Chapter 5

Discourse Communities as Catalysts for Science and Technology Communication

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In the spring of 2009, there was a wave of public unrest in the Netherlands in response to a government vaccination campaign against the human papillomavirus (HPV), an important cause of cervical cancer. There were countless reports of side-effects of the vaccine that were being hushed up, of the alleged lack of effectiveness and of the undue influence of pharmaceutical companies. Parents were not sure whether they should let their daughters be vaccinated and young women posted criticisms of the vaccination on a wide variety of social media. Policymakers, scientists and civil servants jostled with one another to assure the public that there was nothing to be worried about. 'That chap from the RIVM [the Dutch National Institute for Public Health and the Environment – the person referred to was Roel Coutinho, Director of the Centre for the Control of Infectious Diseases] keeps on saying that it's all old wives' tales, but the more he says it the less I believe him', wrote one of the mothers in question on an online discussion forum.

This is not an isolated example. It looks as if science is under attack from all sides. Climate change sceptics raise their voice on the Internet, nutritionists are accused of being the lackeys of industry and population groups that used to follow government directives docilely are now increasingly failing to respond to cervical cancer or swine flu vaccination campaigns. Scientists look back nostalgically to the time when they could make bold statements without being continually weighed in the balance and found wanting. The days when the label 'scientific expert' would guarantee faith in any pronouncement they made seem long gone.

But while the public debate about science has definitely become more intense, its root causes are less clear (see also Dijstelbloem and Hagendijk 2011). I will argue that the apparent opposition to the statements of scientific experts is diffuse in nature and not simply rooted in a dislike of science and experts. As part of the substantiation of my claim I will introduce a new perspective on science communication – one that aims to expose the dynamics of the interactions between science and society and may thus provide a new point of departure for communication.

This chapter is divided into three main parts, followed by a conclusion. I shall start by sketching the changing role of science and technology in our society, and arguing that the implications of these changes for the practice of communicating science and technology have hardly been thought through yet. We are brought up with what I shall call happy science, and later in the public domain mainly confronted with constructions of grim technology – both of which are expressions of a limited vision of the social significance of science and technology.

In the public domain, fierce criticism of scientific knowledge is coupled with an almost unassailable position of this same science. As I shall argue in the second part of this chapter, this phenomenon can be understood if we view it in the light of the question: what is an expert opinion, and how is this expertise – consciously or unconsciously – deployed? In order to understand what is at stake in the interactions – sometimes noisy, sometimes less so – between consumer-citizens and scientific experts, we need to dissociate expertise from the traditional roles of expert and layperson, and look at the way in which knowledge and experience are mobilised in real-life settings and what effects this can have.

Research, mainly in science and technology studies, has shown interest in the performative dimension of dialogue between citizens and scientific experts, for example by looking at publics 'doing being a public' (Michael 2009), or the actual construction of publics in public engagement exercises (Felt and Fochler 2010). Also, there has been some consideration of the interactional dynamics of laying claim to different forms of expertise in public dialogue (for example, Kerr, Cunningham-Burley and Tutton 2007). My plea here is both for more detailed studies of interaction, and for paying more – but not exclusive – attention to communities that 'self-organise' in the public arena, thereby going beyond the dominant focus on forums regarding emerging science and technologies that are organised by governments or government institutions. To this end I shall draw from the related traditions of ethnomethodology, conversation analysis and discursive psychology, and use the term 'discourse communities'. Finally, I will illustrate the value of an interactional perspective on science communication through analysis of interactions about a new technology (a glutenneutralising pill) in an online discussion forum for patients suffering from celiac disease, and face-to-face meetings between scientists and patients.

Science and technology from a social perspective

It was more than thirty years ago that sociologists and anthropologists of science decided to take a look in the kitchen of sciences (Latour and Woolgar 1986; Latour 1987; Knorr-Cetina 1981). Scientists were no longer interviewed *post facto* about how they had arrived at their results but were observed at work in their laboratory like some exotic tribe in the jungle. Latour and co-workers concluded that scientific knowledge did not merely describe reality but actually helped to constitute it. Scientific facts only become facts after they have been fashioned to withstand the storms of criticism they will encounter both inside and outside the laboratory. Scientists are handymen, fact-builders, not just random passers-by in the garden of reality.

Nowotny, Scott and Gibbons (2001) no longer talk about science in relation to society, but about a co-evolution of science *and* society. They claim the emergence, alongside the age-old academic 'Mode-1 science', of a problem-driven, interdisciplinary 'Mode-2 science'. Mode-2 science blurs the boundaries between the private and the public domains, and is publicly called to account at unexpected moments. As a result, the production of knowledge

is no longer the sole province of an elite in their ivory tower: the agora, the new public space where science is put to the test, now furnishes an important measure of the robustness of that knowledge (for a critical discussion of perspectives on 'new knowledge production', see Hessels and van Lente 2008).

Latour and his constructivist colleagues did not claim so much that the ivory tower of science was slowly crumbling away but rather that it had never existed, since the construction of facts always requires a network of allies, not just in the laboratory but perhaps above all in the outside world. Nowotny and colleagues showed that this activity is increasingly played out in the public gaze. It is more visible to society, and is sometimes intentionally organised to be so, for example in the form of public debates and hearings. In a complex and uncertain society like ours, it is inevitable that the type and number of actors engaged in knowledge production should grow: 'not only does science speak to society (it always has), but ... conditions are established in which society can "speak back" to science, according to the authors of *Rethinking Science* (Nowotny, Scott and Gibbons 2001: 245).

In this way, different generations of constructivist work have taken us beyond ready-made science – the congealed facts dished up to us in the science columns of the newspaper or the blogs written by science journalists – to science-in-the-making and science as social controversy. They show us that science in various ways contains more society, and *vice versa*, than we might at first sight have been tempted to think. Note however that these social influences are not always identifiable as well-defined interests. The above-mentioned studies of scientists in the laboratory undermine the idea that facts arise ineluctably from an unambiguous reality. Their construction often involves subtle room for discussion about what constitutes an observation or a reproducible experiment. This room for negotiation is the basis for the constructivist claim that scientific knowledge does not differ *essentially* from other forms of knowledge production. It will be clear that this claim, which detracts appreciably from the superiority of scientific expertise, has not been greeted equally enthusiastically by everyone.

The findings of the first generation of constructivist studies elicited various reactions in the field of science and technology studies – and in that of the public communication of science and technology. In the first instance, they gave rise to questions about just how essential the differences are between scientific expertise and other forms of expertise, and the frictions between them. One of the main protagonists of this line of research is the sociologist of science Brian Wynne (1996; see also Marris et al. 2001). Wynne draws a distinction between various types of lay knowledge. These include knowledge about the – often inadequate – past behaviour of institutes responsible for scientific developments, and the knowledge that formal rules and regulations will not be fully applied in the real world. The idea here is that lay knowledge may differ from scientific expertise, but is not inferior to it. Wynne (2006; see also Irwin 2001) further shows that despite the increasing involvement of citizens in public debate, the tendency of scientists to engage in 'deficit thinking' remains undiminished. According to this line of thought, citizens reject scientific expertise because they do not know enough about the facts in question or about the processes leading to

these facts, or they have little confidence in scientific activity as such. Scientists are not keen to engage in critical self-reflection, but they have no hesitation in pointing out the weak points of the lay public. Wynne revalues lay knowledge by giving it a clearly recognizable face, and showing what it may consist of. But on the same grounds, the approach can be seen to maintain the distinction between technical and lay expertise and partly reify it (see also Potter 1996: 38–39). In doing so, the interest is less in what precisely is at stake in the interaction between scientific experts and citizens. I shall be returning to this point further down in the chapter.

Partly in reaction to studies of this type, which may be seen as upgrading lay knowledge, we see the more recent emergence of initiatives aimed at rehabilitating technical expertise. In a study of expertise in our society, the sociologists of science Harry Collins and Robert Evans (2002: 271) state that the urge to add more and more members to the class of expert involves significant risks. They write in this connection: 'The romantic and reckless extension of expertise has many well-known dangers – the public can be wrong.' Collins and Evans mention the successful campaign by the environmental organisation Greenpeace to block the dumping of the Brent Spar oil platform in the Atlantic Ocean, after which Greenpeace had to admit that their actions had been based on incorrect figures, and the drop in measles vaccinations in the UK due to reports of a supposed link between MMR (measles, mumps and rubella) vaccines and autism in children. A key question here, however, is what precisely these examples show. Is it simply a case of non-scientists or pseudo-scientists who were unable to judge the true significance of the facts?

Collins and Evans suggest that the boundary between scientific and lay expertise – they call it experience-based expertise – should be maintained to ensure that we are not left with a big grey lump of mush that gives us no leg to stand on when we want to reach a definitive decision about the rights and wrongs of a scientific issue. It is not that experience-based expertise is not useful; it is more that it is not useful nor legitimate in every stage of decision-making. According to Collins and Evans, current debates on science and technology are handicapped by the 'Problem of Extension' (2007: 10, my italics): 'How do we know how, when, and why, to limit participation in technological decision-making so that the boundary between the knowledge of the expert and that of the layperson does not disappear?'

In other words, it is the boundary between expert and lay knowledge that is at issue here in the first place, and that needs to be rehabilitated. Collins and Evans do not themselves use the terms 'expert' and 'layperson' without qualification, but distinguish between various types of omnipresent and specialist expertise. While certain types of expertise, such as experience-based knowledge, are important in political decision-making, another more specialised expertise is needed to make a contribution in the domain of science and technology.

But the pre-assignment of certain types of expertise to certain domains and stages in decision-making creates a new issue to be solved: who is to be the judge when the boundary between the political and scientific stages has to be defined? Collins and Evans apparently assume this to be a relatively unproblematic matter. In many public discussions, however, scientists claim that the scientific and technological phase has already reached a definitive

conclusion – think, for example, of the old wives' tales ascribed to opponents of HPV vaccination – while other parties to the discussion claim that there are still plenty of factual uncertainties that need to be cleared up.

As constructivist research has shown, the boundary between science and society is not a clear-cut dividing line but one of the main points of discussion – perhaps the most important one – in debates between scientists and non-scientists. The sociologist of science Thomas Gieryn (1983, 1999) demonstrates that the answer to the question of where science ends and politics or society begins is not a simple side issue, but is key to the quest for intellectual authority and the denial of such authority to others. *Boundary-work* in this context refers not to the policing of fixed boundaries but to the flexible setting and resetting of such boundaries with the aim of achieving key objectives. The distinction that Collins and Evans make between a scientific and a political phase ignores the difficulty of determining beforehand what knowledge is useful when, and the risk of missing out on valuable knowledge at a stage where that knowledge is neither expected nor permitted.

Probably more important than the question of the feasibility of the policing of the borders is the observation that this activity hardly ever seems to be useful in practice. We see examples nearly every week of debates about science and technology where the hammering on the facts and the discounting of the other party's facts seem to lead to little more than a stalemate. Apparently, 'hard' facts do not carry enough authority to end the debate or to get the right on your side – irrespective of whether the facts really are hard and whether the debate really needs to be ended.

In the Machiavelli Lecture to which I have already referred, Roel Coutinho (2009: 6) concluded that it would have been better in the vaccination campaign against cervical cancer if: 'we had not felt the need to refer to old wives' tales in the heat of the discussion about the HPV vaccine but had patiently explained, point by point, where all the counter-arguments went wrong.' While this statement is obviously an expression of good will, the question is whether this analysis of the problem is fruitful in the long run. It tends to lead in practice to undue stress on 'the facts', which are assumed to bear the main load of the argument. This does not mean that facts are not important, simply that the 'bare facts' do not provide an adequate basis for better interaction between scientists and the other parties concerned.

Boundary-work, the laying of dividing lines between science and society, is neither good nor bad in itself. The assumption that the two are interrelated does not mean that we have to accept all mutual influences. What is important here, however, is the goals that are consciously or unconsciously served by this division and more generally what all participants in the debate – not just the scientific experts – achieve by deploying certain sources of knowledge or experience at given moments. Statements on online forums that HPV vaccination can lead to paralysis can be characterised as examples of lay expertise, but that does not tell us precisely what these statements are a reaction to or how they, intentionally or unintentionally, affect other people.

It should be noted here that when I use the term 'goals' above, I am not referring to the everyday definition that ascribes an intentional strategic purpose to the activities in

question – at any rate not on the part of the researchers concerned. The goals in question are those oriented to by the participants in the discussion themselves, and that gain significance through the interaction between the participants, ranging from the construction of a particular identity to the assigning of responsibilities.

Our interest in the interaction between science and society should not limit itself to the organised arenas of debate. In this context, the question posed by Collins and Evans – how can we give participation such a form as to maintain the boundary between expert and layperson – is no longer so relevant. The one-sided decision as to who may or may not participate in the debate has long been taken out of the hands of the authorities or the bodies that organise such debates. *Society talks back*, say Nowotny, Scott and Gibbons (2001). I argue that society not only talks back, but actually initiates the talking.

However, we see relatively little of this dynamic picture of science and technology in current practices of popularising science. Happy science is still a dominant picture of science presented to us from our very first science lessons in primary school. I call it happy science – not to be confused with Nietzsche's concept of 'gay science'² – because this science is a finished product, with little or no evidence of the turbulent events that may have been involved in its creation. It has had the rough edges rubbed off before we catch sight of it. Mitroff (1974) put this idea in a slightly different way when he talked of *the storybook image of science*.

In contrast to this image of happy science, the technology we encounter in the organised public debates on emerging technologies is usually characterised as 'grim'. I use the term 'grim' here to refer to the fact that these debates – on such topics as biotechnology, cloning or more recently on nanotechnology – focus primarily and sometimes exclusively on the risks to health, safety, the economy and the environment that are involved (see also Swierstra and te Molder 2012). The happy science is transformed from a black box full of happy truths into a landscape crowded with potential hazards – a minefield. 'Happy science' and 'grim technology' contain a grain of truth but both have their limitations. For example, they do not reflect the interactional dynamic through which science and technology arise. An understanding of this dynamic is crucial, for example, in order to explain why people seem to hate science at some moments and love it at others. To this end, you need to examine not so much the nature and content of expertise as such, but rather the relationships between the participants in the debate and what they achieve in these relationships by making use of the knowledge and experience available to them at particular moments.

Uncoupling the debate on science and technology from the roles of expert and layperson in the first instance will widen the playing field of science and technology communication. We will expand our perspective to cover not only the arena of organised debate but also everyone who has something to say, directly or indirectly, about science and technology.

This wider arena includes self-organising *discourse communities*, which sometimes claim or capitalise on their right to speak at unexpected moments. The *Verontruste Moeders* (Concerned Mothers, a Dutch online forum campaigning for 'more honest information about vaccination') is a good example, but so are the scientific experts taking part in the vaccination debates – not so much because they *are* a community, but because they present

themselves as such in a certain context, claiming a right to speak on the basis of a specific expertise, for example expertise that non-scientists in the debate have no direct access to, and achieving particular goals in doing so.

In a study on activist health groups that have emerged from online discussion groups, Akrich (2010) points to the fact that non-scientific epistemic communities (Haas 1992), which engage themselves in policy enterprises in which knowledge plays a major role, often emerge out of opposition. They 'are created in response to/oppose other epistemic communities mainly formed by professionals, or at least groups that have a dominant position due to the authority conferred on them by knowledge' (Akrich 2010: 31). While these communities do not necessarily manifest themselves online, it is clear that the online environment offers unique opportunities for mobilisation.

In order to understand what is going on between and within these communities, we need to go beyond the mere arguments that they exchange and provide a fine-grained analysis of arguments-in-context. Consumer choice, for example, is often presented as an opportunity for the consumer to emancipate, but the 'choice argument' can also be used to define difficult questions as private issues and to remove them from the public agenda (see also Swierstra and te Molder 2012). Likewise, the statement that certain kinds of food are unnatural seems at first sight to be merely an argument against new food technologies but can also be drawn upon by citizens to claim new territory: I have the right to decide on this issue, not you. For insight into this action-oriented dimension of talk, the (often standard) cognitive perspective needs to be replaced with a truly interactional approach. As I will illustrate in the third section, such an interactional perspective shifts the focus from – merely – looking at evaluations of the pros and cons of a given technology to – also – analysing, in detail, what the participants *achieve* by introducing these evaluations into the debate at given moments.

From cognition to(inter)action

Let us have a closer look at this interactional perspective. It makes use of discursive psychology as developed by Edwards and Potter (e.g. Edwards 1997; Potter 1996), an approach that has its roots in ethnomethodology and conversation analysis. The basic assumption of ethnomethodology (Garfinkel 1967) is that members of society continually order reality so as to give it a rational, legitimate form. This ordering is not some kind of random sideline but constitutive for each interaction. If a question is not followed by an answer, or a greeting by a counter-greeting, the situation is given meaning by treating it as a departure from a certain rule or expectation. The participants to the conversation judge whether a given action constitutes an implicit accusation or is free from hostile intent by determining the status of this action with reference to a given norm., Norms are thus seen as reflexively *constitutive* of actions rather than standards that behaviour simply has to *comply with*.

We constantly attribute meaning to utterances by declaring that certain rules or expectations apply to them. It follows that language is not an objective reflection of reality but rather a toolbox that can be used to *do* things. Suppose a mother walks into the kitchen and tells her daughter, 'There's a whole pile of dirty dishes there', to which the daughter responds, 'Well, I've been too busy to wash them up.' It is clear that the girl treats her mother's comment not simply as a statement of fact but also as a complaint, since she responds by defending her actions (or rather lack of action). The pile of dishes has now become an accountable phenomenon; that is, it is treated as such by the girl.

This normativity can take various forms and is not always predictable. For example, we observed in a study of the new technology of nutrigenomics that participants held themselves and others accountable not only for activities that were associated with an unhealthy lifestyle, but also and particularly for those that were associated with a *healthy* lifestyle (Komduur and te Molder 2011). In other words, they treated the choice of a healthy lifestyle as behaviour that required explanation, not simply as something that could be taken for granted. The normativity of interactions is ever-present but not always observed – it is 'seen but unnoticed' in the words of Harold Garfinkel, the founder of ethnomethodology.

Conversation analysis reveals the continual focus on what is 'normal' and 'correct', and the assigning of significance to language in this way, by studying the structure of everyday conversations. Conversation analysts prefer to work on detailed transcripts of natural conversations - in other words, conversations that are not brought about through the intermediacy of the researcher. They may vary from phone calls between friends to conversations between a doctor and his or her patient. One of the most striking characteristics of conversation analysis is that it does not confine itself to the study of 'important' conversations - such as political debates - but is also interested in seemingly inconsequential chit-chat. It takes work to determine what is normal and correct, and to assign significance to language, even in the most innocent of conversations. The ordering of our life is a task that is always with us, according to the founder of conversation analysis Harvey Sacks. The researcher should want to understand what this work consists of, and what it is consciously or unconsciously applied to. In a study that has become a classic in this field, Sacks (1984: 415) focuses on 'doing being ordinary': the pursuit of ordinariness as a task that demands continuous effort, not just something that you simply are. For example, an emotional outburst from an expert in a public debate may require explanation, while a layperson who is invited to the same discussion would be allowed more leeway. Apparently negligible details not only make the conventional framework that we call 'society' visible and relevant, but also keep it in existence: 'institutions are ultimately and accountably talked into being', according to the conversation analyst John Heritage (1984: 290).

Conversation analytic studies demonstrate that what people *do* with language, such as building up expertise or assigning responsibility, is not brought about on the basis of a single turn of the conversation but involves a whole series of turns. The meaning of an utterance can never be assessed without taking its interactional context into consideration. This may

be a commonplace, but there are few disciplines within the field of the social sciences that take it as seriously as conversation analysis does.

Conversation analysts look at the things people do with their language – the interactional effects – through the eyes of the participants in the conversation themselves. 'Those facts don't add up' becomes an accusation if it is treated as such, for example by replying, 'I never said they did.' This is a theoretical principle, but it is also of methodological importance. The interpretations of what is said and done, which are available not only to the participants in the conversation but also to the researcher, form the main input for an understanding of the course of the interaction. Although I use the term 'interpretations' here for the sake of convenience, a conversation analyst would prefer to speak of the way a particular expression is *treated* by one of the people taking part in the conversation. This seems like a complicated way of describing the matter, but it can be ascribed to an important analytical principle: the researcher refrains from making judgements about the truth or authenticity of the thoughts and feelings expressed.

Assumptions about the truth or falsehood of descriptions mainly impede the understanding of the *course* of interactions. By putting reality between brackets (Heritage 1984: 228–229; see also Edwards 1997: 62) and temporarily suspending judgement on the truth or falsehood of statements about the world, we clear the way for what Whalen and Zimmerman (1990) call *practical epistemology*. This approach allows us, without prejudging the issues involved, to examine the way the participants in social intercourse use their expertise and to what ends, consciously or unconsciously.

Such an agnostic attitude towards cognition – motives, intentions, attributions, perceptions etc. – forms the point of departure of discursive psychology (for an elaborate discussion on the status of cognition in interaction analysis, see te Molder and Potter 2005). I will draw upon this non-cognitivist perspective on interaction to put flesh on the claim that I made in the introduction of this chapter, namely, that critical statements about science and technology are not necessarily evidence of an anti-scientific attitude. In the next section, I will illustrate the empirical application of this perspective with examples from a study of an online discussion forum for patients focusing on a gluten-neutralising pill.

Towards an interactional perspective on science communication

In a conversation analytic study of how members of focus groups talk *about* experts, and *as* experts, Greg Myers (2004) shows that there is no single source of authority that they blindly accept, or that puts an end to the discussion. Scientific expertise – referring to risks in this study, for example the risks of spreading mad cow disease (BSE) – is cited very frequently, and rejected just as often. This applied equally to the experience of the focus-group members. However, unlike claims of experience-based knowledge, claims of scientific expertise often come with a built-in assumption that once they are put forward, this will immediately

preclude the need for any further discussion. It is precisely this expectation, Myers argues, that seems to be challenged in debates.

These observations are in line with what I mentioned previously in connection with the discussion about vaccination against cervical cancer: scientific certainties are introduced into the debate in the expectation that they will put an end to the discussion. We could encapsulate this idea in a variation on the closing words of the *Rijdende Rechter* [*The Travelling Judge*, a popular Dutch TV programme modelled on the American TV show *The People's Court*]: 'These are the facts, and you'll just have to accept them.' Unfortunately – or not – however, 'the facts' often do not close the discussion but rather mark a new beginning.

Myers argues that expertise should not be seen as a fixed characteristic of certain persons, but rather as an *entitlement to speak* (see also Heritage and Raymond 2005; Sacks 1984; Whalen and Zimmerman 1990) This entitlement is reinforced – and not just by scientists – in all possible ways and by all available means, including an appeal to an authority based on scientific knowledge. The same entitlement is however undermined by a claim that the knowledge introduced is the alpha and omega of the discussion. The fact that expert knowledge is so often challenged seems due not so much to any doubts about its correctness per se – this also applies to other sources of knowledge – but rather to its claim of precedence, of a decisive voice in the debate that is not open to question.

Let us assume for the moment that expertise can be defined as 'entitlement to speak'. The conversation analysts John Heritage and Geoff Raymond (2005) argue that the right to speak and the responsibilities of speakers are regulated not just sometimes and in a random manner, but always and everywhere. If I, as the first speaker, say 'Science delivers hard facts', I am claiming the primary right to make this statement. Someone who replies, 'Yes, I think so too', not only agrees with my statement but also confirms my primary rights to make it. If, however, the answer is, 'That is indeed what science does', this lays claim to an independent opinion that existed before I made my statement. In this way, speakers show not only *what* they agree about but also *who* agrees with *whom* (Heritage and Raymond 2005). This example simplifies the interactional reality, but also illustrates the indirectness of negotiations about entitlement to speak.

The following examples from a study of an online discussion forum dealing with a glutenneutralising pill provide detailed illustrations of what may be at stake in talk among patients and medical experts about a technology introduced by medical experts (te Molder et al. submitted; see also Veen et al. 2011). The discussion on the gluten-neutralising pill was part of an online forum for celiac disease patients (www.celiac.com). Celiac disease is a genetic disorder that causes an auto immune reaction to the wheat protein gluten, which results in serious damage to the small intestine. At the moment, a lifelong diet is the only remedy. This not only requires discipline, but is also difficult to implement as gluten is found in many daily foods.

The analysis below demonstrates that patients did not so much reject the technology on offer (a pill), but rather the assumptions indirectly underlying this offer. The question 'how much would you be willing to pay each day if you could take a pill that would let you eat a

normal diet?' presupposes among other things that the patients definitely want such a pill and that the only potential problem is the price. Extract 1 shows a (self-reported) scientific expert introducing the pill. The analytic focus is on what the expert's question is *doing* – in terms of discursive action – by looking at how the participants in the online discussion forum *treat* the contribution:

Extract 1

16

How Much Would You Pay For A Pill? Cost of therapy

Pills? Thanks any way. Sammy.

```
Researcher (Sept 6 2004, 09:38 AM)
1
2
    Newbie
3
4
    I am doing some research on developing potential new therapies for celiac
5
    disease and am wondering, how much would you be willing to pay each day if
6
    you could take a pill that would let you eat a normal diet? How much would
7
    you pay per year?
    (9 lines omitted)
8
9
10
    Sammy (Sept 9 2004, 08:04 PM)
    Member
11
12
    I wouldn't give one red cent for a pill. I have taken pills all of my life
13
14
    because of this disease. I would just keep on with the diet as is. I feel
    better than ever and have more energy than most 60 year olds should have.
15
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The topic is initiated by a researcher, obviously not a celiac patient and in this respect an outsider on the forum. Notice how by inquiring into the amount of money that patients would be willing to pay each day (5–7), the need or desire to have this pill is already presupposed. Second, the pill is presented as an *easy solution* to the disease in comparison to the current treatment ('a pill that would let you eat a *normal* diet', 6). Sammy's contribution (10–16) challenges the validity of both presuppositions. By saying that she 'wouldn't give one red cent for a pill' (13), she claims to reject the pill irrespective of the price. She grounds the rejection in her elaborate experience with pills (13–14). If you have used pills all your life, and the disease has ultimately been treated effectively by a diet, it makes no sense to go back on a pill and give up the diet and its pay-off ('better than ever' and 'more energy than...', 15). Sammy's reply thereby questions the assumption in the researcher's post that the pill will change her life for the better, and is therefore obviously needed and desirable.

In the introduction to another discussion thread, the possibility is raised that a pill 'may come'. Note how this introduction evokes a response that is very different from the one in the first thread:

Extract 2 If they came out with an anti-gluten pill thingy, It may come ... eventually

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If they found a pill that would neutralize the effects of gluten on your body
132
     (sort of like the pill people take who are lactose intolerant), would you use it?
133
134
135
     Yes, definitely – all the time
                                                                     [18]
                                                                             [43.90%]
136
     Sometimes, but only when I am eating out
                                                                     [12]
                                                                             [29.27%]
     Sometimes, maybe once or twice a week
137
                                                                     [4]
                                                                             [9.76%]
     No, I'd be afraid that it wouldn't work
                                                                     [4]
                                                                             [9.76%]
138
139
     No, I don't think I could ever look at wheat the same way
                                                                     [3]
                                                                             [7.32\%]
     Total Votes: 41
134
141
142
143
     Ronald (Apr 9 2004, 12:35 PM)
     Advanced Member
144
145
     It could happen, eventually.
146
```

The title of the discussion thread is formulated in terms of a possible future: 'It may come ... eventually'. Furthermore, the introduction does not presuppose a need or desire of celiac patients to have a pill; instead, participants are invited to answer a hypothetical question: 'If they found a pill ..., would you use it?' (132–133). While the responses to this question (135–140) point in the direction of a generally positive attitude regarding the pill, the question itself sets up an environment in which different options, including non-use, are inquired into rather than presupposed. The response pattern found in this thread, as exemplified by Ronald's cautiously optimistic response 'It could happen, eventually' (146), indeed treats the question as a possible scenario that is worth further exploration (for more on this, see te Molder et al. 2011).

This then illustrates that it is not the pill *itself*, but the assumption that patients will need and use it *as a matter of course* that is dealt with as disputable. Sammy (in Extract 1) rejects being characterised as a passive patient. She presents herself as a healthy individual, who is able to maintain her vitality in the face of adverse circumstances. By resisting the notion that they would straightforwardly accept the pill, patients constructed themselves as proactive, thoughtful people with a healthy way of living. Presenting new possibilities as

cure-alls made the gluten-free diet appear as a hardship, and undermined the complexity of the patients' relation to their disease, including the positive values embedded in that relation. The study shows that an apparent straightforward rejection of a new medical technology is drawn upon by patients not so much to display a concern about the pill's impact on their health, but about how the presentation of this innovation impacts their sense of achievement, or more precisely, their primary rights to speak in first position about their own lives (see also Veen et al. 2011b).

A study of face-to-face meetings between scientific experts and celiac patients about a gluten-neutralising pill in the making (Veen et al. 2011b) shows strikingly similar results. The meetings were organised by the Celiac Disease Consortium (CDC), a Dutch innovative genomics cluster consisting of representatives of scientific research, patient associations, dieticians, general practitioners and industry. The CDC organised the meetings to inform patients about current research developments and receive feedback on those developments from patients. Interestingly, the predominant yes/no interrogatives used by the scientific experts to ask patients about the future of the pill, such as 'Will you use that pill?', systemically biased the patient's reply to acceptance of the use of the pill in question, including acceptance of presuppositions regarding the patients' quality of life (problematic) and the safety of the pill (100%) that appeared in the question's preface.

An example of this pattern is shown in the following extract that takes place after an elaborate answer to a patient's question about the pill. One of the patients observes a transition from information giving in the meeting to requiring patients' input:

Extract 33

Group 1, 24:26-26:20

1 **P1** So you really want to know what we ↓think of such a pill. (1.5) 2 **Ex** Yes for us that is a eh very relevant question. (.)°Yes° (0.7) I can imagine ↑right. What I hea:r here is of course like yes, the 3 4 diet is fine but it is hard. Hard to accept. Ehhh \u214hh. (.) 5 Holiday a drag. Ehhh well the question is just (1.8) say such a 6 pill is coming. And this pill turns out to be completely safe. 7 (2.1) Will patients then ↑use it or ehhh (.) are we just sitting around here ehhh developing [some-8 9 **P4** [I guess we'll see how it ↑turns 10 out, hehehehhh 11 ((laughter)) 12 **P4** Yea [hhh] 13 **P2** [Yes] I think it that it really depends 14 Because I think that the diet in the sense of eh (.) excuse me

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- not right now, that (0.4) seems much harder to me than that you
- 16 (.) know, well, >not↑allowed< that's clear, ↓done. So I will
- ehhhh yes, for convenience's sake, that is (.) for yourself it's
- difficult, 'because something like' yes you don't really need
- to, I don't need to be so-g loyal, because I have an
- alternative, that feels different than I know what I'm up
- 21 against I cannot ↓eat it because >if I eat it < I get sick. (1.0)
- 22 So then I'm like <u>if</u> there is something then I would like to have
- 23 something that helps me get rid of it †across the- because eh
- 24 (.)>once in a while< tha- that doesn't do it for me.
- 25 (1.0)
- 26 **Ex** Yes.
- 27 **P3** Yes all the time or not all the time.
- 28 **P2** Yes all the time or not at all.

The patient's turn establishes what patients '↓think of such a pill' (1) as a new topic on the agenda. Although acknowledging the relevance of this question (2), after a preface (3–5), the innovator-expert ends up asking a different set of questions (5–8) that shift the focus to patients' *use* of the pill. This reformulation is achieved by a description of dietary practice as a burden ('hard to accept', 'a drag', 4–5). Furthermore, this description is presented as something the patients *themselves* have said ('What I hea:r here'). So the question the expert finally asks is accounted for as occasioned by the patients' own presentation of the diet as difficult.

The question offered by the patient in line 1 explicitly constructs the innovators as requiring information from the patients (*you* want to know what *we* think), and asserts no knowledge concerning a likely answer. In the question the expert poses, however, this information gap is much smaller. It is prefaced by a description of the situation of the addressees, implying that the questioner knows their situation, as well as the possible reactions they might have to it. It is just a matter of knowing which reaction is relevant here. This leaves much less room for epistemic maneuvering on the part of the respondent.

There is also a difference in the presuppositions set up by the patient's turn and the innovator's. Wanting to know 'what patients think of such a pill' (1) presupposes that patients have an opinion about the pill but it does not make any assertions about how to frame this opinion or what it means for the development of the pill. The expert, on the other hand, asks patients to assume in their answers that a particular pill is on its way. The preface to his question (2–5) is set up as a first part of a contrast in which either the pill will be used by patients or it will have been a waste of time for its designers. The patient's turn invites patients' responses in terms of asserting opinions, the innovator's turn in terms of making a choice. This invokes a fundamental difference in the relationship between patients and innovators. In the first case, patients are involved in terms of their thoughts and opinions about the innovation process in general; in the second case, in terms of choosing between available options that have already been decided.

The first response to the expert's question (9–11) is constructed jokingly, followed by the patient's laughter and that of others, including the expert's. P4 displays reluctance to answer the question by not providing a type-conforming 'Yes' or 'No' response. This reluctance can be seen as resisting the constraining character of the expert's question. The joke is, of course, that this patient gives a literal answer to the question 'will patients use it', by taking it up as a request to make a prediction about the future of patients' behaviour. By withholding an affirmative response to the expert's question, she also resists affirming what the expert constructs as being at stake in the question regarding use of the pill: 'are we just sitting around' suggests that if the pill is not accepted, it is the innovators who will be negatively affected.

The second response (13–24) starts with a type-conforming 'Yes' but proceeds to qualify this affirmation by making the response to the question contingent on another factor: 'it really depends on how you use it' (13). P2's description of a pill alongside the diet as 'much harder' than the current situation challenges the presupposition in the expert's question that the pill would make things easier for patients. Her account is a departure from what was asked for – namely, whether patients would use the pill or not. Rather than taking the pill as a given, and evaluating it, P2 poses conditions on the *kind* of pill that she would want: 'if there is something, then I would like to have something that...' (22–23). She treats the version of the pill that the expert is presenting as only one of more possibilities, thereby challenging the terms of the expert's question, in which the only choice is between affirming the option presented by the innovators and discarding it entirely.

The analysis shows how, in both settings, the innovators' questions build 'offers you can't refuse' by presupposing the absolute safety and/or efficacy of the pill, in contrast to the patient's problem-ridden life. In doing so, however, the innovators claim direct access to the patients' everyday life – thereby failing to treat them as having privileged access to their own experiences and having specific rights to narrate them. By resisting the question format and/or unpacking its assumptions one by one, patients are shown to (re-)claim epistemic ownership.

Conclusion

'The regulation of knowledge is among the most basic mechanisms by which social relationships are managed and constituted, says Raymond (2010: 104) on the relationship between expertise and identity. Opinions, truths and half-truths do not so much follow from a particular identity but rather form an integral part of it (cf. Myers 2004: 178). If we add to this the claim that science is the epitome of true knowledge, it is easy to understand why the reactions to scientific and technological pronouncements are often so fierce. It is not just the truth but our own identity that is at stake here.

It is no easy matter to look beyond the arguments as such and to widen one's perspective to include *how* these pronouncements are understood by those who take part in the

discussion – for example, as an accusation or an infringement of one's entitlement to speak. But such an effort often makes the difference when we want to gain a better understanding of the interactions between science and society: an utterance that at first sight looks like a rejection of technology may then be revealed as a reaction to an infringement of someone's entitlement to speak.

Hobson-West (2007) showed in a study of childhood vaccination in the United Kingdom that rejection of the vaccination campaign set up by the authorities was targeted not so much at the vaccination itself but rather at the suggestion that what the authorities really wanted was blind trust from the population – and these were the same authorities who had in the first place trained the population to make independent choices and above all to learn to think critically.

There is a great risk, however, that such interactional concerns will not be recognised or acknowledged either by scientific experts and technologists or by the potential users of the technology themselves. The philosopher of technology Tsjalling Swierstra talks in this context of 'soft impacts' – foreseen or unforeseen consequences of technology that are treated as 'soft' and that elicit no response (Swierstra and te Molder 2012). While some concerns are difficult to recognise, as we have just mentioned, others stand out quite clearly but it is difficult to assess their real significance. A preliminary study (ibid.) of soft impacts in food technology has shown how concerns about whether food is natural or not can relatively easily be sidetracked. Scientific experts and technologists treated the issue of naturalness as a well-known, prototypical public concern that required no further examination. This may explain why the precise meaning of 'natural', and to what purposes it is put to use in, for example, public debates, remains unclear.

One of the important tasks of science communicators is to raise awareness of interactional concerns in people who are taking part in debates about science in the widest sense of the term. These concerns cannot be met or eliminated by concentrating solely on the 'literal' content of the arguments. The historian of science Steven Shapin (2007: 185) expressed this insight as follows: 'You cannot use better logic or more evidence to refute a different kind of concern'. Logic and facts are not used solely to transmit information; they are also drawn upon to perform different sorts of interactional business. This business may relate to *what* is and may be said, but also to *who* is the first, or the only, one allowed to address the issue in question. Such negotiation about the entitlement to speak is directly related to the identities we ascribe to others and to ourselves.

Our analysis shows that these concerns are often not or only indirectly available for the debate facilitator. Likewise, participants themselves tend not to have direct access to interactional concerns although, when confronted with them, they will recognise them immediately. The discursive action method (Lamerichs and te Molder 2011) is a method that aims to turn participants into analysts of their own discourse by making these interactional concerns visible and open for discussion. This is not only relevant for expert-designers or policymakers but just as well for users of technologies. Natural food may be reshuffled

into a private consumer concern with which a food expert should not be preoccupied, but 'naturalness' may just as well be drawn upon by consumers to delineate their territory such that no expert is allowed in.

The method enables participants to reflect not only on what they say but also on the effects, consciously or not, of saying certain things, in certain ways, at certain moments – for example, what their questions convey irrespective of their intentions. Previous applications of the method in the context of adolescents' health-related behaviour (Lamerichs, Koelen and te Molder 2009) have shown that adopting a non-cognitive stance offers a non-threatening and attractive point of entry for participants. The questions asked by the facilitators – as part of guiding the participants through their own talk – invite them to look at what is *achieved* with people's utterances rather than to reflect on themselves as a person, or judge the behaviour of fellow participants. By providing a safe environment in which highly recognisable topics can be discussed and critical comparisons with alternative discursive strategies can be made, the method is also able to unlock participants' motivation to develop their own activities and enhance a sense of ownership in developing and implementing them.

The question 'Why that now?', as conversation analysts so elegantly put it (Heritage 2010) – why that particular remark, at this particular moment? – should be part of the permanent armoury of the science communicator. He or she should learn to put it to different discourse communities – scientists, groups of citizen-consumers, members of industry etc. – and to (help) answer it, also, or perhaps especially, when accounts of science and technology are treated as 'old wives' tales'. This brings us beyond happy science – by looking at facts in context – and beyond grim technology, namely, by talking about more than the risks attendant on emerging technologies.

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Notes

- 1 This chapter is partly based on the inaugural address that I gave at the University of Twente, the Netherlands, on 15 September 2011, titled: Beyond Happy Science and Grim Technology: Science Communication in an Interactional Perspective.
- 2 In his book *Die fröhliche Wissenschaft* (1882) translated into English as *The Gay Science* Friedrich Nietzsche advocates radical modification of the efforts and results of science, to make it more life-affirming. The modifications I propose are less radical and are derived from other motives.
- 3 Transcription Notations

P1, P2, and so on are patients, Ex is the expert. Based on Jeffersonian transcription (Jefferson 2004).

[text] Overlapping speech (x.x) Pause of x.x seconds

(.) Micro pause, less than 0.2 seconds

(text) Speech unclear

↑word, ↓word Onset of noticeable pitch rise or fall

wo:rd Colons show that the speaker has stretched the preceding sound

word Signals sound stress

°text° Material between degree signs is quiet

((text)) Transcriber's remarksNo pause between words

>text< Fast speaking