone "shields," whose market depended on such concerns and, to an extent, upon a public dislocated from scientific advice (Jasanoff 1997), joined the advocates of anecdotal evidence. The Web site of "Microshield" warned: "*Anecdotal evidence: Ignore it at your peril!*"<sup>6</sup>

The image of "anecdotes as nonscience" served a purpose for all actors. It polarized the debate, sharpened distinctions, and allowed either side to

construct a target. But it does not fairly reflect the more considered opinions held by most of the scientists in the debate. The mobile phones health issue was the stage for negotiations between experts and nonexperts, including negotiation of the role of different classes of evidence. As such, the more interesting contested territory is revealed when anecdotes are viewed alongside science, rather than in simple opposition. More recent developments in the mobile phones health debate show us the complications of the boundary work treatment of anecdotes. And we also begin to see the transformation of anecdotes as they pass into scientific discourse.

### The IEGMP

By 1999, the credibility of the NRPB in handling the public context of mobile phone risks had plummeted (Stilgoe 2005). Different understandings of the value of anecdotal evidence between nonexperts, and the NRPB played a significant part in the collapse of public trust. In 1999, a new, independent group was set up and given a broader remit:

“To consider present concerns about the possible health effects from the use of mobile phones, base stations and transmitters, to conduct a rigorous assessment of existing research and to give advice based on the present state of knowledge. To make recommendations of further work that should be carried out to improve the basis for sound advice” (IEGMP 2000, 11).

The Independent Expert Group on Mobile Phones, chaired by Sir William Stewart, became the new site for public engagement with expertise, and the new site for negotiation of the role of anecdotal evidence. From the conclusions of the Science and Technology Select Committee, their own (poorly attended) public meetings and evidence sought from nonscientists, the group began to see the contested scientific and policy territory. One of the members offered an explanation of “anecdotal evidence” in the context of his group’s work:

“The great problem that the committee felt was that every time there was some evidence coming up of adverse effects, the first thing that the NRPB said was “was it . . . peer-reviewed?” Now, because it’s not peer-reviewed doesn’t mean to say it hasn’t got some substance to it . . . anecdotal evidence and non-peer reviewed evidence often leads to pointers about the type of research that needed to be done . . .” (Interview transcript, No. 30).

At a public meeting in Liverpool, a woman asked the IEGMP about one of the many news items that had suggested new hazards from mobile phone use.

"There's anecdotal evidence about the part of your body that it's actually held against. I've seen some evidence on television."

Sir William Stewart responded by making clear the group's intentions, distancing himself from the NRPB's style of scientific advice:

"You see, the sort of question you're asking is the sort of question we want to find more about, and basically what you're raising tonight is that you're raising an issue, which you consider to be important."<sup>7</sup>

Within the citadels of expertise, "anecdotal evidence" had, by the time of the IEGMP's formation, begun to stand for people who associated their symptoms with exposure to mobile phones or their base stations. An NRPB scientist defined "anecdotal evidence" like this:

Well, that will be people saying, oh, I use my mobile phone and I get a headache. There are people who say all sorts of claims about how mobile phone masts affected [them and their] children. [People claim] there are children with learning difficulties due to a mobile phone mast being put up. So that's the anecdote. (Interview transcript, No. 21)

The "evidence" from such people was, for many experts, inseparable from the people themselves. Again, the contrast with science and its norms of disinterestedness and impersonality is marked.

Much of the evidence heard and read by the IEGMP has a narrative structure, detailing the circumstances of individual exposure, injury, and illness. The suggested causality of symptoms is concurrently environmental and political. These "anecdotes" fit with Brown's analysis of people engaged in "popular epidemiology" attributing disease not just to exposures, but also to the social structures that made such exposures possible (Brown 1990). This type of evidence has a narrative structure, but it also acts as testimony. As Judith Herman describes, "testimony has both a private dimension, which is confessional and spiritual, and a public aspect, which is political and judicial" (Herman 1992, 181). A significant feature of such testimonies is a narrative of unjustified rejection by expertise. One woman at an IEGMP meeting put forward her point of view:

“In July of this year, my husband was diagnosed with brain cancer. Who is gathering all this anecdotal evidence? Because it seems to me until people start gathering this in some proper scientific evidence, various people for various reasons will continue to talk about anecdotal evidence, and so wriggle out of it.”<sup>8</sup>

To the IEGMP, it was clear that “anecdotal evidence” had come to represent a body of claims, scientific and political, encompassing issues of trust, control, scientific uncertainty, public engagement, and the distribution of risk. In the group’s attempts at reestablishing some public credibility for scientific advice, it was therefore only partly a surprise to find the following pair of recommendations in the group’s report:

Paragraph 1.70 We recommend that in a rapidly emerging field such as mobile phone technology where there is little peer-reviewed evidence on which to base advice, the totality of the information available, including *non-peer-reviewed data and anecdotal evidence, be taken into account when advice is proffered.* (emphasis mine)

Paragraph 1.58 We recommend that a substantial research programme should operate under the aegis of a demonstrably independent panel. The aim should be to develop a programme of research related to health aspects of mobile phones and associated technologies. This should complement work sponsored by the EU and in other countries. *In developing a research agenda the peer-reviewed scientific literature, non-peer reviewed papers and anecdotal evidence should be taken into account.* (emphasis mine)

The inclusion of the term “anecdotal evidence” in these recommendations reveals the distance the IEGMP desired between its reconstruction of knowledge and advice about mobile phone risks, and the more rigid, “science-based” construction maintained by the NRPB:

“Anecdotal” is often used pejoratively. We didn’t mean it pejoratively.” (Interview transcript, No. 20 [IEGMP member])

The IEGMP realized the political weight that had accumulated around anecdotes. Rebuilding dialogue therefore required addressing the issue of anecdotal evidence in scientific advice. But the epistemological claims of anecdotal evidence were less-easily formalized. The latter of the above recommendations initiated the Mobile Telephones Health Research (MTHR) program, which provided a new site for the negotiation of the relationship

between science and anecdote. And it is the MTHR program that provides the clearest indication that anecdotal evidence can perform epistemological roles more interesting than simply "nonscience."

The broad research remit of the MTHR program has led to some novel research projects, the product of public arguments about what counts as relevant questions for science. Public concern, represented by many advisory scientists as "anecdotal," had crystallized around two issues: The possible sensitivity/vulnerability of a subgroup of the population and the possible effects of exposure from base stations. Public meetings of the MTHR committee were the stage for arguments about what types of science would be useful, persuasive, and credible. Nonexperts argued that the public were not interested in in-vitro experiments. They wanted experiments which studied the effects, on humans, of the kinds of exposures being experienced in normal life.

After its third call for proposals, the MTHR program announced, in March 2003, the funding of a pair of studies which were prompted by evidence that had come to be regarded as "anecdotal." One study would investigate whether symptoms experienced by mobile phone users was linked to EMF exposure. And an epidemiological study would look at childhood leukemia and other cancers around base stations. The press release announcing the studies emphasized that the research was directly addressing public concerns.

- "An epidemiological study of early childhood leukemias and other cancers near to mobile phone base stations."
- "A study to investigate whether exposure to radiofrequency signals is linked to symptoms reported by mobile phone users."

The MTHR chair, physicist Lawrie Challis, was quoted in the press release justifying these new studies according to the high levels of public concern about base stations and electrosensitivity.

In arguments about the risk or safety of mobile phones, there was no file of evidence marked "anecdotal." What, or who, counted as anecdotal was defined along with the controversy. The term meant different things to different people. Scientists used it to define the boundaries of science, or to discuss the problems of weighing evidence in controversial areas. Non-scientists typically regarded anecdotal evidence as multidimensional. It represented evidence of scientific uncertainty about, for example, unexplored effects or worrying new illnesses. But it was also evidence of the inadequacy of regulation, the obstinacy of the scientific establishment or the

lack of engagement between experts and the public in previous discussions. The claims with which it is associated are thus both epistemological and political. The woman quoted earlier, whose husband had a brain tumor, gave meaning to her situation by ascribing a dual medical and political causality to illness. And she emphasized the importance of anecdotal evidence in addressing the questions that concerned the public. This is one example of the use of anecdotes that suggests they have much to tell us about the tensions of authority and credibility inherent in doing public science.

### **Anecdotal Evidence in the MMR Controversy**

In February 1998, a press conference was called at the Royal Free Hospital on the eve of the publication in the *Lancet* of Wakefield et al.'s (1998) paper "*Atypical lymphoid-nodular hyperplasia, nonspecific colitis, and pervasive developmental disorder in children.*" The paper presented a study of "the link between the bowel and the brain in autism" (Murch Thomson, and Walker-Smith 1998), and mentioned MMR only as a potential environmental risk factor.<sup>9</sup> The study itself "did not prove a causal association between MMR vaccine and the syndrome described" (Wakefield et al. 1998). The reason for suspicion of a link with MMR was the reported temporal association of the vaccination with the disease symptoms by eight of the twelve parents of the children in the study group. Questioned at the press conference about the consequences of the research, Dr. Wakefield declared: "One more case of this is too many," referring to the behavioral and bowel disorders that gave the paper its title. "It's a moral issue for me and I can't support the continued use of these three vaccines given in combination until this issue has been resolved" (Deer 2004). The paper was presented by the press as suggesting a link between MMR and autism. MMR uptake declined following the publication of the controversial study. It is currently around 86%, well below the 95% required for herd immunity.<sup>10</sup>

This case study focuses on the early construction and contestation of anecdotal evidence.<sup>11</sup> It does not attempt to provide a microsociology of the handling of anecdotes in clinical settings and their effect on parental trust and risk communication,<sup>12</sup> or on parental attitudes and beliefs regarding the MMR vaccine.<sup>13</sup> Although the publication of Wakefield et al.'s paper is generally taken to be the origin of the controversy (Hobson-West 2003; Horton 2004), their paper drew on research conducted over a number of

years, in which the parents played a significant role. Parents did not simply identify a problem and submit it to medical science, rather they actively shaped the production of new scientific knowledge claims. This point is important because the role of parents was directly addressed in the later construction and assessment of "anecdotal evidence" by government experts. The presentation of the case will thus begin by showing the way in which the contestatory scientific claims about the MMR vaccine were produced by parents and a small group of clinical researchers. It will then detail the official expert response to this particular construction of anecdotal evidence in the form of the Medicines and Healthcare Products Regulatory Agency (MHRA) report to the CSM.

Anecdote, observation, and subjective experience were the origin of the first claims of a link between the MMR vaccine and some form of autism. In the early 1990s, following the introduction of the combined MMR vaccine in the United Kingdom in 1988, a number of children experienced unusual symptoms, and their parents became concerned that the MMR vaccine could have caused them. Jackie Fletcher, founder of the campaign group Justice, Action, Basic Support (JABS), was one of those parents. Fletcher's son was given the MMR vaccination in November 1992. Exactly ten days later, he "reacted quite badly" and was hospitalized, and now still has severe epilepsy, lost his speech and developed an immune system problem (Interview transcript, No. 4).<sup>14</sup> At the Royal Manchester Children's Hospital, Fletcher met Gill Dean, whose daughter had suffered similar problems to those of Fletcher's son, and who had also been told that the event was rare and coincidental, and nothing to do with the vaccine. Indeed, the doctors—"anyone with a white coat we met in hospital," as well as Fletcher's general practitioner—were curtly dismissive. They "all kept saying, no, the vaccine couldn't cause that kind of problem" (Interview transcript, No. 4). The parents' claims of a novel syndrome and an association with the MMR vaccine began to crystallize at this early stage. One of the first things JABS did was to systematically gather anecdotes from the families that had contacted them. This carries strong echoes of the "popular epidemiology" carried out by Lois Gibbs in the case of Love Canal in the United States of America (Tesh 2000, 31) and the activists described by Brown (1995) in the case of pollution in Woburn, Massachusetts. The parents would be sent a questionnaire to detail their experience, inviting parents to tell their own stories. "We didn't provide tick-boxes to fill in, it was literally 'here's an empty page, tell us what happened to your child'" (Interview transcript, No. 4). The questionnaires reported effects including epilepsy, meningitis, and autism.

Parental experience and observation at this point formed the basis of the scientific claims. Yet, these claims developed further through the involvement of the activists with a lawyer and a scientific research group. Some of the parents gathered together by JABS took up a legal action against the vaccine manufacturers. This began in the early 1990s—Richard Barr, a solicitor representing the parents, says parents first started coming to him reporting vaccine damage in 1992, after a booster campaign, and in September 1994 more than a hundred families who blame their children's deaths or injuries on the MMR vaccine won legal aid for Barr's firm to investigate a claim for compensation (Dyer 1994). Fletcher first encountered Dr. Wakefield, she says, in the spring of 1995. JABS began suggesting that parents of children with autism and bowel complaints ask their General Practitioners to refer them to Dr. Wakefield at the Royal Free Hospital unit for investigation and treatment (Interview transcript, No. 4). Thus, initial parental suspicions had led, through a process of social networking, to the production of scientific knowledge claims, in the form of Wakefield et al.'s (1998) paper.

### **Expert Response: Putting Anecdotes in Their Place**

In June 1999, the CSM published a Report of the Working Party on the MMR Vaccine, produced by a working party formed early in 1998<sup>15</sup> to examine the information gathered by the groups of parents and assess their scientific claims. This review focused tightly on the suggestion that MMR or MR vaccine may be a contributory factor in the conditions identified by JABS and Dawbarns solicitors.<sup>16</sup> During 1996 and 1997, Dawbarns solicitors had informed the Medicines and Healthcare products Regulatory Agency (MHRA) that they had received more than five hundred reports of children who had developed autism, Crohn's disease, or similar disorders after immunization with the MMR vaccine. In 1998, the CSM recommended the formation of an ad hoc Working Party

“to assess these parent reports together with medical evidence received from GPs and specialists” (MHRA 1999, sec. 1.2).

In an echo of the original action undertaken by JABS, the Working Party sent questionnaires to the parents via the solicitors. Yet, in contrast to the work done by activists,

"further questionnaires were sent to the doctors (the GP and at least one specialist) who had cared for these children" (MHRA 1999, sec. 1.1), in order "*to validate information received from parents.*" (MHRA 1999, sec. 1.1; italics mine)

The parental claims reported in the 1998 Lancet paper drew two main criticisms from the CSM's scientific expert group: That they were subject to bias; and that they may be products of suggestion. Their report emphasized that these methodological weaknesses arose from the way in which the cases had been brought together.

"The children had been brought to the notice of the solicitors because of a reported association between the administration of MMR or MR vaccine and the appearance of certain symptoms and signs. They were not a randomly selected or population-based group and there were no controls" (MHRA 1999, sec. 1.3). Furthermore, "*there was frequent divergence between parents and doctors regarding specific details of the illnesses.*" (MHRA 1999, sec. 5.2; italics mine)

The report concluded with a firm rejection of the claim that there was a new condition of autism and bowel disease, and thus also a rejection of the association of this condition with vaccination. On the question of anecdotal evidence and listening to parents, Dr. Peter Dukes, research strategy manager at the Medical Research Council, declared:

"Lots of people have heard about a possible link with MMR, so if you ask them the cause of their child becoming ill, one of the things they are going to think about is MMR." (Watson, *The Independent*, 28 June 2002)

A study published in the *British Medical Journal* in 2002 supported this suspicion, declaring that "a review of each record showed that in 13 children the history given by the parents had changed after the extensive publicity about MMR vaccine and autism" (Taylor et al. 2002, 396). This criticism of parental anecdotes was echoed in the wider scientific and medical community. A report on a meeting entitled MMR: Learning Lessons, hosted by the Science Media Centre (SMC) in May 2002, complained that

"much of Wakefield's research (and indeed the media) treated the parents of autistic children as experts on the disease, rather than as experts on the *symptoms* of the disease" (SMC 2002, 7).

“Anecdotal evidence” became a focus of the heated political debates between MMR-critical actors and various public health officials and medical scientists. Andrew Wakefield wrote an “author’s reply” (separate to the reply of his co-authors)<sup>17</sup> to the *Lancet* shortly after publication, which reveals a striking, and already politicized, concern for anecdotal evidence. Wakefield’s response began:

“Our publication in *The Lancet* and the ensuing reaction throws into sharp relief the rift that can exist between clinical medicine and public health. Clinician’s duties are to their patients, and the clinical researcher’s obligation is to test hypotheses of disease pathogenesis *on the basis of the story as it is presented to him by the patient or the patient’s parent*” (Wakefield 1998, 905; italics mine). Parents have said “my child has a problem with his/her bowels which I believe is related to their autism”. Hitherto, this claim had been rejected by health professionals . . . “[but] [t]he parents were right”. He continued, “this is a lesson in humility that, as doctors, we ignore at our peril” (Wakefield 1998, 905).

The MMR-critical scientific claims asserted the importance of a purported susceptible subgroup, and argued that the appropriate methods for investigating such a subgroup were not the same as those appropriate for investigating a more general causal relation. David Thrower, of *The Informed Parent*, wrote in the *Lancet* that “careful review of the numerous epidemiological studies . . . exposes each one as flawed, with unsupported assertions, questionable hypotheses, and overstated outcomes” (Thrower 2004). Thrower, in the same letter, criticizes one epidemiological study on the grounds that “[n]o children were clinically examined, and no parents interviewed” (Thrower 2004).

Anecdotal evidence was understood by MMR-critical actors as supporting claims of expert ignorance, in that it pointed to the existence of a new syndrome. They regarded it as indicating the presence of a hypothetical vulnerable subgroup and they drew on this understanding of anecdotal evidence to support calls for new research and a particular research design (clinical rather than epidemiological studies). In a broader sense, anecdotal evidence exemplified claims for inclusion and crystallized the impression that the parents were not being listened to. The official response adopted a clear and narrow definition of anecdotal evidence as subjective reports, which they regarded in this instance as products of suggestion and bias. This narrow definition served to invalidate the assertion of the existence of a new syndrome, and thus to foreclose any accommodation of the broader demands in terms of shaping future research agendas and research designs,

and ultimately to exclude parental voices from engaging in the scientific policy debate.

## Conclusions

"Anecdotal evidence" was used in the mobile phones case to demarcate the boundaries of science. It was situated in a hierarchy of evidence and held to be subordinate to epidemiological and population studies. Yet, there was an eventual acceptance of anecdotal evidence as a guide to the investigation of new hypotheses along lines identified by the lay actors. Although clearly skeptical of the scientific plausibility of the anecdotal claims, the experts came to take the anecdotes seriously on grounds that they represented public concerns, and on those pragmatic grounds ought to be acknowledged and addressed through research programs. This could be interpreted as maintaining a distinction between "public concerns" and "real risks." But, it also admits public involvement in the development of research programs to address risks as they are experienced by various publics.

The MMR case shows a similar expert assessment of the epistemic status of anecdotal evidence, using it to demarcate the boundaries of science. The MHRA report shows that anecdotal evidence was understood to mean subjective reports. It was framed in terms of a hierarchy of evidence, and evaluated according to its usefulness in addressing particular questions of causality. The expert treatment of anecdotal evidence in our cases diverges, however, on the matter of lay involvement and accommodation of anecdotal claims. In both cases, the lay actors regarded their anecdotal evidence as grounds for further investigation of their conditions and the environmental factors that they had identified. Yet in the MMR case, parental calls for more research and particular kinds of research design were rejected, principally on the grounds of the vulnerability of anecdotal evidence in this case to misreporting, suggestion, and bias. The value of anecdotes as an indicator of expert ignorance, and as a source of potential issues for further investigation was complicated by the fact that research had already been conducted on cases brought together by networks of parents who, in association with a researcher, had already developed working hypotheses and a case definition for a putative new syndrome, and had used the media to bring attention to their work. The selection bias and the suggestion that undermined the value of the anecdotal evidence in the estimation of the expert working group were a direct product of the "popular epidemiology" done by the parents.

It is possible to interpret these cases in terms of concepts of lay knowledge such as popular epidemiology, focusing on the epistemic character of the claims made by groups of lay people and the ways in which they collaborate with experts and engage with the research process. Yet, we did not attempt to define anecdotal evidence as an epistemic category. We examined anecdotal evidence as a site for contestation and negotiation between experts and lay actors in public scientific controversies, and we have shown that the lay claims that can fall under the term anecdotal evidence have both epistemic and political dimensions. Anecdotal evidence can represent epistemic claims in the form of assertions of the existence of a particular syndrome and its possible environmental risk factors, yet it can at the same time represent political claims for inclusion in policy debates or regulatory processes, in the form of shaping research programs, demanding policy change, or calling for studies of putative new phenomena and for particular research designs. Anecdotal evidence is a contact point between individuals, expert institutions, and policy decisions, and displays a flexibility between epistemological and political domains that can offer opportunities for participation and engagement, as well as exclusion and alienation.

This has consequences for ideas of inclusion and participation, which are becoming predominant in public science debates. In contemporary democratic societies, expertise must be both authoritative and credible, and public engagement is no longer optional (House of Lords Select Committee on Science and Technology 2000). At some stage, therefore, experts and decision-makers must manage the claims made by nonscientists in public controversies. In this article, we showed that constructions of “anecdotal evidence” provide a touchstone for expert opinions of the adequacy of scientific knowledge and lay contestation of the boundaries of that knowledge. The contrasting handling of anecdotal evidence in our cases suggests that there is quite a wide scope for authorizing lay voices in a scientifically defined policy or regulatory debate, providing opportunities for the inclusion of lay voices (in the case of mobile phones) or their exclusion (in the case of MMR). The flexibility of the term “anecdotal evidence” at the boundary between science and its publics offers possibilities for addressing epistemic and political claims, both of which are vital for the responsible management of public controversies over science and technology.

## Notes

1. The distinction between expert and lay is in practice far from clear-cut. “Experts” in our cases may also be parents of children who are to be vaccinated, and they may be users of

mobile phones. "Lay" people can acquire specialist knowledge and become experts themselves (see Collins and Evans 2002). Also, one might be an expert in one scientific subdiscipline but not another. Referring to the measles, mumps, and rubella (MMR) case, Lindsay Prior wrote that Dr. Wakefield, although expert in gastroenterology, had no expertise in epidemiology. Drawing on Collins and Evans' distinction between license and expertise, she described Wakefield as a "licensed nonexpert" in matters of epidemiology (Prior 2003, 52-3).

2. Interviews played a smaller role in this study than anticipated, because very few of the prominent actors in the controversy agreed to be interviewed.

3. The judge in this case followed the precedent set by the landmark *Daubert vs. Dow* case. For an insight into the importance of this case to the assessment of science (and "junk science") in the courtroom, see Solomon and Hackett (1996).

4. ... also referred to as "electrical/electromagnetic hypersensitivity" or "microwave sickness."

5. Memorandum submitted by Ms. Sarah J. Scott to the House of Commons Science and Technology Select Committee, 23 June 1999.

6. Microshield "Symptoms" page, <http://www.microshield.co.uk/~symptoms.html> (accessed September 23, 2003).

7. IEGMP, Open Meeting, Liverpool, December 9, 1999, Transcript.

8. Trudy Clarkson, IEGMP public meeting, Liverpool, December 9, 1999, Transcript.

9. Specific claims that thiomersal, a mercury-based preservative used in many vaccines, is responsible for developmental disorders, which are currently the focus of vaccine-critical activism and some autism research advocacy work, were not central to the early formation of anecdotal evidence presented in this case study. Autism is just one of a number of conditions put forward by parents in connection with the MMR vaccine, and the MMR vaccine is just one of a number of causes put forward by autism campaigners (see Jane Gross and Stephanie Strom 2007).

10. According to the most recent communicable disease report (CDR) weekly published by the Health Protection Agency, the proportion of children in the United Kingdom in the period July to September 2006 who received their first MMR vaccination at 24 months stands at 85.9% (<http://www.hpa.org.uk/cdr/pages/immunisation.htm>, accessed June 19, 2007).

11. This presentation of the case is not concerned with the wider role of autism activist groups such as Autism Speaks, Safe Minds, and others in funding autism research, constructing clinical research networks, developing new empirically based therapies (for which, see Silverman and Brosco [2007]).

12. Trust has become a prominent conceptual tool in attempts to understand how people respond to risk within social networks (Brownlie and Howson 2005), and a number of studies have indicated that the interpersonal encounter between patients and primary health professionals is crucial to the production of trust in vaccination policy (Bellaby 2003; Petts and Niemeyer 2004). Critical trust is a term used by Poortinga and Pidgeon (2003) to describe the fact that people can combine skepticism with a reliance on a person or institution for information and knowledge.

13. See Pareek and Pattison (2000); Evans et al. (2001); Ramsay et al. (2002); Bellaby (2003); Vernon (2003); Bardenheier et al. (2004); Poltorak Leach, and Fairhead (2004).

14. Telephone interview, 19 April 2004.

15. The first meeting of the working party took place on February 27 1998, a second meeting on July 1, 1998, a third on November 5, 1998, a fourth on March 5, 1999 and a final meeting on May 10, 1999 to finalize the report.

16. The firm handling the parents' vaccine damage compensation claim.

17. Wakefield's co-author's wrote a separate "author's reply" to *Lancet*, in which they defended the substantial results of their research on the relation between the brain and the bowel in autism and insisted that the research paper itself was not primarily about vaccine safety at all (Murch, Thomson, and Walker-Smith 1998, 905).

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