Just Around the Corner:  
Rhetorics of Progress and Promise in Genetic Research

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The emerging “diabetes epidemic” threatens to affect 366 million people worldwide by 2030. In the UK almost 2 million people (about 3.9 per cent of the population) are currently diagnosed with diabetes and it is estimated that a further 1 million people have the disease but do not realize it. The prevalence of diabetes, its complications and their effects on the lives of those living with diabetes mean that diabetes research has the potential to bring significant benefits. In this paper, we are concerned with the research involving human embryonic stem (HES) cells that sees diabetes as a potential therapeutic location. Drawing on the idea of the “certainty trough” we examine how the hopes and uncertainties associated with this complex research agenda are understood. We show that those at the research front and those most opposed to the research agenda appear to be the most aware of the uncertainties that need to be resolved. In contrast, funders, typically one-step removed from the research work, see the promise of the research as more real and more likely to be achieved. Significantly, these optimistic funders are supported in their beliefs by the research scientists as constitutive claims are reproduced within the contingent forum. The effect is a collaborative project in which the promise of a technical solution “just around the corner” is sustained whilst concerns about the future difficulties are marginalized.

Keywords

Certainty trough; stem cell research; diabetes; public engagement with science and technology.
Because the science is so new, we are very hopeful that breakthroughs, particularly using cells in the pancreas for the treatment of diabetes, are on the horizon.

1. Introduction

Like much medical science, regenerative medicine is both a science and a source of succor (Collins and Pinch, 2005). On the one hand, there is the hope that medical research will lead to new cures and transform the lives of those suffering from diseases like cancer, Alzheimer’s and diabetes. On the other hand, given the complexity of these illnesses and the difficulties of the research, it is entirely possible that even if a cure is found, it will be several generations before it is widely available. In such a context, the funding of stem cell research, the claims made for it and the expectations it creates amongst its potential users are matters of both scientific and social concern.

This tension between hope, hype and caution arises precisely because medical research is directed both towards the understanding of disease and the development of profitable products (Suarez-Villa, 2001; Sismondo, 2004). These interconnections are clearly visible in the alliances that form around medical research. Patient activist groups, industry organizations and scientific research laboratories are all implicated in modern medical science (Brown et al 2004; Brown and Zavestoski, 2005; Hess, 2004; Ganchoff, 2004). As such, it is no surprise that finding a cure for degenerative disease has become a primary target of this “hope economy” (Franklin 2003), with fundraising campaigns emphasizing emotion, empathy and, crucially, cure. As Helen notes:

the power to raise hopes for new cures and better life in people is a crucial characteristic of today’s high-tech medicine. Consequently, it is the people living in such a hope who provide fuel for both technological progress and profit-seeking. (2004: 3)

In this paper, we take diabetes research as a case study and explore these tensions by examining how different groups understand the potential of stem cell research to make a difference to patients’ lives. Our primary concern is with the public presentation of this research and the implications of this for the ways in which lay publics and patients come to learn about their possible futures. In particular, we examine how the institutional position of the expert and the social context of their discourse influence the claims made about the potential of stem cell research. In structuring this discussion we draw on the idea of the “certainty trough” (MacKenzie 1990: 370-371), which suggests that those closest to the research front are better able to recognize the uncertainties of the research, and the recent critique of this by Lahsen (2005), which suggests that, at least in the case of climate change modeling, it is the research scientists themselves who are most likely to be seduced by their own simulations.

In the context of diabetes, the certainty trough manifests itself in the differing claims about the potential of stem cell research to free thousands of people from a life-time of injections and the serious health problems caused by diabetes. For this reason, stem cell research into diabetes is a particularly interesting site for investigating the public presentation of complex science. For example, not only does the research take place at the cutting edge of biomedicine, it also touches on the hopes and concerns of many other groups, including patients, carers, health care providers, policy-makers as well
as lay publics more generally. Moreover, to the extent that medical research relies on charitable and public funding, then maintaining support outside the scientific community for the promise of a cure that is “just around the corner” becomes crucial. In the remainder of the paper, we provide some background information on diabetes and its potential treatments. We then discuss the “certainty trough” in more detail and outline the critique offered by Lahsen. Next, we present our findings, drawing initially on the certainty trough to structure our data. We conclude by examining how context influences the conduct of scientists and argue that what seems to matter is not just who is making the claim, but where and to whom they are making it.

2. Diabetes and Medical Research

Diabetes affects many people and is predicted to affect many more. By 2030 it is estimated that as many as 366 million people worldwide could have diabetes (Wild et al, 2004). Diabetes is caused by the inability of the body to regulate the amount of glucose in the blood. For most people, the pancreas produces insulin, which is then used by the body to remove glucose from the blood and transfer it to other cells where it can be used as fuel. In a person with diabetes this does not happen. Although the immediate symptoms of diabetes can be relieved quite quickly, the disease can lead to serious health problems such as retinopathy (eye disease), neuropathy (nerve damage), nephropathy (kidney disease), hypoglycemia (low blood sugar), and heart disease and stroke.

Diabetes is conventionally divided into two main types. In the case of Type 1 (or juvenile onset) diabetes, the insulin producing pancreatic beta cells are destroyed by the person’s own immune system. A person with Type 1 diabetes is therefore unable to produce any insulin and is dependent on insulin injections. In contrast, Type 2 diabetes develops when the body can still make some insulin, but not enough, or when the insulin that is produced does not work properly (known as insulin resistance). In either case, there is no cure and treatment focuses on the control of blood pressure and blood glucose through a combination of diet, exercise and, where necessary, medication. Research into the treatment of diabetes focuses on all these aspects of the disease.

Psycho-social and Other Lifestyle Therapies

Living with diabetes can be difficult, particularly for those diagnosed with Type 1 diabetes at an early age. Whether living with Type 1 or Type 2 diabetes monitoring what you eat, and when you eat it, becomes an essential part of controlling your blood glucose levels daily life. Psycho-social and lifestyle interventions address these problems through programs of empowerment and education that help people living with diabetes to find better ways to manage blood sugar levels and enjoy previously taboo activities and foods. In the case of type 2 diabetes, research into its prevention is also gaining in importance.

Techno-Scientific Solutions

For many people living with diabetes, diet and lifestyle regimes need to be complemented by some form of medication. For type 2 diabetes this may be medication to make the available insulin work better or reduce the levels of glucose in the blood. In the case of type 1 diabetes, and those with type 2 diabetes who need exogenous insulin, treatment involves identifying and developing different forms of insulin that can be combined to mimic human insulin as closely as possible (e.g.
Barnett and Owens 1997). In addition, there is a range of technologies being developed to improve the way insulin can be used. The two main areas are improving the accuracy and frequency of blood glucose measurement and making the insulin more convenient to use (e.g. inhaled insulin). For those patients for whom insulin therapies do not work, then transplants of new islet tissue, typically from cadavers, are possible. At present, however, the transplants (known as the Edmonton Protocol) are used only in life threatening cases and are usually seen as a last resort. Even if the transplant is successful, the patient will be dependent on immunosuppressant drugs for the rest of their life.7

**Stem Cell Research**

Stem cell research is a branch of regenerative medicine. The aim is to restore the patient’s damaged beta cells and hence enable them to produce their own insulin once more. The approach is similar to the transplant route, but hopes to avoid the need for immunosuppressant drugs and to get around the problem created by the lack of donors (the Edmonton Protocol requires two donors for each transplant) by creating a new source of islet tissue. If successful, stem cell research would eliminate the need for insulin injections and prevent the longer-term complications caused by diabetes. The challenges involved, however, are substantial. Not only must the stem cell lines be stabilized, the cells must then be made to develop into fully functioning insulin-producing cells. Once implanted, any new cells must be protected from the body’s immune system so that they are not destroyed. Whilst these problems are not resolved at present, the researchers and their funders obviously believe that, one day, they will be.

3. **The “Certainty Trough”**

The “certainty trough” provides a way of analyzing how the potential of stem cell research is presented. According to MacKenzie’s original formulation (1990: 370-371), the certainty trough was an extension of the original science studies slogan that “distance lends enchantment” (Collins 1992:145). This development was needed to incorporate the finding that, although those “one-step” removed from the research front did tend to appear more certain about the science, there remained others who could only be described as “extremely disenchanted.”8 What is more, these groups were typically not practicing researchers so their skepticism could not be accounted for by their close engagement with the research work. Rather, what seemed to be happening was that the research program and its uncertainties were being interpreted in the context of different value commitments, leading to a very different kind of uncertainty to that expressed by the front-line practitioners (cf. Evans and Plows, 2007).

In a recent paper, Myanna Lahsen (2005) has questioned the applicability of the trough metaphor. Drawing on the example of climate change modeling, she argues that categories such as “users” and “producers,” as well as the idea of “certainty,” are all more complex and multi-faceted than suggested in MacKenzie’s original model. For example, in the case of climate change modeling, Lahsen found that it was difficult to distinguish “knowledge producers” from “users” as each scientist’s research was often dependent on code or data from other models. She also found that the scientists themselves sometimes blurred the distinction between their simulations and the real thing. As one of scientists explained:
You start referring to your simulated ocean as “the ocean” – you know, “the ocean gets warm,” “the ocean gets salty.” And you don’t really mean the ocean, you mean your modeled ocean… there is a tendency to forget that just because your model says x, y, or z doesn’t mean that that’s going to happen in the real world. (Lahsen 2005:909).

In making statements in this way the climate change modelers are arguably presenting their research as “more certain” than it is. The value of the prediction depends on accepting the assumption that the model accurately represents all relevant aspects of the global climate and that all other inputs are correct. These are big assumptions to make and, as Lahsen observes, these caveats tend to be introduced by groups such as meteorologists, whose social position keeps them somewhat alienated from the climate change modeling program, rather than the climate change modelers themselves.

In interpreting this more recent research, two explanations seem possible. One is that climate change modeling is different. Perhaps in this particular multi-disciplinary context, or for simulation models more generally, there is a tendency for scientists to come to see their model and the object that model represents as identical. In other, more experimental, sciences this tendency may be less pronounced. If this is correct, then Lahsen’s work suggests that more research may be needed to understand how certainty is produced and, more critically, how and where best to maintain an appropriately critical distance.

The other is to examine more closely the context in which the certainty or otherwise of scientific results is discussed. It is well known that scientists draw upon different repertoires to construct accounts of the research (Mulkay and Gilbert 1984). It is also known that, in different contexts, scientists will tend to behave in different ways, often appearing more confident and certain when speaking to external audiences than when discussing the same science with close colleagues (Shackley and Wynne 1995).

An important distinction in this context is that between the constitutive and contingent forums (Collins and Pinch 1979). The constitutive forum, which includes journals, books and formal conferences, is the forum where scientific knowledge is formally ratified. Standards of evidence are high and the style relatively impersonal and universal. In contrast, the contingent forum, which includes everything else that scientists do that is connected with their work, tends to be much more informal, varied and contextual. It would be wrong, however, to think that the contingent forum is less important. As science studies has shown, the work done in the contingent forum is as epistemologically significant as that done in the constitutive forum. Moreover, given that the contingent forum is where most non-scientists will encounter science, the presentation of science within this context is arguably a key influence on public perceptions of stem cell research.

In the remainder of the paper, we explore the relationship between these different forums and their influence on the way certainty is expressed in more detail. We confirm MacKenzie’s certainty trough model by showing that there are settings, including the research interview, where scientists are very cautious in the claims they make for their research, that research funders are often more certain that the research will succeed, and that there are a number of groups, some with substantial technical expertise, who remain alienated from the genetic paradigm and who continue have serious reservations. That said, however, our data also show that the ways in which
scientists present the uncertainty about their work does vary with context, suggesting that Lahsen’s concerns about the generalization of MacKenzie’s model are justified.

4. Research Design and Sample
The results presented below draw on a series of interviews conducted as part of a longer-term project investigating the contribution of lay and expert groups to policy-making through evaluating a deliberative process. In that process, which takes treatments for diabetes as its case study, focus groups comprising patients, carers and lay citizens deliberated over a range of treatment options derived from the interviews. The final stage of the project was a roundtable workshop, discussing the same options, attended by representatives of the different focus groups together with scientists and research funders. The overall aim of the project was twofold. Firstly, it explored the difference that experience – either of scientific research or of living with diabetes – makes and, secondly, it examines the effect of face-to-face interaction on the understanding of alternative viewpoints and concerns.

The data that we describe in this paper comes from the first stage of this project, in which we conducted interviews with a range of scientists and activist organizations. In selecting respondents for these interviews, we used the “certainty trough” idea to construct a sampling frame that would include a range of views, knowledge claims and values. Our sample includes scientists based in some of the major UK based research laboratories, representatives of diabetes charities and activists based in a range of social movement organizations known to be skeptical of the “genomic revolution.”

We have also been present as participants at a variety of conferences and public engagement events where genetic research was discussed, and have transcripts and recordings from several events at which we were unable to be present.

5. Certainty Trough or Certainty Gradient
We begin our analysis by examining the extent to which our data corresponds to the certainty trough model proposed by MacKenzie or the “certainty gradient” described by Lahsen. We group our respondents according to their position along the social-distance axis and explore the ways in which stem cell research is described, paying particular attention to the ways in which the potential for a treatment to be developed is considered.

Cautious Experts
A key justification for use regenerative medicine to treat diabetes is the belief that it will enable people with Type 1 diabetes to produce their own insulin. By repairing or replacing the damaged islet tissue and allowing new beta cells to develop, people with diabetes will be freed from their dependence on insulin and from the risk of complications. Whilst more expensive in the short-term, the long-term outcome could be considerable savings as complications and follow-up treatments are avoided.

In describing this research, scientists are well aware of the potential impact of their research on the lives of those living with diabetes. As the certainty trough model predicts, however, their day-to-day experience of work in the lab and their knowledge of what their colleagues can or cannot do ensures they are also very aware of the difficulties that needed to be overcome, the time this would take and the relatively small number of patients for whom these therapies would be suitable.

The first and most basic problem that must be resolved is to make HES cells differentiate into pancreatic beta cells. To do this, the embryonic stem cells, which are
the pluripotent cells found in the blastocyst, must be proliferated in vitro, immortalized and stabilized as a stem cell line, and then made to differentiate into specific kinds of cells on demand. Unfortunately, not only is stabilizing the stem cell line very difficult, forcing the stem cells to differentiate into the beta cells that produce insulin is an even more intractable problem. To make matters worse, the scientists still do not know if it will be enough to just produce beta cells, or if all the islet cells need to be reproduced and encouraged to work together. As one of the leading researchers explained:

Even with mouse embryonic stem cells, the number of functional beta cells that you make is incredibly low and with human cells it’s almost non existent. Over the course of the last 4 or 5 years we have spent a lot of time trying to make islets, out of stem cells, from human embryonic stem cells, even from mouse cells, and it’s been a complete failure. It’s been very, very disappointing. It’s the one thing that human cells seem not to want to make with any frequency whatsoever. (Scientist A)

What is more, the experience of this laboratory is not unique. As the same researcher explained:

There’s only one group in the world who’s had any success at all … After about 5 or 6 years of incredibly hard work they have one cell line where they can get about 10% of the cells to make beta cells. But that’s one cell line. On the other 5 or 6 cell lines that they work with they get what we get … It’s really very curious and nobody really understands why. (Scientist A)

In addition to the basic problem of getting the stem cells to differentiate into islet cells, there are a number of other technical difficulties that need to be resolved. For example, the cells must be able to produce insulin, something that appears very difficult to do. One scientist described the outcome of a substantial research effort aimed at just this problem as follows:

You could get the cells to produce a tiny, tiny amount of insulin [but] certainly not enough that would ever be useful enough for a treatment … So while it helps you understand the process, you’re not actually going any closer towards producing a cell that you could put into a patient. (Scientist B)

Another concern is the manufacture of therapeutic stem cells. At present, stem cells are grown on compounds derived from animal products. This represents a potential risk that must be eliminated before any clinical trials can begin:

There are lots of problems before you can go into clinical trials with these cells. At the moment a lot of the cell lines have been growing up with animal products, so there’s problems of zoanosis. (…) So all those things have got to be got rid of before you’ve got GMP standard – Good Manufacturing Practice – until you’ve got products which are suitable. (Scientist C)

Finally, the researchers are also well aware that as long as islet cells are derived from standardized stem cell lines and not stem cell lines created from the patients’ own cells, then problems of tissue-matching and organ rejection will also have to be resolved. In the case of stem cell research the number of stem cell lines needed is believed to be several orders of magnitude larger than that which is currently available, which means that new ways of reducing rejection are needed:
The problem there is the numbers that are required. It really depends on who you talk to but the transplant immunologists say, to match people of high fidelity so you would not need immunosuppression, you would probably be looking at least 100,000 cell lines. Now, who’s going to come up with a facility to generate 100,000 cell lines … I just don’t think we’re going to do that for every person that you want to use cells on, so we’re either going to have to come up with better immunosuppressant regimes or figure out a way to knock off, through genetic engineering, molecules that promote immune response. (Scientist A)

Described this way, the potential of stem cell therapies seem somewhat distant, although as the same scientist also made clear, from a research perspective there are factors which give grounds for hope. The success of Edmonton protocol proves that it is possible to cure diabetes whilst the limitations of the procedure provide a clear indication of where future research should be directed. The trick is to be realistic about the timescale involved. As one American scientist recently explained:

… years – even decades – of experience may be needed before we learn how best to deliver cells as medicines. Just as small-molecule pharmaceuticals revolutionized medicine in the last century, cellular therapeutics are destined to emerge as a major modality for treating the degenerative diseases of an ageing population, but it may take the better part of this century to get it right. (Daley, 2002: 611)

Seen this way, for stem cell therapies to be anything other than a last resort, it must be possible for immunosuppressants to be avoided and this requires a significant number of technical hurdles to cleared. As one of our own respondents put it:

Treatment against cure? I think the cure may be a bit further off than some people imagine it to be. (Scientist B)

Alienated Opponents

At the opposite side of the certainty trough are the alienated opponents of the technology. Although often well informed about the science these groups refract the scientific uncertainty through a very different lens and amplify rather than attenuate the importance of the uncertainty associated with the science. When coupled with a political and moral stance that opposes several of the assumptions embedded in the genetic paradigm, the outcome is a highly negative evaluation.

Opponents of a technological trajectory often have two distinct sets of concerns. Firstly, they are aware of the technical difficulties involved in the research. Thus, for example, charities and genetic watchdog groups know that stem cell research is targeting diabetes but tend see the auto-immune response of the patient as a fundamental obstacle:

I think the idea of therapeutic cloning for Type 1 diabetes is fairly nonsensical because it is an autoimmune condition. OK, you will be able to put back into the patient some more pancreatic cells, but those cells are likely to be immediately attacked by the patient’s autoimmune system. So, I don’t really see how therapeutic cloning it is to work for that type of diabetes. (Campaigner A)

Similarly, the difficulty of growing a sufficient number of suitably pure stem cell lines is seen as effectively preventing the research ever reaching its goals:
You need to have a lot of cell lines and to observe a consistent pattern in order to get any valuable information. Because it’s so difficult to get stem cell lines, they’re only talking about working with a number that is not going to be statistically significant. So, I think that’s one problem. I also think cloning is likely to create gene expression problems in stem cells that are for treatment or transplantation. So equally it’s going to create gene expression artifacts in stem cells that are being used for research. So the very method is creating a fairly obvious artifact in the experiment and I don’t see how they’re going to get to get around that.
(Campaigner A)

In a similar vein, the spokesperson for a different organization also emphasized the technical problems and the uncertainty they create in order to question the potential of the research:

If we look at forms of diabetes that do have a component of genetic susceptibility, or are largely genetic in origin like MODY [Maturity Onset Diabetes in the Young], then you’d have to not just clone the cells, you’d have to genetically modify them to avoid the genetic fault that’s there in the first place, so that would be in addition … Then, obviously, in all cases there’s the whole issue of side effects, which in the case of the embryonic stem cells and stem cells in general are probably more related to whether you get tetranomas or if you get cancer related problems with cells growing uncontrollably. So there are all these kind of technical issues. Obviously we don’t know the potential to overcome these issues, but [it] clearly shows that there’s no major breakthrough around the corner … you’re not going to have personalized cloned treatments for everybody with diabetes. It’s just never feasible. (Campaigner B)

In addition, opponents of a technology trajectory can also raise concerns about its social and institutional implications. Whilst the proponents of a technology tend to see it as fitting fairly smoothly into existing institutions and practices – improving them by increasing the availability of transplant tissue, for example – opponents tend to see these benefits as a loss for someone else. In the case of stem cell research, the key problems raised typically relate to the source of the HES cells and the steady supply of oocytes that their use pre-supposes:

There are still huge unanswered questions about the science … but also very practical issues like where will the eggs come from. We think one of the very obvious problems, which doesn’t get much debate once it’s been raised, is even if this technology was to work, if you’re talking about type 2 diabetes and the number of cases, where are you going to get the eggs from to supposedly individually clone each treatment? Who’s going to pay for that? There’s clearly huge potential to exacerbate inequalities, even if the treatment should work, because your egg is most likely to come from poor women and people who need treating are going to be elderly or middle aged wealthy people. (Campaigner B)

In contrast to the research scientists, therefore, the skeptics tend to see the technical issues as further constrained by a series of moral or political issues. It should also be noted that, in the research described here, we only interviewed those organizations that are prepared to accept that there is a role for research on embryonic stem cells. Not represented in the data are the whole gamut of pro-life groups for whom any experimentation on embryonic stem cells is unacceptable for moral and religious reasons.
Optimistic Supporters

Located in-between the “knowledge producers” and those “alienated from the technology” are the groups who are committed to the technological program but are users rather than producers. In the case of stem cell research, this location is mainly occupied by the charitable funding organizations and patient advocacy groups. Whilst these groups may not be exactly the same as the “program loyalists” identified in MacKenzie’s original study, it is certainly the case that they are pre-disposed to accept the claims that stem cells research is the route to a cure. It is certainly the case, for example, that an optimistic interpretation of the research prognosis fits the stated aims of organizations such as Diabetes UK, which include a commitment “to work towards a future without diabetes.”

As suggested by the certainty trough, the main difference between these groups and the scientists lies in their assessment of the uncertainties that the technical difficulties create. For the research funders and other supporters the difficulties seen by the scientists are recognized as real and are reflected in the research topics that are selected as priorities for funding. The difference is that, even though the same problems are identified, the overall tone of the assessment is markedly more confident. Thus, a spokesperson for the Juvenile Diabetes Research Fund, when asked if they could see any problems that might arise from using stem cells as a source of islet cells for transplants, responded as follows:

I can’t see that there would necessarily be any [problems]. I mean we, the scientists, have … produced cells that will secrete insulin from the stem cells but the problem is that the more they differentiate the cells, the longer they try and grow them, they either lose their functionality or the potential of forming tumors [increases], that’s happened. The other problem is that we need to make these insulin producing cells produce insulin in response to glucose, so not just pump out insulin but actually produce insulin in response to glucose. So once we’ve done that I can’t see that there will be a huge problem, because once we can perfect the technique you would only need a very limited number of stem cell lines to produce the cells that you need for all these different people. (Funder A)

Whilst many of the research funding charities are somewhat removed from the day-to-day work of the laboratory and may therefore be less aware of its difficulties and contingencies (cf. Collins 1999) it would be wrong to think that optimistic attitude is precipitated entirely by ignorance. The charity, in common with most others, has a scientific panel to review grant applications before they are considered by a lay committee. Nevertheless, it appears that, for whatever reason, the research funders hear the scientists as telling them that the research will lead to a cure for diabetes. Thus, the diabetes research charity spokesperson justified their faith on the basis that this was exactly what the scientists were saying:

A number of scientists who I’ve spoken to believe that diabetes can be cured. It’s an incredibly complex condition, so it’s going to take an approach that comes from many different areas because we have to fix all sorts of problems. But we believe that given enough time and enough money we can find a cure. I’m afraid I can’t give you any more of a scientific answer, as I said I’m not a scientist. (Funder A)

As the quote above makes clear, the diabetes charities think that the research will lead to a cure for diabetes and they think this because the scientists have told them so.
Such pronouncements seem somewhat at odds with the carefully nuanced statements described above. They do, however, correspond closely to the findings of Shackley and Wynne (1996) that scientists make stronger claims to external audiences than amongst themselves. Even so, it should be noted that, in our interviews with scientists, we also encountered some quite positive assessments about the potential of stem cell research. Thus, for example, we were told that:

That’s the goal … if we can show that we can generate a cell that looks and functions like a beta cell from human embryonic stem cells, there is no reason that we can’t generate huge numbers of these cells, as long as we have a protocol to do it. From what we know about human embryonic stem cells, it should be possible to generate almost unlimited numbers of cells. Now that will be expensive and … I think the Government is going to have to put money into dedicated facilities for cell therapy. But then those will be readily available to any one who wants them on the NHS, or cells for cardiac disease or cells for diabetes. I think the therapies will be there. (Scientist A)

Given that scientists can give both optimistic and cautious interpretations of their work it is perhaps not surprising that funders give more weight to the optimistic part. Nevertheless, this difference in perceived certainty raises important questions. In MacKenzie’s work, and its subsequent use by Shackley and Wynne and others (e.g. Jasanoff, 2003), the presumption is usually that the more accurate assessment of uncertainty is the one made by the scientists “talking amongst themselves.” These difficulties and problems are then “left behind” as knowledge claims move away from the site of production. If all the epistemologically significant work of science took place in the constitutive forum, this may not matter, but STS has shown that actions in the contingent forum can be as important in creating scientific consensus as those in the constitutive forum. The use of different discourses in different contexts therefore raises important questions about the ways in which the wider society is able to engage with debates about research funding and regulation.

6. Collegiate and Community Forums
Under the definition proposed by Collins and Pinch (1979) the contingent forum includes all activities that fall outside formal publications and conferences. This includes a wide range of activities. In the following we propose a distinction between the “collegiate forum,” in which scientists are mainly engaging with other scientists, and the “community forum,” in which scientists interact with the more heterogeneous set of groups that make up the wider community. By understanding the different dynamics of these two settings we can also raise some more critical questions about the orchestration of public engagement with science.

Experts amongst friends – the “collegiate forum”
Scientists are generally relatively open about the uncertainties and problems associated with their work when they are talking informally to colleagues. The social contexts that facilitate this recognition of uncertainties can be thought of as the “collegiate” part of the contingent forum. By this we mean those settings in which the interlocutors are all scientists or researchers linked by a shared set of academic values and experiences. This does not mean that they all agree slavishly with each other about the correct interpretation of data, or the best methods for collecting and analyzing it, but that they recognize themselves as being members of the same academic community. In such a context, they will tend to talk about their work in a
way that differs markedly from the rhetoric used in other settings. In the remainder of this paper, we consider an alternative setting, which we call the community forum, in more detail as it is here that scientists appear to draw their positions more starkly.

**Experts on stage – the “community forum”**

The “community forum” refers to those contexts when scientists address a wider community. In such settings, many of the difficulties that are expressed by scientists in the collegiate part of the contingent forum are often glossed over. To give a particularly accessible example of this more general trend, at the Cambridge Science Festival in 2005, Professor Roger Pedersen told the audience at a public lecture about stem cell research that:

> The most obvious target, the soft spot, for the development of therapies from these cells would be diseases that could be treated by a single, purified cell type. It seems to me, at least as a first approximation, far too complicated to try to make tissues or organs, so I am talking about cells for the treatment of Parkinson’s Disease, where *all you need* is to get a single, purified cell type that makes dopamine and put it in the right place in the brain; or cells for the treatment of diabetes, where *all you need* is a purified cell type that makes insulin. (emphasis added)

This is clearly implies a very different picture of the progress that needs to be made in order to produce a stem cell based therapy for diabetes than the scientists we interviewed. Whilst scientists no doubt feel that public lectures require suitably uplifting claims to be made, it is not clear how glossing the uncertainties described in the earlier sections under the phrase “all you need” will promote a genuine understanding of the research. Any support based on taking such statements at face value is based on a different understanding of the problems that need to be resolved to that of the scientists and this creates the opportunity for disappointment or controversy later on.

But why does this happen? As shown above, scientists are well aware of the risks of exaggerating the benefits of medical research. Part of the explanation must lie in the influence that the public, and patients in particular, can exert on the scientists’ ability to carry out their research. The result is a clear incentive for scientists to present a positive message in order to retain support for their research. In some cases this will be financial support but there are also cases where scientists, patients and others have formed alliances – “ethno-epistemic assemblages,” as Irwin and Michael (2003) might say -- to campaign for changes in legal or regulatory processes that would facilitate scientific research.

Science in these community forums is thus a much more heterogeneous mixture of actors and agencies. The difficulty arises when these different elements come together in conferences and meetings that take on the form of science but subvert the conventional hierarchies of knowledge to make, and apparently substantiate, claims that might normally be seen as belonging in the constitutive forum. In these forums, there is a tendency for the uncertainty that scientists express in more collegiate settings to be overlooked as delegates focus on the positive promise of a potential cure. We saw a particularly clear example of this at a conference on patients’ perception of stem cell research. The conference was organized to lobby European Parliament and argue for a more permissive stance on stem cell research. During the conference a member of the audience, who had Parkinson’s disease, announced that
she had been sent by Professor Eldad Melamed of Tel Aviv University to share some exciting news:

**Patient:** Professor Eldad … and his research team in the Tel Aviv University has succeeded to cure – really cure – a mouse that had the Parkinson’s symptoms. The team, this research team can, will be ready to develop a method for curing Parkinson’s disease on patients within less than a year, possibly within 8 to 10 months, when he comes back from the US where he went to collect 2 million dollars that he's short to end his research. I think that this is a very, very important breakthrough.

**Moderator:** Thank you very much for telling us about that,

**Patient:** Yes, everybody speaks about 5-10 years. If this will be a reality, it will be 1 year.

In this case, the patients’ legitimate role as political actors was extended, apparently at the behest of the scientific community, to include the more traditional scientific roles of reporting new knowledge. It seems likely, however, that the scrutiny and assessment given to knowledge claims in such settings differs from that which would be produced by scientists in a more collegiate context.

Whilst the increase in certainty produced by pro-research conferences is to be expected, it does have some potentially important consequences. Firstly, it creates a context within which the belief that a cure is “just around the corner” is able to develop and circulate. Uncertainties and doubts that exist within the collegiate forum are silenced within the community forum as patients and funders encourage an optimistic account of the research prognosis. Medicine as succor overwhelms medicine as science. Secondly, it means that an important part of the scientific debate is not heard in the contingent forum. The public face of the critical debate is, instead, that of the alienated opponents. Whilst this means that some of the possible uncertainties surrounding stem cell research are aired, others remain silenced. Ironically, this bifurcation is reinforced by the structure of many public engagement events, in which a scientist working on stem cell research will typically appear on a panel containing a spokesperson for a skeptical NGO, a representative of a patient group and a member of a pro-life campaign group. Under such circumstances, the tendency towards reducing uncertainty is likely to be exacerbated and now appears to be such a common outcome that many of the scientists we interviewed were limiting their participation in these activities for just this reason:

I haven’t done a huge amount. I’ve done things like, when Diabetes UK was deciding whether or not they would fund research projects that involved human embryonic stem cells, they decided to have this issue debated and voted on by the members. So they had sort of a research day that I participated in. There were about 3 - 400 people, mostly either diabetics or carers of diabetics, and CORE was there as well, and that was my first introduction to them. This was soon after we got our license and that was quite interesting … and I’ve done a few things other where I participated in some public forum or debates where you discussed the therapeutic applications of stem cells. Again pro-life does tend to come to these things, and they tend to be very vocal and very aggressive, so I am now a little bit more cautious about what I agree to do. (Scientist A)
Nevertheless, and despite their reservations, scientists seem to have little choice but to continue to engage with the users in the patient and medical communities as they compete for a share of the available research funding. To do so, however, it seems that they must strike a balance between avoiding unrealistic claims and emphasizing the potential of their work to really make a difference. The tension and ambivalence is clearly expressed by one of our interviewees, as they described what they saw as the future for stem cell research:

there’s also the other [problem], and that’s people who work in this field saying that there have been huge steps forward and that embryonic stem cells will offer a cure for diabetes, because we don’t know that yet. We honestly don’t know whether they will offer a cure … I don’t think that’s going to happen with regards to stem cells in the immediate future … But I don’t want to put a complete downer on it. There’s a good chance. I wouldn’t be working in this field if I didn’t think that this had some potential for human benefit. (Scientist B)

7. Conclusions

Medical research requires faith on the part on its practitioners and its ultimate users. This is as true for diabetes as it is for other areas of medical research where patients live in hope of a cure, if not for them but for those who come after them. Medical researchers know this and strive to maintain a balance between explaining the promise of their research and raising false hopes. In practice, however, it is difficult to do this. The demand characteristics of the community forums within which scientists communicate to the wider society seem to militate against attempts to fully convey scientific doubts and uncertainty. The question remains whether or not this is a good thing and, if being aware of the limitations of a science is desirable, how this can be promoted without undermining the research endeavor itself. To some extent this is a problem faced by all science, but it is particularly acute in the case of medical research which must provide both science and succor.

In analyzing how scientists talk about their work, we showed that scientists’ expressions of certainty varied with the context in which they were talking. In collegiate contexts, scientists and researchers appeared to conform most closely to MacKenzie’s version of the certainty trough. Researchers were clearly aware of a range of scientific and technical difficulties that needed to be resolved before stem cells could be used in any significant therapeutic intervention. In presenting their work in this way, the researchers also constructed a particular version of the scientific domain, in which the research program became a series of technical problems to be resolved through incremental progress.

In more public contexts, however, the presentation of these same steps is subtly different. As predicted by MacKenzie, the funders and other supporters of the research tend to be more confident about the likelihood of the research to deliver a breakthrough than the scientists when they were talking amongst colleagues. In these community forums, however, the distinction between the scientists and their supporters breaks down. In some extreme cases, patients speak for scientists. A more general finding, however, was that the qualifications and contingencies that marked scientists’ discourse in the collegiate setting tended to disappear in front of these more heterogeneous audiences. Although the same breakthroughs are needed, the funders are encouraged to see the problems as small steps on a journey towards a cure. Without actually saying that the cure is “just around the corner,” the effect is nonetheless created that this is what is on offer. In making this observation, we are not
suggesting that the scientists are being disingenuous. Rather, what they are presenting is a different, but equally honest, account of their work that emphasizes its potential benefits rather than its current difficulties.

This emphasis on incremental technical progress does, however, have a pernicious effect on the broader debate. The problem is not that, by becoming the dominant paradigm, stem cell research takes money from other research programs. Rather it is that it allows the public debate to be framed in terms of the social and moral agendas of the alienated opponents. Whilst there is clearly a place for such debate, what is missing, however, is a more realistic debate about the nature of scientific research itself. As a result, the broader social and moral issues that may prevent the wide scale application of stem cell research are regularly rehearsed but the equally significant technical challenges that need to be overcome remain obscured. This not only perpetuates a particular view of science but, in this unspecified waiting period, allows other forms of treatment to be seen as less important precisely because the “real” treatment is “just around the corner.”

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2 A stark illustration of the stakes that are involved in stem cell research can be found on the website of the Multiple Sclerosis Resource Centre (MSRC, www.mrsc.co.uk). Already it appears that there are patients who see scientific caution about stem cell therapies as delaying treatment for them until it may be too late. The website contains numerous testimonies from UK patients who have paid to undergo what many scientists would see as risky and untested stem-cell treatments in the Netherlands and Belgium together with appeals from others desperate to raise money to do the same.

3 The research presented here forms part of a larger project in which we examine more directly the effect of different kinds of information and different kinds of experts on the opinions of both lay and patient groups (ESRC grant number ??????, awarded to QUALITI). In this context, diabetes research is a particularly interesting research site because it combines leading edge science with an active patient lobby and potentially controversial regulatory decisions. In this paper, however, we are simply concerned with the kinds of arguments and claims to which such groups may be exposed and the circumstances that shape the public presentation of science.

4 At present, the cause of diabetes is largely unknown. There is a genetic pre-disposition to the development of both Type 1 and Type 2 diabetes, but the actual onset of the disease appears to be triggered by environmental factors. It should also be noted that, although we follow the conventional distinction between Type 1 and Type 2 diabetes in the main text, there are forms of diabetes that do not fit either category exactly. For instance, neither latent autoimmune diabetes in adults (LADA) nor maturity onset diabetes of the young (MODY) maps neatly onto the dichotomy.

5 This typology is of our making and reflects our analytic purposes in this paper. It is not intended to represent the ways in which researchers or people living with diabetes distinguish between different kinds of treatments and research.

6 Research in this vein would include ‘expert patient’ programmes through which patients are encouraged to take greater control of their diabetes and reduce their dependence on medication (http://www.expertpatients.nhs.uk/), the Dose Adjustment for Normal Eating programme, which aims to help people with type 1 diabetes match their insulin dose to their body’s needs (http://www.dafne.uk.com/), and the DEPICTED study, based at Cardiff University (http://www.cardiff.ac.uk/medicine/general_practice/about_the_department/research/Projects/DEPICTED).

7 For more info see, e.g. http://diabetes.niddk.nih.gov/dm/pubs/pancreaticislet/

8 It is important to note that this outcome is not inevitable, however. The idea of international expertise (Collins and Evans 2002, 2004, 2006) suggests that, if research funders were to engage more closely with the research community, then they could develop a similar understanding of the complexities even if their experience of them was linguistic rather than embodied.

9 In total, we conducted 15 interviews and attended or organised 5 conferences. In selecting interview participants we were able to keep the roles relatively distinct. Thus, for example, the scientists were not active in raising money for diabetes charities, although they did receive grants from them, whilst the charity representatives were not medical or biological scientists, although such people did sit on the funding panels. It should also be noted that pro-life charities were not included in the sample.

10 Lahsen’s model is not a straight line, so is not strictly linear. There are no turning points, however, so uncertainty always increases with social distance from the research front.

11 Although the quotes presented are from individual interviews with scientists, we are using them to represent something more than the individual opinion expressed at a particular moment in time. Instead we are taking them as perspicuous examples of a discourse that constitutes a form of life (cf. Collins 1983). As we show in the text that follows, the views expressed by this particular are representative of a particular representation of stem cell research that is available to, and recognised as legitimate, by research scientists.
The same concerns appeared in other interviews and can also be found in the publications that appear in the constitutive forum. See, for example, add reference here.

12 To give an idea of how much who you talk to matters, there are some scientists who claim that 150 HES-cell lines obtained randomly are needed to ‘provide a worthwhile HLA match for most potential recipients’ (Taylor et al., 2005: 2019).

Unlike Lahsen’s examination of climate change models, where the distinction between users and producers seemed to break down with all ‘producers’ also being users of some other ‘producers’ code or model, the distinction between producers and users does appear to hold for stem cell research.


15 Although we do not discuss these settings in this paper, they are the focus of much STS research. See, for example, Collins (1992), Mulkay and Gilbert (1984) or Shackley and Wynne (1996).

16 Available online at: http://www.eescn.org.uk/media/pedersen.html. The quote reflects sentiments we heard expressed at many of the seminars we attended throughout the project. Using this particular extract has the advantage of allowing the reader to check the original for themselves.

17 For example, presenting science in this way might contribute to the ‘flip-flop’ evaluation of science described in the Golem books.

18 The argument can be seen by considering the opposite effect. MacKenzie argues that, in the context of nuclear weapons policy, that:

Crucial decisions bearing on matters of nuclear life and death have to be taken by those who are not ‘experts’ in the sense of having access to insiders’ uncertainties. That is both right and probably inevitable: right because it is the only way that is at least partially compatible with democracy, inevitable because any significant decision will straddle more than one area of expertise, and there is no good reason to expect experts drawn from two areas to agree. Given that uncertainty should incline to caution, any softening of the public image of nuclear facts that can be achieved is thus worthwhile. Giving voice to insiders’ uncertainties is one way to help (MacKenzie 1993: 420).

If, as MacKenzie suggests, uncertainty leads to caution, this would help understand why public discussions of medical research emphasise certainty rather than uncertainty.

19 One example that is of particular relevance to stem cell research is the creation of the Society of Stem Cell Research by Jürgen Hescheler, head of the Institute of Neurophysiology at the University of Cologne, as a political tool to gain public support for a less restrictive laws.

20 Eldad Melamed has links with the Rabin Medical Center, the Sackler School of Medicine at Tel Aviv University and serves on several committees, including National Parkinson Foundation's Center for Research Excellence in Israel and the Michael J Fox Foundation for Parkinson's Research.