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Promoting Deliberation Through Research: Qualitative Methods and Public Engagement with Science and Technology

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Abstract

This paper explores the contribution of qualitative research to public engagement with science and technology by critically evaluating a deliberative exercise designed to incorporate several aspects of contemporary science studies. The project used in-depth interviews, reconvened focus groups and a roundtable workshop to simulate 'upstream' public engagement by investigating how patients, carers and lay citizens evaluated different treatment options for Type One diabetes. By comparing how these treatments were discussed in focus groups and a roundtable workshop we show how the choice of research setting makes a significant difference to the data collected. In particular, we show that the relatively homogeneous focus groups allowed more perspectives to emerge than the apparently more heterogeneous roundtable, which was ultimately dominated by the patient perspective. In reflecting on these events, we acknowledge both the vulnerability of deliberative methods to factors beyond the researchers' control but also ask what status the outcome of such deliberations should have if these vulnerabilities could be eliminated.

Introduction

As science and technology have become more controversial, social researchers have become increasingly concerned with the role of the non-expert citizen in decisions about technology (Guston, 1999; Kerr et al, 2007; Evans and Plows, 2007; House of Lords, 2000). Public understanding of science has become public engagement with science and technology and a range of methods are being developed to promote a more inclusive and open investigation into public attitudes and decisions (Rowe and Frewer, 2004, 2005). Although the approaches adopted in different studies vary in the details of their implementation, many utilize the ethos of participatory research and seek not just to understand citizens' views but also to give citizens a voice in debates from which they have traditionally been excluded. In this paper, we describe our own attempt at such an exercise and reflect on its successes, its problems and the challenges it raises for social science more generally.

Our starting point is that, despite the upsurge of interest in participatory or deliberative research, relatively little is known about the advantages and drawbacks of this kind of research. Instead, it seems to be taken for granted that because these approaches incorporate participatory values they must bring tangible epistemological gains. In this paper we offer a more reflexive evaluation of the relationship between participatory methods, deliberative forums and social research by examining the results produced by the relatively familiar method of reconvened focus groups and the less familiar roundtable workshop. Specifically, we report on a study in which three types of citizens were asked to contribute a hypothetical decision about research into treatments for Type 1 diabetes and document how the same participants made different choices and expressed different opinions in the different research settings. By examining the factors that led to these differences we reveal both the contingency of research data and the limitations of all research methods. Whilst our argument is not an argument against innovation in general, and we certainly do not claim that traditional methods like focus groups are perfect, we do suggest that deliberative methods pose particular, as yet unacknowledged, challenges for qualitative social science. We begin, however, by documenting

the different rationales for participatory and deliberative research and situating our own research in relation to the existing methodological literature.

Focus Groups and Deliberative Research

Focus groups are a well established method in qualitative social science. They are used in mainstream qualitative research as well as scoping studies, policy research, marketing exercises, and product or process evaluations (e.g. Krueger, 1994). Focus groups are typically considered to be particularly suitable for uncovering complex motivations, knowledge, attitudes and practices. Partly as a consequence of these perceived strengths, and partly because they are seen as representing good value for money, focus groups are now widely used as a method of organising citizens' engagement in policy debates or as a way of providing a benchmark against which more innovative forms of engagement can be compared.[1]

One consequence of this variety of usage is that what counts as a focus group varies considerably. In some studies, focus groups are groups assembled solely for research purposes, participants are not known to each other, and the moderator exerts a strong influence on the discussion. In other studies, focus groups participants may be familiar with each other and the discussion proceeds with only limited influence from the moderator. One manifestation of these different research styles is the difference between market research, which tends to prefer a more structured approach to focus group moderating, and academic social science, which typically adopts a less directive moderating style.[2]

There are some limits, however. Not any group can be a focus group. For example, it is generally agreed that group discussions that use unstructured questions, are conducted in an informal setting and which use nondirective interviewing should not be called focus groups (Frey and Fontana, 1991; Morgan, 1996). Similarly, most definitions emphasise the importance of interaction in generating the data (e.g. Morgan, 1996: 130) and thus exclude

techniques such as nominal groups and Delphi groups, which do not allow for group discussions, from focus group methods. Some critics of focus group research make a similar point, arguing that the distinctive strength of focus group data – their origins in participants' interaction – is not always realised in practice. For example, discourse analysis of focus group interactions has shown that usually it is the moderator rather than the group that determines the agenda and the form of the discussion (Saferstein, 1995 cited in Morgan 1996, Agar and Macdonald, 1995).

From Discussion to Deliberation

Perhaps the most significant recent development in focus group methods has been the growing concern about the relationship between the researcher and the research participants. In the case of focus group research, this shift is seen in the move from focus groups as 'discussions' to focus groups as 'deliberation'. Rather that the traditional idea of using research to give participants a 'voice' that is then interpreted and re-presented by the researcher, now the emphasis is on creating a process in which the participants work to produce conclusions that the researcher can then relay to others (e.g. policy-makers).

In this context, the idea of deliberation invokes more than just its dictionary definition of 'careful thought'.[3] Instead it draws on theories of 'deliberative democracy' in which the process of deliberation is seen as a viable alternative to the 'aggregative political processes' more commonly found in representative democracies (March and Olsen, 1989, see also Dryzek 1994; Fishkin 1991; Young, 2001). In a deliberative process citizens engage in public debate through discussions in which officials, politicians and technical experts explain policy issues in an accessible way and 'ordinary people' evaluate and reflect on this information, together with their own experiences, in order to reach conclusion. In contrast to more conventional representative democratic institutions, in which preferences are typically expressed and aggregated, deliberative forums assume that allowing citizens to resolve the problem of including, reconciling and synthesising different standpoints through debate will produce a more inclusive, informed and legitimate decision.

Achieving this kind of deliberation imposes a distinctive and demanding set of conditions on participants. These demands arise because, properly conducted, deliberation is 'a joint social activity, embedded in the social action of dialogue – the give and take of reason' (Bohman, 2000: 32, quoted in Davies et al 2003: 30). What this means in practice is that participants must question each others views carefully and explain their own clearly. Deliberation is, therefore, a highly discursive process in which citizens come together in a non-coercive environment to explore their differing perceptions and experiences, relate these to a specified set of public problems and work together to identify possible solutions. In an ideal deliberative scenario, participants would consider all relevant facts from multiple viewpoints, re-evaluate their own perspectives, and reach a robust consensus about the merits of different policy options. The outcome of such a process would thus represent the considered option of lay citizens and, in principle, form a powerful input into any decision-making process.

Limits of Deliberation

The difficulties of 'doing deliberation' are obvious. In the ideal scenario sketched above, the participants in the deliberation recognise different standpoints and build relationships in order to achieve a shared understanding of both the problems and their solutions. In practice, however, achieving the disinterested deliberation necessary for such citizen empowerment to result in real civic gains is difficult and simply labelling a group discussion a 'deliberative forum' does not resolve the many practical problems.

One particularly acute problem in deliberative settings is importance of reaching consensus. It is frequently unclear how consensus ought to be reached and, if it is to be reached, how (and by whom) the principle of giving equal value to all opinions is to be enforced. Whilst the expectation is that each participant is willing and able to consider the viewpoints of all the others, the reality is that some individuals or groups may come to dominate the discussion, thereby introducing power imbalances, excluding some viewpoints and undermining the deliberative process. For example, when Pelletier et al, (1999) examined the

effects of democratic deliberation on views about a local food system they found that the outcome reflected the values and interests of some stakeholders more than others, with some participants altering their viewpoints in ways that appeared contrary to the values and interests they expressed prior to the event.

Similar tendencies have been noted in other deliberative process. The Deliberative Mapping study, which investigated the different ways in which the number of organs made available for transplant surgery could be increased (see Burgess et al, forthcoming; Davies at al, 2003), also found clear differences between what people thought as individuals and what they felt able to articulate and discuss in the group setting. The reluctance of some participants to make their views public by expressing them to others is known as 'disarticulation' and reflects the ways in which:

> 'the position of an individual in the public arena produces the by-product of a split between opinions that can be expressed and intimate convictions (Callon and Rabeharisoa, 2004: 21).[4]

There are also other, less individual, obstacles on the path to deliberation. As Barnes argues, 'whilst cultural diversity and different personal histories are an important resource in terms of the substance of deliberation within these forums, experience of other contexts in which citizens collectively organise can also affect the form such deliberation takes' (2005: 255). Analysing attempts to involve older people in deliberations about public services, Barnes concludes that deliberation in the ideal sense rarely happened. In practice what happened was that questions or comments were directed to the speakers on the platform and not the other citizens on the floor of the council chamber and that there was little evidence of conflicting views being debated. It was also noticed that men were more frequent contributors than women and many in attendance took no part in the proceedings beyond observing and listening to the others (p. 256).

All this makes the organisation of deliberative workshops a complex and challenging task if they are not to become victims of the problems they claim to

overcome. In particular, before deliberative methods are widely encouraged and used, it is important to know:

- Are the different publics invited to participate in deliberative events able to inhabit the roles imagined for them? Do they have the skills, time and abilities necessary to deliberate in the required manner? (Davies, 2006)

- Are deliberative methods logistically practical? Deliberative methods are time consuming and require sustained commitment on the part of all participants. Is this enthusiasm present and, if it is not, how can citizens be encouraged to participate?

- How can information be exchanged openly and fairly? Deliberation requires that participants be informed about complex and potentially controversial topics in an accessible and non-biased way. But, if information is also a source of power, who should have control over it within the deliberative forum?

- What is the role of the social scientist in a deliberative exercise? Social scientists could act as facilitators, smoothing the flow of knowledge between participants, or they could act as interpreters and analysts in their own right. Whilst the former role is more in keeping with the spirit of deliberation, it is only the latter role that retains the idea of the social scientist as an expert in their own right.[5]

In what follows we explain how some of these challenges were addressed in our own study and identify some of the more specific problems we encountered trying to organise a genuinely deliberative forum.[6]

Background to the study

The focus groups and workshop described in this paper were part of a research project that examined the role of different qualitative methods in policy-related research. The underlying approach that informs the project is based on developments within Science and Technology Studies (STS) where the idea of the 'deficit model' has enabled a powerful critique of expert-led policy to be

developed (see e.g. Wynne 1995). According to the deficit model, regulatory institutions fail and the authority of science is undermined because those promoting science assume that the concerns or doubts expressed by citizens are caused by a lack of relevant expertise or knowledge. It follows from this diagnosis that the problem is solved, and legitimacy of decisions or scientific advice restored, when this 'deficit' in understanding is filled with the appropriate scientific knowledge. The key finding of STS research, however, is that this explanation does little to account for public opposition to science and technology and also fails as a solution (see e.g. Yearley 2000).

In opposition to this view, and as an explanation of its failure to restore public confidence in times of scientific controversy, STS research suggests that the problem is not the citizens' understanding of science but the scientists' understanding of society. Rather than seeing the public as acting out of ignorance, STS argues that lay citizens should be seen as resourceful and knowledgeable in their own right. In some cases citizens do understand the technical issues raised by the scientific part of analysis but, like other dissenting experts, believe that conclusions drawn are not supported by the available evidence. In other cases, however, detailed technical knowledge of the scientific debate is less important. In these cases citizens reach judgements based on more general criteria, such as the priorities and values embodied in claimed innovation or their past experience of similar institutions (see e.g. Wynne 1996, Irwin 1995). In these cases, relatively ubiquitous social knowledge is 'transmuted' into a technical judgement so that a decision about who to trust becomes, at the same time, a decision about what to believe (see Collins and Evans, 2007 for more on 'transmuted expertise').

This criticism has proved to be very effective. In an influential report, the House of Lords Select Committee on Science and Technology noted that there was a 'crisis of confidence' in science and recommended that increased public dialogue about science was essential (House of Lords 2000; for similar concerns see RCEP 1998, POST 2001, OST 2002, CST 2005, Pattison Report, 2005). As a result, there have been a wide range of experimental forums created, ranging from local citizen panels to the national GM Nation? debate of

2003, in which ideas of deliberative democracy and citizen participation have been put into practice (see DTI 2003 and Horlick-Jones et al 2007 for more on the GM Nation? debate; for Citizen Juries see Wakeford 2002).

Our own project built on this research but also developed it in a new way. In particular, the project was not simply about proving that citizens can participate. We took it as read that this has been accomplished (cf. Irwin and Michael 2003). Instead, our aim was to investigate in more detail the kinds of knowledge and experience different participants can bring to the deliberations and, just as important, those areas in which they are unable to contribute and what the consequences of this might be.

Methodology

The study combined expert interviews and reconvened focus-groups in a cumulative process that ended with a deliberative roundtable workshop. In this section we provide an overview of each stage before discussing the focus group and roundtable stages in more detail in the next section.

Stage One: In-depth interviews

The research began with 12 in-depth interviews with research scientists, clinicians, regulators and representatives of patient organisations and genetic watch groups. These interviews identified a range of treatment options for Type 1 diabetes that were being actively researched and to which new research funds might, therefore, be directed. The sample was chosen to ensure that a wide range of perspectives, experiences and expertise were included. The outcome of the interviews was:

- a list of the potential therapeutic pathways for Type 1 diabetes. These ranged from improvements to existing treatments, to research involving more novel and experimental techniques such as stem cell therapies and a 'vaccine' that would prevent diabetes from developing

- a list preferences and concerns held by different kinds of 'official' stakeholders that summarised the kinds of concerns that would be raised in a more conventional 'expert-committee' consultation.

These two lists, which were supplemented by a review of the related literature, then informed the second stage of the research in which we organised focus group discussions to evaluate the different treatment options against the range of criteria identified. Both the treatments pathways and the criteria on which they were to be evaluated are summarised in Figure 1.

Figure 1: Treatment pathways and ranking criteria

Stage two: Focus Groups

The focus groups were designed to represent three distinct populations, each of which brought a different set of expertise and experience to the discussions. In making these distinctions the research breaks with previous research to some extent by disaggregating citizens into groups based on types of expertise set out in Collins and Evans (2002, 2007). The groups were:

- **patients**, defined as people living with Type 1 diabetes. These have substantial expertise about diabetes and the problems it causes and correspond to 'contributory experts';

- **carers**, defined as close relatives of people living with Type 1 diabetes. These may also have substantial expertise about diabetes but lack the embodied experience of living with the condition and correspond to 'interactional experts';

- **lay citizens**, defined as people who do not have diabetes themselves, are not are involved in caring for people with diabetes, and who do not have any specialist training in diabetes care or biomedical research but who may have more general experience of using health and other related medical services. These correspond to non-experts and must, therefore, rely on transmuted meta-expertises alone to make their judgements.

When recruiting the participants for the patient and carer groups we were aware of the distinction between 'active' and 'ordinary' patients.[7] For our study we wanted access both groups and so, rather than recruiting patients and carers through patient organisations (despite their offer of help), we recruited patients and carers through the local diabetes clinic. Our assumption was that only the more active patients would be members of diabetes charities or support groups, whilst both kinds would be registered at the clinic. After gaining approval from the relevant ethics committees and establishing contacts with the clinic we arranged for each patient with Type 1 diabetes who attended the clinic during a three week period to be given a letter about the project. The letter provided a brief outline of the research and asked the recipient to contact the research team if they, or their partner/carer, wanted to take part in the study.[8]
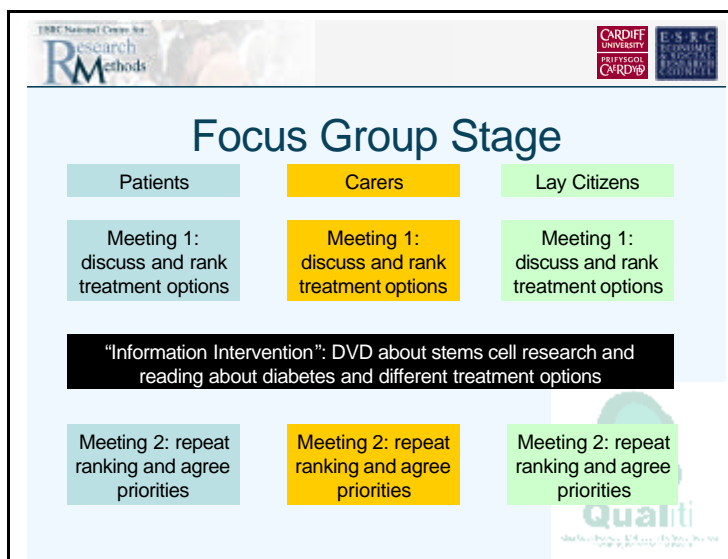
Lay people were recruited via two local schools and the University's on-line notice board which appears when staff and students login to their computers. Although recruitment of carers was formally attempted through the diabetes clinic (as noted above) this did not work as well with this group and most of the carers were actually recruited via the University notice board. The number of focus groups, together with some basic demographic data are summarised in Table 1.

Table 1: Focus Groups

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

The overall design of the focus group research is summarised in Figure 2.

Figure 2: Focus Group Stage

The research required each group to meet twice over a 2 week period. On each occasion they discussed the same question: how should the treatment options identified in the first stage of the research be evaluated and which one should be given priority for funding. In between the two focus group meetings, participants were given an information pack, which consisted of some basic literature about diabetes and the various treatment options, a set of additional material that provided more detailed information about each treatment and a DVD explaining stem cell research. Participants were also able to discuss the research with friends and family and seek further information if they wanted to. In this way the research design created a context in which participants attended

the reconvened meeting after having had the chance to reflect on their own views and to become more informed about the different technological options being discussed.[9]

The differences between the groups and the fact that they met twice enabled us to investigate two different influences on opinion. By looking across the groups and comparing patients, carers and lay citizen's perspectives we could investigate the extent to which different kinds of experience and expertise give rise to different evaluations,[10] In addition, by comparing the first and second meeting of each group we could investigate the extent to which new information and time to reflect changed options.

Stage Three: Roundtable workshop

The final stage of the project was a day-long deliberative roundtable workshop attended by some of the people who had taken part in the earlier stages of the project. Participants included some of the experts we interviewed in the first stage and a sub-sample of the focus group participants. The aim of the roundtable was to investigate how face-to-face interaction between these different groups would influence the kinds of discussion that took place. For example, STS research stresses the importance of social interaction in the transmission of tacit knowledge, and the idea of interaction is also important in distinguishing between the different kinds of expertise identified by Collins and Evans (2002, 2007). As such, allowing experts, patients, carers and lay citizens to ask questions of each other directly should create a very different context for debate and decision-making to the more homogeneous focus groups.

The roundtable workshop was attended by just over 20 participants. These included a leading stem cell research scientist, representatives of diabetes charities and research funders as well as a number of patients, carers and lay people. The workshop was organised in the style of an 'upstream' engagement event in which a hypothetical benefactor was seeking advice on which kind of diabetes related research he should support. In making their recommendation,

the participants were asked to choose between three of the treatment options that had been discussed in the focus groups:

- **insulin pump** developments leading to an artificial pancreas that would automatically monitor blood glucose levels and administer insulin as and when it was needed
- **stem cell** research leading to replacement beta cells that could be transplanted into the patient to restore pancreas and allow patients to produce their own insulin
- a **vaccine** that would prevent the autoimmune disorder that destroys pancreatic beta cells from developing.

As before, the options ranged from the relatively near term to the more uncertain and offered a range of different possibilities, costs and benefits. The aim of the workshop was to encourage participants to imagine and explore the possibilities offered by each of these techniques and then to choose between them. Participants were thus asked to consider issues such as:

- how different social groups influence research funding in practice and how this differs from what they considered to be the 'ideal' process
- what would the socio-technical futures associated with each treatment look like and what might prevent that future from being created
- which of the three different future scenarios was preferable and why.

Constructing or Collecting Data

In what follows we examine the extent to which our methods constructed our data as opposed to recording an independent or naturally occurring event. The distinction between collecting and constructing highlights the importance of considering the how the research methods used can constrain what happens. In this sense, the researcher is not simply as another body in the room at the time data are generated but also the designer of the settings in which the

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interactions that become the data take place. By explaining in some detail how we organised both the focus group and roundtable stages, and how the reality matched our expectations, we highlight how the different methods used created different data and, hence, supported rather different conclusions.

Focus Group Data

Reconvened focus groups are typically organised when researchers want participants to discuss complex issues. In our cases, we wanted participants to evaluate a range of treatments options for Type 1 diabetes. In order to stimulate discussion about the pros and cons of these different treatments, and to encourage a wide range of criteria to be used, what our participants actually did was complete and then discuss a 'ranking table'. This 'ranking table' was a presented as grid on a single sheet of paper. The treatment options were listed down the side and the criteria upon which these were to be evaluated were listed across the top. Participants were then asked to rank **each** treatment option on **each** criterion by identifying which performed the best, which the worst and arranging the remaining treatment options in order between these two. The ranking task was first completed individually, to give a base line measure for each participant and to allow initial views to be developed, and then, at the second meeting, collectively.

Although the ranking exercise did produce a table of numbers, we did not treat it as quantitative data. Rather the tables and the rankings they produced were used as mechanism for generating discussion and to encourage participants to consider a wider range of criteria than they might otherwise have done. In addition, ranking treatments also helped to reinforce the point that there was a choice to be made. This last point was particularly important in the context of the 'upstream' engagement idea as, with finite resources, a decision to invest in one technology or research programme is simultaneously a decision to not invest in another one. By asking different groups to complete the same task, with and without additional information, the focus groups enabled us to explore the differences between citizens with different kinds of knowledge about diabetes.

Ranking Task

As noted above, each participant in the focus group stage completed the ranking table twice. In the first focus group meeting, we asked participants about their knowledge of new genetic technologies and of diabetes and its treatments. We then asked them to fill in the ranking table individually and then, when they had done this, transferred their individual scores onto an integrated table (see Figure 3). As expected, the rankings produced by different participants often varied significantly and these differences and similarities then formed the basis of a lively discussion that included topics such as: the participants' experiences of filling in the table (e.g. how difficult or easy different criteria were to apply); the issues they saw as being more or less important; the evidence or experience used to make judgements; and the different reasons given for their decisions.

Figure 3: Composite Ranking Table

When discussing the table it became apparent that by choosing to simulate a decision-making situation in which a choice between the different options was

necessary, we did make some participants uncomfortable. Some would clearly have preferred a situation in which they could have said that all treatment options were equally important and found making a decision the most difficult part of the process. More generally, almost all participants struggled with making decisions based on what they perceived to be very limited information. Although not the most extreme example, the quote below gives a good idea of how participants experienced the 'ranking table':

M: while you're filling it in, can you tell me what are you thinking of, what's on your mind?

P3:   just the 'risks to patient's safety' [criteria]. I'm just trying to think which are the most risky. I've worked up and now I'm working down. It's difficult to know what the risks are without knowing more about anything of these.

P2.   Because you don't know what rejection is like

M: How do you interpret this option, 'risks to patients' safety'?

P3:   Well, how harmful some of these could be with side effects, is it very invasive? If it's an operation involved, which drugs they will have to take? But that's the hard bit, really, not knowing enough about it, to make informed choices. So, we are just guessing, really, in some of these.

(lay women, group 1, meeting 1)

In addition to making a decision, we also wanted participants to consider each treatment option against a range of evaluation criteria, even if they did not think these criteria were all equally important. In other studies participants were given a chance to think about, discuss and agree upon the evaluation criteria among themselves. With just two group meetings planned, we could not afford this opportunity, and so used the criteria developed by participants in previous study evaluating medical technologies (Davies et al, 2003).

Although this did save time, and enabled us to present participants with a comprehensive set of criteria, it must be noted that the method was not ideal. In particular, the discussions that followed the ranking task invariably began with

some light-hearted but critical comments on the difficulties of completing the table. For example, it quickly became apparent that the ranking table was too large and too complicated. The number of treatment options (8) and the range of criteria (13) meant participants had to fill in over 100 cells in order to complete the table. In such situation, participants' evaluations were often influenced by the associations triggered by keywords such as 'prevention', 'transplantation', 'drugs' and 'vaccination' that appeared in the name of the option. Most participants explained that their attention began to drift after the first three to five columns, and the following comments are typical of the responses we received:

P   'very rushed job and I wouldn't have minded a bit more time to think about it and maybe give some equal scores, 1+ and then 3, 4, 5=, 7 and 8– something – but that's not the spirit of it'

(lay men, meeting 1)

P2:   You just put whatever you think. I have no idea.

P1:   I'm guessing them all. Well I'm trying to think (…) it's becoming like a SUDOKU.

P2:   Numbers are definitely not my thing.

(lay women, group 1, meeting 1)

As we discuss in more detail below, it subsequently became apparent that these doubts about the veracity of their own rankings translated into a reluctance to use the ranking table, or their own judgement more generally, as a basis for decision-making.[11]

Ranking the Ranking Criteria

Given that we had asked participants to judge the treatment options against a range of criteria, we were particularly interested in how they interpreted the criteria we provided. Somewhat surprisingly, especially given their self-confessed lack of knowledge about most of the treatments, most participants seemed to find those criteria that implied 'facts' easier to use than those that

called for value judgements. In practice, therefore, having relatively little information did not prevent participants from completing the table and, when they did warn us against taking their rankings too seriously, they were referring to the lack of time as much as a lack of knowledge. That said, however, there was also a clear recognition that expertise matters, and that whilst some knowledge was better than none, the idea that expert knowledge would be more suitable basis for policy makers was a common theme:[12]

> P2:   I think it needs to be an informed decision – because I think if you'd given us this before your little description of each of them, I don't think it would be worth the paper it was written on, but now *we're a little bit informed, I think, it adds a little bit of value to what we've done.* But then if we were going to go and study medicine and hi-technology diabetes cures for ten years and then come back and do this, it would probably be done completely differently.
>
> P5:   I would rather it be somebody who has the most expertise possible, and the least amount of vested interests.
>
> (lay men, meeting 1)

In contrast, the criteria that participants did find difficult were those that raised ethical issues. This was somewhat unexpected as, given the presentation of citizens in other research (e.g. Peterson 1984), we had assumed most citizens would have views on what was right and wrong. Instead, however, a significant minority of participants reported being uncomfortable with the idea of speaking on behalf of wider society and several participants refused to rank the treatments on the more 'ethical' criteria arguing that they could not present their own ethical judgements as universal.

> P   '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 – so that's why I've left the columns blank – because there's five people sat around this table, I'm sure therefore there will be six

> opinions minimum, and that's why that's column is – I've omitted myself.'

> (lay men, meeting 1)

What this meant in practice, therefore, was that the criteria that related most directly to patients – effectiveness, risks and benefits – were invariably seen as the most important. Ethical acceptability was generally given a low weight, with some questioning whether it was a useful criterion at all. The outcome was, therefore, that although the focus groups did allow participants to express their views on a range of issues, these views ultimately prioritised a relatively small set of the concerns that could have been raised. For example, whilst a minority of lay men did argue that the criteria relating to the wider society – e.g. wider benefits and value for money – were equally important as the patient-centred criteria none of the lay women, patients or carers made such comments. In other words, despite using a relatively diverse set of participants and explicitly orientating them towards a range of criteria we were unable to stimulate a particularly wide ranging debate. Of course it is possible to argue that this accurately reflects the views of those who took part, but if this is accepted, it raises questions about the extent to which increasing public participation can actually provoke wider scrutiny. To make this concrete, issues of social justice and equity that critical social movements see as central to contemporary policy debates were noticeable by their absence from the transcripts.

Participants choices and preferences at the focus groups

If we turn our attention to what participants said about the treatment options, we find that the participants in our study were often ambivalent and had mixed views about the different treatment options (Kotchetkova et al 2008, c.f. also Kerr and Franklin, 2006). This ambivalence was present at the first meetings and continued into the reconvened meeting where participants often reported that, although they now had more confidence in their positions, they still might change them later.[13]

We also found that the expertise and experience different participants brought with them did influence the rankings. For example, patients generally preferred improvements to existing treatment options and openly admitted that this was because of their own self-interest, even if they were not happy about being 'forced' to do this:

> P1: And it's horrible sitting here thinking I've just scored one, two and three of the things that I don't really care about, but I do … From a pure mercenary point of view I have to care about it. I don't want to have to sit here and say well I'm concerned about better quality insulin and forms of delivery and stuff and drugs to help complications should I contract them later on, but at the end of the day
>
> P2: It's the here and now.
>
> P1: Yeah and those research techniques, although they're going to benefit society as a whole 30, 40, 50, 60, 150 years down the line, it's not going to help me.
>
> P2: It's not going to help me, no, no, exactly.
>
> P3: No, I don't think any of them probably would help me in my lifetime.
>
> P2: No, no.
>
> P1: It's horrible. It's horrible being forced, literally forced by society to score those top three that way, but
>
> P2: But that's the way it is.
>
> (patients, group 2, meeting 1)

In some cases, this focus on the 'here and now' was further justified by reference to previous experience of new treatments that had been promised but which never materialised. This caution then acted to further justify the focus on improving existing treatments as these were seen as most likely to deliver a real improvement:

> P3: you know, almost on a daily basis you get some kind of sensation or headline about what genetic modification can do; what technology can do and all the rest of it. And stem cells fit into that

> whole body of activity. And I'm very suspicious of it in terms of what is promised and then what is subsequently delivered. They tend to be different things.
>
> (patients, group 1, meeting 1)

In contrast, lay people and carers tended to distinguish between the need to help current sufferers and the need to consider the long term implications and future generations. They felt uncomfortable being put in the situation when only one priority was available. However, when 'forced' to make a decision, then prevention was chosen over other options. In making this decision participants often quoted the catch phrase 'prevention is better than cure' to prioritise the future over the present and thus reverse the rankings given by the patient groups:

> P2: Hopefully it will go to prevention, that's what I'd like it to go to, prevention and health promotion. Because, as you say, that's the scary bit – all these side effects of medicines and tablets and things.
>
> P3: [the best option would be] I would say preventing it definitely and not putting anybody through anything. Just stopping it in its tracks. But then prevention is always better than cure isn't it. That's what I would go for. I would rather not have something than have to have it treated.
>
> (…)
>
> P1: I also think the same as she said- we have to prevent it … awareness of this disease and how to prevent it was more important than to cure it.
>
> (lay women, group 1, meeting 1)

In contrast, when the same dichotomy prevention vs. cure was invoked in the patients' groups cure was preferable to prevention because of its direct relevance:

P5: If it's a preventative treatment then I'm not too bothered because it's not going to affect me (…) That's like the last column: I put 1 in prevention. When you look at society as a whole, society as a whole, if you take a commercial view, has got to try and prevent it rather than cure it.

(patients, group 2, meeting 2)

The ways in which common knowledge and the everyday associations of particular words framed participants' views was also visible in the discussion of other treatment options, where words like 'transplants', 'drugs' and 'vaccination' also triggered a range of associations and references that participants used to form and justify their views. This was inevitably going to be the case at the first group meeting, when participants typically knew relatively little about most of the treatment options. More surprisingly, however, these associations remained a powerful resource at the second, reconvened meeting and, in many cases, appeared more important than the new information they had received. This suggests that participants interpret treatment options and give them meaning by locating them relation to a wider set of knowledge and experiences. Making new meanings requires these initial associations to be broken but this may require a substantial intervention if participants have strong preconceptions.

The differing ways in which the 'same' treatment can be embedded in different networks of association is clearly illustrated by the discussion of 'islet transplantation. Almost none of the lay participants knew what islet cells were and what the transplant procedure involved but they were nevertheless able to make judgements about its value based on their knowledge of transplant surgery in a more general sense. For some, islet transplants were seen as a good option because they were seen as part of a well-established medical procedure that was already saving thousands of lives:

P2: I just think we've come a long way with transplantation. When we first started to transplant livers, my mother's friend had liver disease and she was put forward as a candidate for liver transplant. And at that particular time, I'm talking about probably

fifteen years ago, it was a very new thing, and people sometimes didn't even survive for four or five months after the operation. Whereas it has almost become, well it's like when hearts were first transplanted very few people survived, and then the survival rate, you know, [improved]. I think with transplantation now we are quite successful.

P1:   I think it's quite a good option.

(Lay women, group 1, meeting 1)

For others, however, transplant surgery was seen as a risky procedure and something of a last resort treatment. From this perspective, options that eliminated the need for a transplant operation in the first place were preferable and were seen as a higher priority. As in the more positive interpretation, participants reasoned from what they knew about conventional transplant surgery to make judgements about the more uncertain and speculative stem cell transplants:

M: Moving into the better islet transplantation, why did you put it in the last place.

P3:   Just for all the reasons that transplants aren't always the answer. In the past you get rejection, and you have to have even more drugs to stop rejection and they can cause side effects. So maybe in the long term it is not such a good idea to do a transplant.

(Lay women, group 1, meeting 1)

Similar differences also appeared during the discussion of other treatment options. In the case of 'developing drugs to treat diabetes and its complications', some participants thought of 'dangerous side effects' and 'commercial interests' and so came to relatively sceptical views.

P3:   I just thought of the drugs the possible side effects really and if they are producing even more drugs, and then more drugs to treat the complications

M: So do you think that drugs are the most likely to produce complications.

P3:   Yes

M: Because you said transplants are actually quite dangerous as well, but you put drugs on top, the drugs are the most risky ones?

P3:   I think so. Because a lot of people are in hospital because of the drugs' side effects, and people maybe are long term disabled because of drugs side effects. We don't realise the risks that drugs do have. We think "oh yes" this will cure it

(lay women, group 1, meeting 1)

Others were more supportive, however. For these participants, drug therapies were seen as an established technology that can enable patients to achieve a good quality of life and avoid more serious medical interventions:

P3:   I think because there's a lot of work already being done, it seemed to me that it would just be a very relatively simple small step to make improvements like that

P1:   I felt they are fairly well developed.

(lay men, meeting 1)

In summary, therefore, participants at the focus groups did express a wide range of views. In most cases, the evaluation of the treatment options depended on the associations they evoked. The most systematic difference that emerged, however, centred around the choice between 'prevention' and 'cure'. For patients, their need for improved medical treatments in the near term meant they tended to prioritise 'cure' over 'prevention', whilst the other groups tended to reverse this and emphasise the longer-term benefits of prevention over cure.

Deliberation within the focus groups

One final feature of our focus groups was to experiment briefly with deliberation. It is a routine observation that focus group discussions are led by the facilitator. This is particularly obvious in our case, where a large part of the interaction was

organised around the completion and then discussion of the ranking table. Nevertheless, we also wanted to encourage some deliberation between participants, partly as a precursor to the roundtable workshop and partly to see what happened when we took a less directive role.

To this end, we allocated half an hour at the end of the second focus group meeting for participants to deliberate (i.e. agree through the reasoned consideration of different points of view) and produce a consensual group ranking for the different treatment options. At that moment we either physically left the room or moved to a far corner of the room in order to make it clear that we were now handing the organisation of the discussion over to the participants. In most cases, however, this was not enough to get a deliberation going. Instead of than carefully listening to each other reasons and trying to find an agreed view that reconciled the different viewpoints and evidence, most groups collated their individual ranks and followed one of two strategies:

1. They calculated an 'average' for each treatment option and presented this measure of central tendency as a 'group' decision. When this strategy was used, the final ranking did not usually correspond to any individual's ranking but neither could it be explained as anything other than the outcome of the calculation that had produced it.

2. They adopted a voting strategy in which each option was ranked according to the most common individual score so that the final ranking was the one that satisfied the majority. Minority positions were, therefore, dealt with using procedures of representative rather than deliberative democracy.

The practical accomplishment of this group decision is illustrated in the extract below, which shows a typical example of the discussions we observed at this stage.

> P3:   Right. So we're going to put what as our five [i.e. rank as 5 out of 8]?

P5:   I'll stick with the artificial pancreas just because it answers the question and it makes me feel better.

P3:   So we think that the artificial pancreas might be five.

P2:   Yep, five.

P3:   Two of you do.

P5:   You [P3] don't.

P3:   I'm prepared to be flexible and P4 is shaking her head.

P4:   I'll go for five.

P3:   Right. Terrible! There's some arm-twisting going on here. So what about number [i.e. rank] six, then? P5 go first.

                                    (Patients group 2, meeting 2)

Whilst the time allowed for deliberation in the focus groups was very brief, the extent to which participants struggled to put the principles into practice suggest that reaching decision in this way is not something that normally happens in such settings. Instead, participants were guided by their previous experiences and ideas of what is the best way to find the solution. As such it is not surprising that to find that participants, all of whom lived in a representative democracy, quickly agreed that the right way to resolve a difference of views and take a decision is to vote on it. What this does mean, however, is that the deliberative ideal of valuing all opinions and reaching agreement through critical reflection is not something that comes naturally to participants. Instead it is an unusual and almost 'unnatural' way to proceed and thus probably requires more preparation and coaching than we were able to provide.

One other feature that was also noticeable in the focus groups as a whole was the limited effect of the information provided between the group meetings. At best, it can be said that the information made some participants more aware of the uncertainty and risks associated with stem cell research (e.g. the potential need for immunosuppressant drugs). The information tended to reduce references to general knowledge in the second meeting but it did not appear to change views substantially. Instead, existing views were reinforced and judgements became more confident, though still provisional.

Where the absence of an 'information effect' was most noticeable, was in the deliberations held at the end of the second focus group. In this context, where information and evidence might be seen as important in resolving differences, the information appeared to have a relatively little impact. Even when participants claimed they spent significant time engaging with the information, with some even going beyond what we provided, they typically did not refer to this information in explaining why they wanted to rank the treatment options in one way rather than another. Instead, what did count as evidence in these group discussions were stories from their personal experience or things they had seen or heard on television. These trends were reinforced by the reliance on voting and averaging to reach consensus, with the overall result that deliberation with the focus groups was, at best, limited.

Deliberative Roundtable Workshop

As noted in the introduction, deliberation is distinguished from other forms of discussion by the demands it places on the participants. The Deliberative Democracy Consortium (DDC) defines deliberation as being characterised by:

> its emphasis on individuals being willing to, momentarily, set aside self-interest to examine solutions in terms of a common best interest, e.g. one's neighbourhood or community *as a whole*. Deliberation also presupposes that no individual holds the best answer to a public problem and that a process of structured conversation will yield solutions. Finally, deliberation differs from, for example, negotiation in that participants do not come to the table with strong ideas about what they will or will not 'give up' to accommodate the needs of others. Instead, participants come prepared to engage in the free and equal sharing of information that will help everyone arrive at reasonable, if not ultimately more just, outcomes. (DDC 2004: 3)

Deliberation is closely linked to the idea of public engagement, with Irwin, for example, noting that 'the public can bring a range of relevant and useful observations, questions and opinions to policy debate *once proper deliberation*

has been allowed' (Irwin, 2001:75 emphasis added). In practice, however, the idea of 'proper deliberation' is problematic. As noted in the discussion of our focus group data, whilst the idea of deliberation functions as a powerful heuristic (as perhaps it was intended to), what transpires in practice will almost inevitably deviate from the ideal-type in some ways (cf. Pelletier et al 1999: 105). In the remainder of this paper, describe our own attempts to achieve 'proper' deliberation between research participants, highlighting what we achieved and the difficulties we encountered along the way.

Our deliberative workshop was organised as a one-day event in which participants from both the focus group and interview stages of the research took part. When inviting participants to take part we made it clear that the workshop would differ from events such as citizen juries or consensus conferences, where there is a clear distinction between the expert witnesses and the lay jurors. We specifically emphasised in the written invitations as well as in the introductory session on the day that all contributors would be given an equal status and should work together to reach agreement based on whatever evidence and experience they had to offer.

The day itself was structured around a scenario involving potential future treatments for diabetes. Participants were expected to work in small groups, initially consisting of people with similar backgrounds and then with more mixed groups, to consider the different therapeutic pathways implied by the different treatment options and to evaluate their potential promise and problems. In the invitation, we specified that they would be asked to imagine social and technical futures that might arise if a particular treatment option was given priority and to think about the policies that would be necessary for this future to be realistic. We also stated that the activities would culminate in a recommendation about how the regulators should respond to the scenario, highlighting both the overall verdict and any caveats or conditions that they felt needed to be included.

In staging the workshop, our aim was to create a deliberative process involving the full range of perspectives identified in the earlier stages of the research and explore how their interaction and dialogue shaped the collective decision. We

were thus interested in both the process of deliberation and its outcome. In relation to the deliberation itself, we envisaged that our own role in the process would be limited to introducing the tasks, monitoring time and regulating the recording equipment, with the participants working in small, self-organising groups. [14] The fact that there were 3 researchers and 4 groups of participants for each task meant that we could not retain total control over the individual group dynamics.

In what follows we briefly summarise how the workshop was organised before concentrating on following two broad themes:

- the disappearance of the lay public
- the privileged position of patients

Recruitment of workshop participants

The roundtable workshop included participants from both the focus group and interview stages of the research. Focus group participants were informed of the workshop at the end of the second focus group meeting and most said they would like to take part. Once the date and venue had been agreed by the research team, invitations were sent to all focus group participants. Seventeen responded positively to our call and the remainder sent their apologies. At the same time, we also sent invitations to all the experts interviewed in the first stage. Their response was less enthusiastic, with several not replying at all and some declining.

The patchy response from the experts created some problems for the deliberation. The aim of the roundtable was to initiate interaction and deliberation between participants with different kinds of experience and expertise so it was important that the full range of stakeholder and citizen perspectives were present. In addition to the informal and experiential expertise of the patients, carers and lay people we also needed to have a range of more formal expertises present, such as research scientists, clinicians, funding organisations and social movements. We had hoped that this heterogeneous

set of experts would constitute about one third of the participants but, in practice, it was difficult to persuade representatives of the medical profession and social movements to take part. One direct consequence of this was that, on the day, not all the treatment options that were being discussed had an expert 'on hand' to answer questions. This undermined the credibility of the vaccination option (despite its popularity at the focus group stage) as it now appeared comparatively uncertain and complex.

The difficulty of being a lay citizen

Like the focus groups, the workshop was organised around the idea of making a choice. The scenario provided was that a rich benefactor, who had substantial funds to invest in a research project, had convened the group to provide advice on which treatment option should be given priority. The three treatments considered during the workshop were:

- insulin pump and artificial pancreas technologies
- stem cells as a source of new islet cells
- vaccines to prevent diabetes developing

The workshop itself then organised as a series of discussions and tasks in which participants were asked to consider three treatment options in detail before reaching a shared decision about which one should be prioritised. In theory, these discussions were supposed to develop from 'peer group' interactions, in which a shared identity might be developed, to imagining the socio-technical futures associated with each choice and then, finally, a deliberation that considered the different possibilities from all perspectives in order to reach a shared conclusion. In practice, however, it was rather different.

After the initial introductions, we began the day by splitting the participants into what we had classed as 'peer groups': patients, carers, lay citizens and formal experts. Within each group participants were asked individually, and then collectively, to complete a form that identified what contribution they felt they might make, what special or relevant expertise they had, why their views should

be taken into account and so on. Our idea was that this would give lay citizens, in particular, a chance to develop an identity and rationale for their participation (e.g. the voice of ordinary people) in the deliberations that would follow.

In order to prompt some reflection about how different groups might contribute to decisions about research funding, we also asked the each 'peer group' to sort a series of post-it notes listing various social groups (research scientists, funders, patients, doctors, lay people etc.) into two separate lists. The first list represented the way they thought research funds were actually allocated and the task was to identify which social groups had the most influence, which had the least and so on. The second list used the same groups but now the ordering represented how much influence these social groups would have in an ideal world. Again, the hope was that this would provide an opportunity to think about the actual and potential role of lay citizens as representatives of 'society as a whole' in relation to the more obvious commitments of groups like patients, scientists and clinicians.

It was at this stage that the first of several unexpected challenges to our plan occurred. Several of the 'peer groups' we had created chose to define themselves in ways we had not anticipated. The most drastic re-definition was provided by the group we had initially seen as 'lay people', who chose to present themselves as 'friends of people with diabetes'. Their rationale for this was that diabetes is such a wide spread condition that almost everyone knows someone with the condition. In doing so, they implicitly rejected our acceptance of the conventional (expert) distinction between Type 1 and type 2 diabetes and also redefined ordinary people as somehow connected to people living with diabetes and not separate from them. In a similar move, the research funders and some of the clinical experts also chose to associate themselves with patients rather than the other experts, arguing that research into diabetes treatments was geared towards helping sufferers rather than scientific advancement in general. In different ways, both moves put patients at the centre of the deliberation, something which became highly significant as the day progressed.

A second factor that contributed to the erasure of lay people was the way in which participants typically saw them as a largely ignorant, easily influenced and prone to unreasonable panic. Concerns about the ability and relevance of lay people were particularly apparent in the sorting exercise, where the 'general public' were seen not as the repository of robust common sense that appears in the social science literature but as a undifferentiated mass who were vulnerable to media influence. As a result, all four of our peer groups were reluctant to give lay citizens any authority in decision-making. In addition, patients were particularly concerned that politicians might be more responsive to lay people, because of the number of votes they represent, and not listen as attentively as they should to the people who are actually affected by the condition. As one of the patients commented:

> P   We actually had a discussion about this in that we said that we felt that the lay people certainly in the present may well, again in a similar kind of way the media and celebrity would be on a sliding scale [i.e. their influence would vary] (…) Because when we had a conversation in relation to central government and lay people, we obviously thought of election time and we thought that obviously that's when that group becomes a lot more potentially influential. So we had a bit of a discussion about that, but I think certainly from a perspective of looking at the Utopia side of things, I think we felt that there were people who had more of a direct interest and an impact that were more influential and more important on the funding side than necessarily the lay public.

One consequence of this rhetoric was that in each case, as the discussion switched from the descriptive list to the normative one, patients moved to the top of the 'ideal-world' list whilst lay citizens remained down the bottom. Another way of seeing the same phenomena is to note that there was no spontaneous recognition of a democratic rationale for lay participation in decisions about research funding. Instead, the sorting exercise revealed a relatively narrow focus on the needs of a particular patient group and the extent to which research programmes were able to address them. To the extent that a role for

lay citizens was imagined within these discussions then it was as an outsider: lay people may be aggregated to present general views or act as a 'moral barometer' but they cannot contribute directly or as individuals. These ideas are illustrated in the following two quotes:

> P   Going back to the lay person, the lay person is largely involved in the democratic process rather than the subject matter itself and therefore maybe to involve a lay person you want to involve them more on the analysis side, like a poll or something, to get a broad brush idea of what the lay person thinks, because I think that's the best you can drill down with the lay person's view without having individual opinion affect the result of that analysis. (Patient)

> C   Looking at the charts here, well, I want to defend some of the people at the bottom. I think all of these people have a right to be involved in the process and the lay public are really important because you know, I felt I wanted to leap to their defence at some point because in some ways they can act as a, you know, we haven't got medical ethicists in our chart, we haven't got you know, professional people who think about ethics. It's the lay public's opinion that actually acts as a moral barometer. So there are things that we could possibly do which are not publicly acceptable; for example we could cure all sorts of diseases by you know, growing a clone of me. (Carer)

In these quotes we can see something of the demands that the ideal of deliberation puts on participants. As such, it is not uncommon for the validity of lay participation to be questioned. For example, in an Australian citizens jury held on Container Deposit Legislation (CDL) interest groups argued that they already represented all the legitimate stakeholders and questioned the capacity of ordinary citizens to comprehend their arguments.[15] According to this viewpoint, citizens can only enter the policy debate via a valid interest group and opening participation to all appears to ignore the expertise that long-term investment in an issue can bring.

The Easy Authority of the Patient Perspective

In contrast to the difficulties associated with the perspective of the lay citizen, the role and identity of the patient was very clear and very powerful. As noted earlier, the patients who took part in the discussion represented the experience of living with diabetes. In practice, this typically meant an adult who had been living with Type 1 diabetes for many years. During the focus group discussions, these biographies had often translated into an openly 'selfish' position in which their choices were guided by their immediate interests. In the focus groups, this preference had been manifested in the priorities given to treatments that offered the most benefit within their own lifetime. Although the treatment options were now restricted, the patients brought the same 'here and now' attitude to their deliberations at the workshop, expressing a clear preference for the artificial pancreas technology as they saw this as being the most likely to improve their own quality of life:

> P1   For a personal reason, for me, I would definitely go for the artificial pancreas, the pump, because it's the here and it's the now. I love the idea of the stem cells… but that's not going to happen for a little while longer and I want something more instant.

> P2   I've got the mode of thought that I'd rather crawl before I can walk and whilst genetic research, the stem cells may enable us to walk in this field one day, I'd like to be able to move about a bit first, if you know what I mean. So I'd like some initiative sooner. Also, I'm not getting any younger and maybe if I was 16 I might consider that the stem cell was a very viable solution. I think if I was very egalitarian and a politician I'd probably look at the vaccination idea, but I think from the three this one is the most viable option currently. Certainly here and now is where I'm coming from, so that's my point of view.

Another patient expressed the same reasons for the same choice, but made an attempt to justify it as a rational decision referring to the common good it would potentially bring to all people with diabetes:

> P3   For me, it overwhelmingly has to be the pump and the artificial pancreas, for similar reasons. It's about the here and now, it's much more immediate, it's something that we can do to make a difference to people with diabetes now and also at this time it's the greatest gift to the greatest number

In setting out the reasons for this position, patients therefore argued that prioritising the 'here and now' is the rational choice. Their argument was that, given the limited funds available for medical treatment, and the difficulties they experience in accessing even the basic care they should be eligible to, opting for better management and control is the best option. As one patient explained:

> P   'There are lots of well researched drugs and solutions out there which the NHS won't pay for nowadays and we haven't got access to, so we don't even know if we're going to have access to it should it prove a successful research and testing'.

Whilst the patients could provide a coherent and internally consistent defence of their position, as could the other groups present, deliberation also requires listening and dialogue between groups. It was this part of the deliberative process that was most difficult to achieve in practice, with the alternatives typically being discounted rather than discussed and the embodied expertise (and suffering) of the patients dominating the other perspectives. Indeed, a more critical evaluation of the process would be that deliberation, in the sense of the careful and serious weighing of the reasons for and against a proposition (Fearon 1998:63), was rather limited.

As one of the patients commented:

> P   This isn't a rational issue, this is an issue of people and how they're affected.

These problems are nothing new. Critics of deliberative democracy (e.g. Abelson et al, 2003: 247-8) have already pointed out that deliberative meetings

are vulnerable to capture by interest groups and achieving a 'level playing field' is one of the key challenges in a deliberative exercise. In addition to the potential for well organised interest groups to dominate the discussion, other problems include the normative notions of what is an acceptable rational debate and how these may exclude those whose 'communicative competence' is insufficient or inappropriate (Webler 1995). In our workshop, the scope for deliberation was clearly constrained but this was not as a result of the expert participants being present. Rather the discussion was dominated by the patients whose authority to control the decision making appeared to be recognised and accepted by both expert and non-expert participants.

This deference was expressed in several ways during the day. The first example was the way in which, during the sorting exercise, all the peer groups put the patients at or near the top of the decision-chain. But this emphasis on patients as main reference point remained throughout the day. For example, one of the specialist diabetes nurses, initially invited to represent clinical expertise, chose to identify herself as a representative of the patients' interests and, using a more scientific vocabulary, reinforced the case for the 'here and now':

> E1: The really big important thing is that, in terms of long-term complications, having cells that make insulin naturally and respond to glucose naturally rather than in some artificial manner works much better and will reduce the level and severity of the long-term complications compared with a pump or anything else. But, as somebody pointed out, it's what you have today versus what you might have in the future.

Similarly, when debate seemed to have come to a halt, participants turned to the patients for advice on how to resolve the dispute.

> C4: Can I ask what do the other people who have diabetes think? What are their preferred choices, because we all said it ought to be down to the people who actually have the disease to decide?

> … We felt the ideal world would be, to turn it upside down and put the people with diabetes at the top of the chart, because obviously they're the group that are most affected.

One consequence of this focus on what patients felt mattered – rather than society-in-general – was that the value of the lay perspective was lost. As noted above, many of those invited to participate as lay people chose to identify as friends of someone living with diabetes and thus positioned themselves as quasi-carers rather than genuinely ordinary people. There was only one person who did not know anybody with diabetes and could not identify with this newly formed group. By the end of the day, instead of being empowered she had lost all the confidence gained through participating in the earlier focus groups:

> LP2   Well, when I started the day I felt okay, I felt I could contribute, but as the day's gone on I've become quite overwhelmed with the fact that I haven't got the knowledge almost to participate. I voted for the pump because I listened acutely to the people here who've got diabetes and I noticed in most of us we all put the diabetics at the top and said that's our priority [in the sorting exercise]. Therefore, I was really led by what they were saying, I must admit that. Yeah, but I do feel a bit of an oddity, to be honest, because I don't feel as if I've got anywhere near the knowledge that people here have got and I am beginning to wonder why I was invited at one stage, because I thought I really can't contribute as much as everybody else can and really felt like a fish out of water. I began to wonder whether I should have come at all.

Even the carers' confidence in their expertise and ability to participate in the decision-making about diabetes treatments seemed to have been undermined. The quote below comes from the post-workshop written feedback given by a woman whose partner has Type 1 diabetes:

> 'I also learned that there are lots of different types of diabetics - some who are well controlled, some who are less so - and that there is no

"right" or "wrong" way of dealing with it when you have it. It was also interesting to see how other people felt about it (although this was something I would have liked more opportunity to explore). It did give me a more realistic view on how my opinion does, and should, count towards diabetic research, as I went in feeling I had a contribution to make, however small, but came out feeling that I had over-estimated my worth to the process'.

Outcome of the deliberations

In order to make sense of the outcome of the deliberative workshop we need to consider both the process and the decision that it produced. Proponents of deliberative democracy characterize participation as *transformative:* through discussion with a plurality of differently situated others, people gain new information, learn of different experiences, and come to see the relationship between their own interests and those of others in a new way. (Young, 2000: 26). The extent to which this happens, of course, depends on how participants conduct themselves. Pelletier et al (1999: 105) argue that

> in assuming the ability of citizens to evolve a generalised will through reflections and discourse, the deliberative democracy approach is fundamentally consensus based. As such, it is subject to concerns that the values and interests of some parties may be subordinated, knowingly or unknowingly, to those of more powerful, articulate or persuasive actors in a participatory process. This concern highlights a dilemma for evaluating real world examples of deliberative democracy: agreement on shared goals emergent from a participatory process may reflect domination and co-optation by the powerful or may be taken as evidence that practical learning has taken place.

In the context of our workshop, therefore, the key question becomes: does the deference to the patient perspective reflect the co-option of the process by a particular interest group or the recognition by all present that prioritising the short-term needs of patients is the best option. In practice, there were elements

of both kind of effect. In some cases, listening and talking to others with different kinds of experience did allow participants to visualise the different consequences of choosing different pathways more clearly. Participants, particularly the lay citizens and carers, trusted the opinions of those who had direct experience of diabetes and its treatment and used this evidence in adjusting their own position. As one of the lay people present put it:

LP: And I've changed my mind on the basis of what a diabetic and a diabetic nurse has told me today about how they feel, I've said all that, I've changed my mind. Before I came here today I wasn't at all convinced by these pumps because I honestly couldn't see how they were any better than what we've already got and I just thought it was a low tech solution, whereas I thought the future might be in particularly stem cell research which I do want to see a future in, but I'm not sure how far I can see it in the future, if you see what I mean. I believe in it, but I'm not sure I can see a direct route to it. But I've been persuaded, I've had my mind changed by talking to people involved.

In contrast it is less clear that those who arrived with substantial expertise or particularly strong views underwent a similar transformation. An example of this kind of interaction occurred during the final discussion and suggests that, rather than individual transformation and learning, what we saw was the domination of the discussion by the patients' group. The exchange occurred towards the end of the final deliberation when one of the lay/friend participants expressed the concern that leaving decision making up to patients, with their clear focus on their short-term needs, may not lead to the best outcome in the long-term. This suggestion provoked an immediate and passionate response from one of the patients, who made it clear that such a view would not be considered:

LP: Might the antithesis to that be to take the diabetic out of the debate because are you only ever going to get a short-termist view where the medium-term, long-term strategic view, especially for funding matters, means that the emotive arguments that are

> made really they queer the pitch. It should be that we have some arbiter taking the medium term strategic view.

P1: You see, I would say that I can understand where you get perhaps if we had more lay people here as such, but the problem with that is they're not living day to day with how myself, P3 and P2 have to deal with it and, of course, E2 as well. We live day to day actually with the condition, then you've got the wider people that live with family relatives that have got the condition. So it affects us and therefore we should have the biggest say and the lay people have the least say. That's my opinion, because it affects us directly and it affects our families. My children are affected daily and if I have a hypo it's my 14 year old daughter's got to deal with it because mainly my husband's away.

In this exchange something other than deliberation taking place. Deliberation does not require everyone to agree, but it does require participants to listen to the concerns of others and to justify decisions with reasons they believe all reasonable persons could accept. Arguments can, therefore, be rejected after reasons have been heard but, in our case, it is not clear that this happened. Instead, patients were granted, and then maintained the right to set the terms of the debate and, where necessary, used highly emotive language to suppress the concerns of others.

The effect of this on the final verdict was that developing insulin pumps were selected as the preferred option by overwhelming majority of the participants in the workshop. Whilst this was consistent with the preferences expressed by the patients in the focus group stage, where they similarly prioritised the treatment option that was 'closest to market' and most likely to benefit them directly, it represented a change for the other participants who had previously put 'prevention' ahead of 'cure'.

In part, the low credibility of the preventative option – the vaccination – was related to the lack of an authoritative expert to explain its promise on the day. As a result, it appeared technologically very complex and surrounded by risks

and uncertainties. That said, however, it is not clear that having an expert present would have made a great deal of difference. Stem cell research was eloquently explained and defended on the day by one of the leading stem cell scientists in the UK but was still seen as too uncertain and speculative an option to be prioritised given the accepted need addressed the immediate concerns of people living with diabetes. As one of the carers present argued:

> C: We have a theoretical opportunity to make a difference right now. It [the insulin pump] is not pie in the sky. It exists. We could make a difference right now. [In case of stem cells we do not know] what the effects are going to be like if it's generally successful. So is it going to be as effective as the pump we already have with us that everyone can have access to if there's proper funding? What are the guarantees?

Given these concerns, the outcome of the workshop was a clear recommendation that the benefactor should put their money into supporting the development of something for which tangible results already exist.

In summary, then, the workshop did produce a consensus and it was one that the participants mostly accepted. How far they would defend the importance of focussing on the short term needs of patients if pushed is difficult to assess as, within the debates and discussions, there were several references to the importance of long-term, blue sky research:

> C: I know it's self-defeating because we only know that can work because somebody did the research 20 years ago which is now coming into fruition.

Perhaps the implicit assumption was that this would be funded by someone else but, in any case, it was clear that such concerns could not be prioritised above those of the patients in this setting. In terms of the distinction made by Collins and Pinch (2005) between medical science as providing succour rather than science, the participants in the workshop came down firmly on the side of

succour: relieving the suffering of patients was seen as the clear the priority, long-term scientific research was something best left for another day.

Conclusions

As policy institutions call for more participation, consultation and deliberation about science and other policy domains, social scientists have an obligation to provide more empirical research about how to effectively implement such processes. This means experimenting with new methods, reflecting on their effects and acknowledging where things did not turn out as expected. In some ways, this latter point – admitting to mistakes – may be the most important of all if research methods are to develop and improve. It is in this spirit that we conclude this paper with some constructive criticism of our experiment, and draw the readers' attention to three lessons we learnt during the research.

First of all, it is essential to take into account the emotional politics of the topic that is being discussed. This means being aware that not just the most obvious and traditional power disparities need to be considered. Whilst elite groups may have a tendency to try to dominate the deliberation, it is equally possible that traditionally excluded others will take (and be granted) the opportunity to assert their claims in the new forum. Whilst this might seem, at first glance, to repair the injustice of real life politics in which they remain marginalised, it actually devalues the principle of deliberation by replacing one form of dominance with another. Maintaining the focus on the common good thus becomes crucial, particularly if each participant, but particularly those without an obvious stake in the debate, are to express their opinion and contribute to the final decision.

Secondly, deliberative events are complex logistically as well as socially. What happens on the day is conditioned by many different factors, not all of which can be controlled or eliminated. For example, time restrictions mean that a decision has to be reached by a particular time; or participants may be distracted by outside pressures and unable to turn up as originally agreed. Whilst apparently mundane, these factors cannot be entirely ignored. In

practice, therefore, running a deliberative forum as a one-off event is not to be recommended and it may well be more effective to organise the deliberation so that it occurs over time and in stages. Whilst this may require greater commitment from participants, it does allow the impact of individual circumstances on the deliberation to even out somewhat and, at the same time, provide a greater opportunity for participants to develop the skills needed for a successful deliberation.

Finally, there is a role of the researcher in the process itself and the consequences of deliberative methods for social science more generally. It is clear that, within qualitative social science in particular, there is a strong affinity with, and support for, participatory forms of decision-taking. This no doubt stems from the importance attached to understanding the other's perspective and the skills of qualitative researchers in eliciting detailed descriptions of social worlds are an important part of participatory research. Deliberative methods take the process one stage further, however. In traditional qualitative research, actors' categories are the starting point from which researchers develop of analytic categories that may explain the actors' world in a new and unexpected way. In contrast, deliberative methods remove this role from the researchers' repertoire by requiring the participants to consider evidence, arguments and reach decisions themselves. The researcher thus becomes the facilitator of a debate rather than its reporter or interpreter.

In summary, therefore, methods are important and do have an effect. In our case, interviews, focus groups and a deliberative workshop all produced different data and different accounts of what the future of diabetes treatment might be. Whilst each method could be refined to become more efficient, there is an important difference between the workshop and the other methods used. Interviews and focus groups retain a clear role for the researcher as the synthesiser, interpreter and analysts of the data. To adapt a theatrical metaphor used earlier (see note 14), in these methods the researcher is not only director, he or she is also the reviewer or critic telling those who did not see the performance what it 'really meant'. In the case of the deliberative workshop, however, the researcher becomes little more than the stage hand, facilitating

the performance, but having nothing to say about its value or merits. If qualitative research is to remain 'frontstage', therefore, deliberative methods need to be used not just with care but with caution.

Notes

[1]   As, for example, in the UK's GM Nation debate. See Horlick-Jones et al (2007) for a comprehensive evaluation.

[2]   At the extreme end of the continuum of management styles are self-managed groups where moderator does not even sit at the same table as the participants.

[3]   Chambers on-line dictionary

[4]   It is also worth noting that the same must apply to focus groups.

[5]   There are two different levels of analysis here. One is research designed at improving the process (e.g. identifying barriers to deliberation) so that it can, one day, run without the oversight of social scientists. The other is to see the social scientist as a kind of expert, interpreting and analysing the interactions, theorising the data and providing an account of their own. Strictly speaking, it seems that, to the extent that deliberation works properly then the role of the social scientists disappears, except perhaps as an expert-participant in their own right.

[6]   The research was funded by ESRC as a demonstrator project within Qualiti, Cardiff node of the National Centre for Research Methods.

[7]   This mirrors the distinction made the GM Nation? study, which characterised the people who attended public meetings as 'active participants'. This essentially self-selecting group were seen as representing the concerned and the engaged rather than the "silent majority" of ordinary citizens who do not attend such events and who were represented in the debate via the 'Narrow but Deep' sample.

[8]   It should be noted that this particular clinic did not work with children, and so could only provide access to adult patients. Another local (and University affiliated clinic) specifically working with children refused to help us, explaining that they 'prefer to keep their patients as a pool of potential participants for their own studies' and did not want to risk them developing 'research fatigue'.

[9]   A similar intervention was used as part of the ESRC Genomics Survey (see Sturgis et al 2004). The key differences in our case, however, were both the range of information available and the time period involved. Whereas the Genomics Survey used a DVD that lasted only a few minutes and then administered the survey straight away, we used a larger and more heterogeneous information set and allowed participants a substantial period of time to absorb and reflect upon this information.

[10]   To give a simple example, one thing that frequently exercises people with diabetes (and their carers) is the need to take regular blood sugar readings. Patients often dislike this, carers

may feel that their partner does not take their readings often enough, whilst lay citizens may be unaware of the problem at all.

[11]   We also found that focus group participants employed several different strategies when filling in the table. The majority read it from the top to the bottom, which had the effect of giving higher rankings to the options at the top of the list (improvements to existing treatments). Some thought that the layout signalled our subtle preference of the options on the top and thought we wanted them to give those treatments listed first more attention.

[12]   Participants typically had a fairly traditional model of science in which social factors entered mainly in the form of external or vested interests that needed to be eliminated.

[13]   Significantly, we also found that more information did not, therefore, lead to more support and not necessarily even to more certainty.

[14]   In his ethnographic study of an opera company, Paul Atkinson (2006) suggested that two theatrical roles mirror those of the social researcher. There is the *producer/director*, eliciting and managing the performances of others, and the *repetiteur*, unobtrusively accompanying the actors as they rehearse their lines. Scott (2007) suggests that a third theatrical role, that of the *stagehand*, i.e. the person responsible for making sure that all of the practical aspects of a performance run smoothly, can also describe the social researcher. In our workshop, prior to the event, we were acting as directors but on the day we assumed the role of stagehand.

[15]   Hendriks (2002) provides a detailed evaluation of this event. Carson and Martin (2002) provide an overview, and rebuttal of, some of the more common arguments against citizen participation.

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