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Public opinion as questions not answers:
How citizens evaluate the therapeutic
potential of stem cell research in the context
of T1 diabetes

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Working Paper

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Qualiti Working Papers: Public Opinion as questions not answers: how citizens evaluate the therapeutic potential of stem cell research in the context of T1 diabetes

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‘... there is nothing a government hates more than to be well-informed; for it makes the process of arriving at decisions much more complicated and difficult’ (John Maynard Keynes, quoted in Skidelsky, R., 1992: 630)

Public participation in science and technology

It is now commonplace for policy-makers, think-tanks and social scientists to call for increased public participation in science and technology policy (e.g. House of Lords, 2000; Wilsden and Willis, 2004; CST, 2005). Nowhere is this more apparent than in stem cell science. The recent Pattison report¹ on the UK Stem Cell Initiative called on the government to invest at least £350m in stem cell research by 2016 and also stressed the importance of maintaining a ‘close liaison of parties involved in developing regulation and public dialogue on stem cell research’ (recommendations 8 & 11). Whilst laudable, the idea of increased participation is not without its problems. For example, one frequently expressed concern is that public dialogue comes too late in the process to effect any significant change. From this perspective, consultation exercises are seen as ways of re-building trust so that what is presented as an exercise in democratic participation can often be interpreted as an investigation into how to gain support of the public (cf Irwin, 2001, 2006; Rayner, 2003; Rowe and Frewer, 2004).

Understanding and representing public opinion is, therefore becoming an increasingly important part of scientific innovation in potentially controversial areas like stem cell research.² As such, it is not surprising that research exploring the determinants of public attitudes has become a key part of the social science contribution to the biosciences (e.g. Evans and Durant, 1995; Durant and Legge, 2005). It is also unsurprising that, when evidence of public support or opposition is uncovered it is used by campaigners to bolster their particular case. A typical example of this is the reporting of the *GM Nation Debate* in the UK which, to the dismay of many scientists, was typically presented as having proved that the majority of the British public were opposed to GM crops.

In this paper, we focus on public opinions about stem cell research and argue that it is misleading to talk about public attitudes to uncertain and controversial scientific research in terms of binary oppositions of support and resistance. Instead, we examine attitudes to stem cell research in a more contextual way, exploring how different groups – patients, carers and lay citizens – locate stem cell research in relation to other existing and potential therapeutic pathways.³ The study revealed that participants’ attitudes to stem cell research were ambivalent rather than certain and that, whilst in no way were our participants fundamentally opposed to stem cell research, cautious and critical voices were prominent in all discussions.

Drawing on data from a series of focus groups, we show that participants did not rank stem cell research particularly highly when it was presented as one of several options. We also show that, within the focus groups, different kinds of

participants tended to use different arguments in discounting the importance of stem cell research. Significantly, none of these groups found that the 'ethical issues' which dominate the media debate to be particularly important. In examining how different values and priorities were placed on stem cell research, our research demonstrates that more complex mechanisms are needed to adequately reflect 'public attitudes to stem cell research' and, by extension, other similar areas such as nanotechnology. In the remainder of the paper we describe our research design and our findings in more detail. We begin, however, by scrutinizing the most popular measure of public opinion – the opinion poll – before considering the alternative, qualitative approach used in our own research.

Public engagement in stem cell research

It is possible to argue that the 'liaison' called for in the Pattison Report has already begun. Several public dialogue activities about stem cell research, ranging from citizens' juries, public consultations and opinion polls, have already been completed in the UK.⁴ It is significant, however, that it is only the results of an opinion poll conducted by MORI (MORI 2003), which found that the 'majority (70%) of the members of the British public support the use of embryos for medical research,' that appear to have been noted in Government policy.⁵

As most social scientists know only too well, the apparent objectivity of surveys is as much a matter of their presentation as their methods. For example, although the claim that 'The vast majority of the UK public currently supports the use of embryonic stem cells in medical research' (Pattison report, p.26) is widely reported, this has a very different effect to saying that nearly 1 in 3 citizens do not support the use of embryonic stem cells in medical research. Similarly, the Pattison Report does not mention that the same MORI poll found that only 'one in six members of British public feel the use of human embryos is always acceptable for all types of medical research'.⁶

Determined critics of the research can, and do, go further. In addition to the obvious claim that the poll itself was commissioned by a coalition of public sector and charitable organisations involved in medical research, they can also challenge the ability of respondents to make the judgements required by the survey. A poll commissioned 2 years later (2005) by newspaper The Daily Telegraph found that 60% of those surveyed said they did not feel well enough informed about the relevant science to make decisions about topics such as cloning and stem-cell research.⁷ More generally, it has been shown that question wording has a significant influence on the results, with this effect particularly pronounced in stem cell research (Nisbet, 2004). Whilst these problems are central to all survey research, they become particularly important when survey data are used as evidence in policy debates.

To summarise, therefore, the premise of a key UK policy document – that the majority of the British public supports embryonic stem cell research – appears to

be based on a specific rendering of a single question in a single opinion poll. In framing the question, and hence the legitimate focus of public concern, the poll as it is typically represented, constructs public opinion as being either for or against stem cell research. In so doing, however, it says little about the concerns that might be expressed about the way that research might be used. In our study, we addressed these latter concerns by exploring the issues and apprehensions raised by research participants themselves. Following lead from Wynne and others whose work has shown how framing of issue by lay citizens and other stakeholders may vary considerably, we began from the assumption that opinions may be complex, ambivalent and dependent on nuances of context and application (see e.g. Grove -White et al, 2000; Irwin, 2001).

Talking treatments – research design

In our study, we tried to respond to these problems by enabling groups of citizens to engage in a dialogue about stem cell research. The aim of the project was to organise and evaluate a public engagement process through which expert citizens (i.e. carers and patients) and lay citizens could contribute a deliberation about future treatment options for type 1 diabetes that also included a range of ‘official experts’ such as scientists, clinicians and research funders. The methods used included expert interviews, reconvened focus-groups and a deliberative roundtable workshop.

Unlike the survey, which requires quick answers to fixed questions, we wanted to give participants time to learn about and reflect on the issues before asking them to give their opinions. We also aimed to contextualise their debates: rather than staging a discussion about generalities, we selected a particular context (future treatments for diabetes) and attempted to mimic a real life decision-making process (ranking the different options in terms of their funding priority).

In this paper we will discuss the results of the focus group stage of the study. It comprised 7 reconvened focus groups, conducted in Cardiff during summer 2006 (see the table 1):

Table 1: Group composition

group number	participants	gender	age	number of participants
1	Lay	men	28-57	5
2	Lay	women	33-51	3
3	Lay	women	23-35	3
4	Carers	mixed	21-46	5
5	Carers	mixed	23-48	5
6	Patients	mixed	21-50	5
7	Patients	mixed	45-67	4
Total number of participants				30

Lay people (defined as those who have no training in, or specialist knowledge of, science, medicine or diabetes) were recruited through local schools and the University notice board. Recruitment of carers (people who have close friends or family members with type 1 diabetes) and patients was done mostly through the diabetes clinic – each patient with type 1 diabetes attending the clinic over two week period received a letter of invitation. Although we got a satisfactory response from the patients, this method was less effective for the recruitment of relatives and friends, who were mainly reached through the University notice board. For both patients and carers we wanted to reach people who were not actively involved in the patient advocacy movements or charity groups, hence we did not use diabetes charities, such as Diabetes UK or JDRF (Juvenile Diabetes Research Foundation), to recruit participants, although they did participate in other stages of the research.

Procedures

Each focus group met twice, with a two week gap between the two meetings. In the first group, participants were asked about their knowledge of diabetes and its treatments, their knowledge of stem cell research and other developments in the new genetics. They were then asked to fill in a ranking table with possible future therapeutic pathways, listed in Table 1, in rows and various evaluation criteria (e.g. ethics, risk, safety etc.) in columns. Initially, each participant filled in the table individually, interpreting each treatment and the criteria in their own way. In this way, we hoped to record of each participant’s individual opinions without peer pressure. The individual rankings were then put onto a single, integrated table so that all participants could see each other’s rankings. As we expected, the range of interpretations for the treatments and the ranking criteria varied significantly between participants at this stage. These differences and similarities were then discussed in the group.

Table 2: Treatment Options used in Ranking Table

<i>improving existing treatment options (monitoring and medication)</i>
• finding non-invasive ways of blood glucose monitoring
• producing better quality of insulin and working on better forms of delivery
• developing drugs to treat diabetes and its complications
<i>technological solutions:</i>
• perfecting a closed-looped artificial pancreas
<i>regenerative medicine</i>
• perfecting islet transplantation
• creating ‘universal donor’ sources of insulin through hESC research
• <i>immunological and preventative approaches</i>
• regenerating the body’s own beta cells without islet transplantation
• preventing type 1 diabetes by maintaining or restoring immune tolerance.

At the end of the first group meeting, participants received a range of information materials⁸ relating to diabetes and each of the treatment options that had been

discussed. They were asked to read the material and complete the ranking table again before coming back in two weeks. At the second meeting, the participants compared their new ranking tables with their initial thoughts and with each others'.

One of the main differences between our approach and other projects was that stem cell research was discussed as one of several possible directions for the future treatment of diabetes and not the only option (unlike, for example, in Democs games).⁹ Participants were therefore asked to decide, using the ranking table as a guide, how the eight different therapeutic pathways listed should be prioritised.¹⁰ It is important to note that, when presented in this context, stem cell research, despite initial positive comments, was not ranked very highly by any of the groups.

Results of the group discussions

In this section we provide an overview of the participants' opinions and evaluations of stem cell research and discuss some of the differences that emerged between various groups. We distinguish between the reasons given in support of stem cell research and the arguments against prioritising it over other treatments, which were often voiced by the same people. Like others (e.g. Kerr and Franklin, 2006) we demonstrate that participants were ambivalent and illustrate the mixed views they had about stem cell research. This ambivalence, which was present at the first meetings, continued into the second focus group meeting where participants often reported that, although they had more confidence in their positions, they might change them later. Significantly, we also found that more information did not lead to more support and not necessarily even to more certainty.

The other, more substantive, point to note is that, although the so-called ethical aspects of hESC research (e.g. the use of human embryos for research) are often presented as being the most controversial, most of our participants did not think this was particularly significant. To some extent this reflects the MORI survey quoted above, but where our research differs is that this absence of ethical concerns is not translated into a statement of support for hESC research. Instead, we identify a range of other concerns that led participants to prioritise different treatment options. All these views are examined in more detail below.

Arguments in favour of stem cell research

Participants in the focus groups were by no means opposed to hESC research. Many could make arguments for its support and most could see some benefit in pursuing it. Looking across the focus groups, the arguments these participants made in support of stem cell research can be grouped into three broad categories:

The first reason mirrors popular media discourses and emphasises the 'huge' medical potential of the research, which is seen as leading to cures for a number of diseases. The following extract is typical of this kind of argument:

M: Right, why did you say it was promising?

P5: From the hype, but from what I understand stem cells will grow you a new leg or a new heart or a new lung, or cure all these chronic conditions. (lay men group, initial meeting)

The second set of arguments follow from this optimistic scenario, suggesting that hESC research is the only option for the future. In this account, the promise of hESC research represents the only hope for millions of sufferers.

P3: personally I think I would be for it, because I can't see any other way forward really. It's okay if you haven't got those diseases, isn't it, but if you want to eradicate them or move forward, I don't know, if that's what they are saying, this is the way forward. (lay women gr, 1, initial meeting)

The final set of reasons continued this optimistic scenario, but tempered it with some caution. In taking this view, participants recognised 'the hype' surrounding stem cell research but understood that the potential benefits of stem cell research can never be realised without funding. The necessity of risky investment in medical technology was recognised in statements such as:

P3: We will never know if the research is successful unless we put money into it. (carers gr2, initial meeting)

In making these arguments, participants often referred to the limits of their own knowledge and the role of the media as a source of information about stem cell research. Nevertheless, that many participants had access to these discourses and, to some extent, believed them to be true, is important when interpreting their more cautious comments below. In particular, these were not people who were opposed to science in general or even stem cell research in particular. Almost all recognised it as a legitimate field of scientific research. What they could not do, however, was convince themselves that it was the most important.

Views in opposition to stem cell research

One unexpected finding was that participants did not mention the usual ethical challenges surrounding stem cell research when raising doubts about it. In part this was because many felt that, despite knowing stem cell research was ethically controversial, they could not explain what the source of these concerns was:

P3: Most of what we hear about is the ethical side. And I don't really know anything about it, but some people for some reason say it is possibly unethical but I've no idea why. (lay men group, initial meeting)

Significantly, even when the issues over the use of embryonic cells were clarified the consensus in all the groups was that these were not major concerns. Nearly all participants were prepared to accept the use of embryos for research providing this research fulfils its promise of finding cure for life threatening conditions. They did, however, raise two caveats to this position:

1. using embryos for research when no definite guarantees about its outcome can be given is problematic, and
2. ploughing resources into a field of research if many groups of citizens have serious objections to its ultimate application may be pointless.

As the participants put it:

P2: Mine isn't an opposing view as much on the ethical, moral side. I just don't know whether we're ever going to get to a consensus where we actually do agree to be able to do anything with them (hESCs).

P1: I agree, it might happen that, as you say, they do lots of research but we never use. What's the benefit of that?

P2: I can see the benefit of it but I just don't know whether we're ever going to actually see those benefits. (carers gr1, reconvened meeting)

As noted above, the absence of a radical ethical objection to hESC research did not mean that participants backed stem cell research unreservedly. Instead, they identified a number of other concerns that prompted them to prioritise other options. Examples of these included:

- ? **Emotional investment in here and now:** often manifested in the belief that time is running out for the sufferers who will die before any therapy is developed. Life is 'now' but stem cell science is too speculative to be presented as if it was on par with existing treatments.
- ? **Doubts about stem cell science:** the recognition that stem cell science, even if it does lead to a therapy, may not offer a cure so that diabetes would be 'managed' rather than 'eliminated'. There were also concerns about the problems of rejection, surgery, immunosuppressants and other potential side effects.
- ? **Irritation with the hype:** the sense that there was a lot of noise but few, if any, results. Many were concerned that science and the media might be serving their own, vested, interests and that the complexity of stem cell science was being used to manipulate public opinion.

Not all citizens used all these arguments, though most could appreciate most of them. In what follows we will elaborate on these views, focusing on comparison between lay citizens and the patients, as this does reveal an interesting difference of emphasis.

Lay Citizens

Lay citizens represent the ordinary public and were expected to bring social judgement rather than specialist knowledge to their deliberations (Evans and Plows, 2007). To some extent this was borne out in the focus groups, where all participants said they had heard about stem cell research, but none were able to explain the details. The lay participants admitted that they did not have enough knowledge about stem cell research and that they relied on the mass media for most of their information. Their social judgement, also revealed in other studies (e.g. Kerr et al 1998), was exemplified in their comments about the validity of this information and their concern that the media were simply playing along with those who had a specific interest in promoting stem cell research:

P1: I would take any claim of stem cell research at the moment with a very heavy pinch of salt. The guys in the lab who are pursuing the research programmes or PhDs, the overall programmes, have to keep positive in terms of grant applications.

P2: it is still very young technology in the area of research

P1: Well, five years ago, a cloned human being of a stem cell was promised in five years time - that hasn't happened. (lay men, initial meeting)

Lay participants were thus often concerned with the likely return on investments in stem cell research. They often appeared rather irritated by the hype they felt surrounded research that had not yet shown much evidence of real achievements. In accounting for the press coverage, many were sceptical, suspecting that scientists and media were manipulating them into following a pre-determined agenda. As one participant put it:

'the scientists may be very, very biased, wanting to grow this cell no matter what'. (lay women, gr1, initial meeting)

Despite these concerns lay participants often struggled to define their own role in this debate. One finding of particular relevance for those concerned to promote public participation was that many of the lay participants explained (and justified) their lack of knowledge about stem cell research by saying that that they had no reason to be interested in it: 'It doesn't rock my boat' – as one of them put it. Significantly, even when it came to the discussion of ethical issues, lay participants struggled to see their role in these debates as going beyond stating their own individual views:¹¹

P1: I would not be confident talking about the ethics of it – on others behalf. I have my own beliefs, I have very – I suppose I can make them black and white in my own head, but the idea of getting into the ethical acceptability for a population – no – straws in the wind – (...) – because there's five people sat around this table, I'm sure therefore there will be six opinions minimum. (lay men, initial meeting)

Instead, perhaps not realising that this is also an ethical stance, most participants agreed that stem cell research and therapies should be a matter of personal choice for patients and donors. The donors should have a right to decide if their embryos or gametes are used for research, whilst patients should have the choice to accept or refuse treatments derived from embryonic stem cells. In neither case, should external 'pro' or 'anti' groups enforce their views on the others, even though the existence of these opposing views was also seen as problematic for the long-term development of stem cell research as neither side was likely to concede that the other was right.

The effect of these concerns was that stem cell research was often seen as a relatively low priority, with the lay focus groups tending to prioritise long-term investment in preventative and immunological type therapies that would address the underlying autoimmune condition (find the reasons for the destruction of β -cells) and potentially find ways to stop or prevent this from occurring. This in their view would constitute a proper cure for diabetes. Next in line were improvements to existing treatments, seen as a way of minimising problems until the 'real' cure was found. Creating 'universal donor' sources of insulin through hESC research and artificial pancreas approaches were typically at the bottom of the list, seen as complex, costly and uncertain ways of ameliorating the symptoms without actually addressing the underlying cause.

Patients and Carers

People whose lives were affected by diabetes voiced rather different, more practical, concerns to lay citizens. Rather than focusing on a cure that may be far away and involve other health risks they prioritised research that would improve their life in the near term. This typically manifested itself as a preference for technologies to improve control of blood glucose or the quality of insulin and other medication and thus to minimise the impact of diabetes on their life.

Like the lay participants, they doubted the ability of stem cell research to bring about a treatment or cure in the foreseeable future, but in their case, the scepticism was based on more direct experience – personal expectations of medical interventions they had in the past and that have never materialised:

P4: I've read and heard most of that (the promise of stem cell research). But my attitude over the years has been to sort of switch off to it because you know that it's not going to happen tomorrow and therefore you just think I'll wait until this actually becomes a bit more like reality.¹² (patients gr 1, initial meeting)

A second area of concern for all the patients who took part in focus groups was that a treatment for diabetes should not involve significant health risks. In particular, and this was something that became more important as they found out more about stem cell research, they did not want anything invasive. As a result,

and despite the claims that stem cell treatments might lead to a cure, patients were invariably cautious in their assessment:

P3: Because it's invasive isn't it. It's going to be ... you're going to have to have some sort of procedure done to have the stem cells implanted into you. And take the drugs to prevent rejection. So it's obviously a more dangerous procedure than what I have now. (patients gr 1 , initial meeting)

In making these judgements, patients readily admitted that they were acting 'selfishly', by which they meant that they would prioritise research that would help them over research that might benefit some imaginable sufferers in the future. This not to say they were totally opposed to stem cell research. Rather, the general agreement was that stem cells cannot be considered as a priority for type 1 diabetes because other conditions need this treatment more urgently and, in any case, it is possible to achieve reasonable quality of life through improving current treatments and diabetic care.

P 5: And again, stem cell... I think it's an absolutely fantastic thing that could happen, but I don't, honestly, believe that diabetes is where it should all be geared to, initially. I think that should come in time but I don't think that is a priority. Because we have a condition that is treatable: we can, actually, put our own destiny there. If we want to look after ourselves we'll have a nice long healthy life. If we don't want to bother then we're going to have all the complications from it. Someone with Parkinson's...not a lot you can do. (patients gr1 , reconvened meeting)

Like lay citizens, therefore, patients and carers tended to favour the preventative and regenerating body's own cells approaches over the hESC approach but, unlike the lay citizens, put improvements to existing therapies above either of these.

Public Opinion as Questions not Answers

The presumption of policy documents, including the Pattison Report, is that lay citizens and patients can participate in decision-making. If this is to happen, despite the reticence expressed by the lay participants in our research, it is necessary to understand what kinds of concerns they bring to the debate. If our criticism of survey research – i.e. that it reifies attitudes – is correct then we must also ask what a critical evaluation of our own methods suggests about the views of lay citizens and patients with respect to research priorities and their role in setting the research agenda.

First, it is clear that both lay participants and the more expert patient and carer groups had complex views. All participants saw similar sets of positive arguments for stem cell research but these were offset by slightly differing sets of more negative concerns. Nevertheless, what was particularly noticeable was that, for all groups, the range of important concerns did not include the ethical issues

typically referred to in documents such as the Pattison Report. Rather participants had many different questions and concerns, which moderated the positive claims to a greater or lesser extent. As a consequence, participants did not consider their views as set in stone and were prepared to change them in light of the answers to their questions. This suggests that debates about policy and funding need to consider a broad range of issues and to interpret the opinions given as provisional rather than fixed.

Treating public opinion in this way creates its own problems, however. For example, the potential effect of new information to act as a barrier to participation because people may feel they need more information before they can participate. In the case of stem cell research, the radical uncertainty created by the unknown future of the research meant that participants found it difficult to engage in the debates when, in their own words, they did not have enough knowledge about it. For example, our participants wanted to know how long it would take to produce hESC therapies and how much this would cost. They thus found themselves in a similar position with respect to stem cell research as the citizens described in Irwin et al's study of a life near a chemical plant (Irwin et al., 1996). Both lay and patient participants were, on the one hand, suspicious of the vested interests various stakeholder groups had in promoting stem cell science and, on the other, believed that these same groups were best placed to provide definite answers to specific questions.

One particularly striking manifestation of this expectation of certainty was the way scientific expertise was discussed. In general, participants did not see technical limits or problems as a constraint on hESC research. Instead, almost all participants thought that anything was possible and believed that scientists could differentiate hESCs into everything if only they had enough time and money. Perhaps more surprisingly, this trust in science also extended to its related institutions. Noticeable by its absence from the discussion was any strong concern about the risks that hESC therapies might pose either to patients or public health. This meant that, although participants identified a range of concerns, these did not include the issues that social scientists typically raise. Thus, for example, concerns about social justice and equity were not mentioned. In the case of patient groups, even though they shared rich personal knowledge about the lack of resources in Primary Care Trusts and the difficulty of accessing the currently available treatments they did not consider the effect of stem cell therapies on the resources available for other treatments.¹³

In summary, then, our research confirmed many of the findings of other qualitative studies, in that it revealed the dangers of reifying public opinions (Cunningham-Burley, et al., 2001, Dolan et. al., 1999, Fisher, 1999). In our study participants expressed a range of views and concerns, depending on the specific context and in response to new information. As well as being prone to change, these opinions were presented as narratives rather than a single, fixed answer. Rather than seeing this as problematic, however, we would argue that these

narratives reveal the very ambivalences and contradictions that participants struggled with when asked to have a definite say and which participation processes should allow them to express. Although they did not voice all the questions that could be asked, and perhaps not even the ones that we expected from them, they did nevertheless express the concerns that were salient to them.

Conclusions

The central claim of this paper has been that the standard survey-based representation of public opinion that dominates UK policy documents is misleading. Not only does it convey a false sense of certainty about that opinion, it fails to articulate the concerns people do express when given the space to set their own agenda. These concerns matter because, if a meaningful public engagement with hESC and other nascent scientific fields is to take place, then such a process needs to start from the actors' categories and not the framing preferred by the scientific elite.

What our research shows is that starting from the lay citizens does not lead inevitably to opposition. Rather, what it demonstrates is a concern to strike the appropriate balance between competing claims and concerns. The quotes below illustrate how one participant in our study reflected both on what she thinks and how and why she thinks as she does. Like many others, she felt that she did not have enough knowledge to have an opinion:

P2: I mean I know it's [hESC research] controversial and I know that people perceive it as being controversial and that your ... you know, you'd be making a fundamental change to something that is ... is a certain way. So I know that ... but, as a personal opinion, I don't really have a strong personal opinion because I think I'd need to know more about it to have one. (carers gr1 , initial meeting)

In explaining this, she describes herself as being torn between a personal preference and the idea of more general moral position:

P2: That's where I have like two sides of me that'll sort of argue with each other, that there's a side of me that says: personally, people I know have gone through real horrible things; if you can stop that then that would be fantastic. But then the other half of me, you know, can see where you're coming from and I think: is this morally right? And I really struggle with it. I really do. (carers gr1 , initial meeting)

Significantly for those who still hold the deficit model and hope that explaining more about the science will solve the problem, the information materials provided about stem cell and other treatments, did not help this person to end their inner conflict:

P2: (...) I still... even with reading everything, I still found myself in a real sort of like what do I think. (...) I just think are we going to get hung up on deciding that this is the way we want to move forward when we could be investing things on other things that we've got the green light on now. And are we... you know, so I just found myself in even more of a quandary that I was before by the time I'd read and watched everything. (carers gr 1, reconvened meeting)

The key issue for public participation is to know what to make of such ambivalence. The crucial step, recognised in other studies, and made explicit in our research is that it should not be concealed, eliminated or dismissed. Rather, if stem cell research really is seen as complex and controversial, then ambivalence may be a more accurate reflection of what people think than aggregate findings that a particular proportion of the public does or does not support stem cell research. Framing the statement in this way reinforces polarisation – the very thing that participants were worried about. Moreover, presenting public opinion as blocks of undifferentiated support or opposition may be harmful in the long run as it misrepresents the variety of views held by different publics. If this is correct then, rather than being taken by the simplified representations about public opinion, policy makers should be open towards more genuine understanding of diversity, ambivalence and uncertainty of public views.

There is also a more positive conclusion that can be drawn from this. To the extent that this ambivalence of the wider society is an accurate reflection of the uncertainty within the scientific community, then it must be a legitimate input into the regulation and governance of science for setting the priorities for future research. This is not to say that citizens should decide when a scientific claim has or has not been falsified, but that the hopes and concerns of lay citizens and patient groups are important and should be encouraged at much earlier stages of the scientific and policy process. In particular, giving greater emphasis to such unstructured public dialogue at an early stage in the development of new research fields like stem cell research and nanoscience allows both funders and scientists a greater insight in the needs of those they claim to serve (Macnaghten et al, 2005). In the case of treatments for diabetes and the role of stem cell research in their future development, both patients and lay citizens currently prefer a future that is rather different to the one envisaged by the scientists and funders.

Finally, we should be clear in saying that identifying the different priorities accorded to stem cell research by scientific and other communities does not imply that lay citizens or patient groups should have a veto on scientific research. Rather, it calls for a reconfiguration of the relationship between science and the wider society and the context within which scientific research takes place (cf. Wilsdon and Willis, 2004). Rather than being presumed autonomous, whilst in practice tied to a particular world view, promoting upstream public engagement

promotes a debate about the purposes that science should serve. In this way, public opinion becomes the mechanism through which society poses new questions to science rather giving its verdict on their answers.

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¹ Pattison report, UK Stem cell initiative. Report&recommendations. November 2005. (available to download from <http://www.advisorybodies.doh.gov.uk/uksci/index.htm>)

² Although some authors demonstrated that broadening public participation have only limited value in improving public confidence in the regulatory regime as many other factors inhibit this outcome (see Rothstein, 2004). Irwin (2006) argued that that openness might *create* further grounds for criticism and concern.

³ In our research project we investigated public perceptions of the risks and benefits of innovative medical treatments for type 1 diabetes, including islet transplantation, various mechanisms of insulin delivery, vaccination, and regenerative medicine.

⁴ For example Citizens Jury by Techniquist in Cardiff, a series of Democs games across the country, HEFA consultation as well as academic studies, e.g. by Sarah Parry's project *The -Social-Dynamics-of-Public-Engagement-in-Stem-Cell-Research* (<http://www.innogen.ac.uk/Research/>).

⁵ It is questionable to which extent government makes use of public opinion polls if they contradict what government wants to hear. In 2004, a Harris poll suggested that nearly three quarters of Americans support stem cell research. This number increased from a similar poll in 2001.

⁶ Online at <http://www.mori.com/polls/2003/amrc.shtml>

⁷ YouGov online survey: It's called Abortion, Euthanasia and Cloning, 30/8/2005 Available online www.yougov.com/archives/pdf/TEL050101042_1.pdf
A survey of the UK public's attitudes to current ethical and moral issues has indicated there is support for reducing the legal time limit for abortions.

⁸ Information materials consisted of 1) main booklet, where the information about diabetes, current treatments and each of the potential treatment options was described in an accessible format; 2) complementary materials – these included more detailed information about each of the new treatment options. This information was collated from various sources to represent the range of opinions and kinds of discourses on each topic: scientific articles, media reports, Q&A sections from charity websites, articles from diabetes journals (Balance); 3) a DVD – A Stem Cell story produced for public use by EuroStem Cell.

⁹ Democs, which stands for '**DE**liberative **M**eeting **O**f **C**itizens', was developed by The New Economic Foundation (NEF), with the support of the Wellcome Trust. Democs is part card game, part policy-making tool and enables small groups of people to engage with complex public policy issues. It has been recently adapted to discuss stem cell research and applied across the country. For more information go to: <http://www.neweconomics.org/gen/democs.aspx> [accessed 1 February 2007]

¹⁰ We must emphasise that we did not want to use ranking table as a data-generation tool, e.g. by treating the rankings as serious ordinal data. Instead, the table was a tool for facilitating discussion and making explicit the opportunity cost of choosing to prioritise one treatment rather than another. The data thus comprised the discussions about participants choices and the explanations they gave for these .

¹¹ When asked who should be involved in the ethical debates, they often named religious groups or 'professors of ethics or professors of philosophy, doctors as well, scientists a big group need to really look at the ethics of it' (lay women, gr 1 meeting 1). There was some inconsistency, however. Participants generally thought that it was desirable to have lay people on these committees to represent the 'ordinary public'. Nevertheless, when asked to do this, they typically felt unable or unwilling to fulfil this role and found it very uncomfortable to speak for the collective or for others. More generally, we found that participants found 'ethical criteria' particularly difficult to interpret or operationalise, with the result that several participants declined giving any 'ethical' ranking.

¹² The difference between the lay and patient groups thus maps neatly on to the distinction between 'ubiquitous' and 'local' discrimination described by Collins and Evans (2002, 2007)

¹³ Similarly, despite a number of recent stories about the availability of drugs such as herceptin, none of the lay groups raised the question of whether or not the opportunity cost of stem cell research and treatments would be acceptable.

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