What choices should we be able to make about designer babies? A Citizens’ Jury of young people in South Wales

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Abstract

Background Young people will increasingly have the option of using new technologies for reproductive decision making but their voices are rarely heard in debates about acceptable public policy in this area. Capturing the views of young people about potentially esoteric topics, such as genetics, is difficult and methodologically challenging.

Design A Citizens’ Jury is a deliberative process that presents a question to a group of ordinary people, allows them to examine evidence given by expert witnesses and personal testimonies and arrive at a verdict. This Citizens’ Jury explored designer babies in relation to inherited conditions, saviour siblings and sex selection with young people.

Participants Fourteen young people aged 16–19 in Wales.

Results Acceptance of designer baby technology was purpose-specific; it was perceived by participants to be acceptable for preventing inherited conditions and to create a child to save a sibling, but was not recommended for sex selection. Jurors stated that permission should not depend on parents’ age, although some measure of suitability should be assessed. Preventing potential parents from going abroad was considered impractical. These young people felt the Human Fertilisation and Embryology Authority should have members under 20 and that the term ‘designer baby’ was not useful.

Conclusions Perspectives on the acceptability of this technology were nuanced, and based on implicit value judgements about the extent of individual benefit derived. Young people have valuable and interesting contributions to make to the debate about genetics and reproductive decision making and a variety of innovative methods must be used to secure their involvement in decision-making processes.
Introduction

There has been much research on the public understanding of genetics in the last decade.\textsuperscript{1–7} It is sometimes suggested that the public understanding of the new genetics is poor,\textsuperscript{8} yet it has been demonstrated that the public can hold complex social and ethical views on the subject without necessarily having complete or even accurate information, and are capable of conducting sophisticated discussions on genetics.\textsuperscript{9} Most people have some conversational familiarity with genetic terminology, often because of exposure to stories in the media.\textsuperscript{10} Public understanding is not necessarily linked to technical knowledge and increased knowledge does not translate automatically into acceptance of new genetic technologies. Calnan \textit{et al.}\textsuperscript{11} has shown that most people are positive about science and technology, but with a substantial minority consistently showing scepticism about some of its benefits. Others argue that some applications of genetics are perceived to be unacceptable because they violate a society’s religious or moral standards, or are rejected as not useful to society; other applications might be useful but they are too risky, while others may be judged moral, useful and safe but remain unwanted because those controlling the technology are not to be trusted.\textsuperscript{12}

Research in this area has been mixed and ranges from public opinion polls to the use of deliberative techniques, such as focus groups or consensus conferences, in an attempt to untangle what the general public thinks about the new genetics and how it impacts on their social world. Very little of this research however, is fed directly into the policy-making process and there is restricted discourse between ordinary members of the public and policy makers. Furthermore, most of this research has been conducted with adults.

Public consultation on genetics and reproductive decision making

In July 2004 the Human Genetics Commission (HGC) launched a public consultation – Choosing the Future: Genetics and Reproductive Decision Making – which sought the views of the British public on these issues.\textsuperscript{13} The HGC argued that the term ‘designer babies’ could be used to refer to a range of reproductive techniques including the use of sex selection techniques to prevent the birth of children with X-linked diseases; preimplantation genetic diagnosis to select for embryos free from genetic disorders; selection techniques for egg, sperm or embryo donors with particular characteristics, and the enhancement of features such as intelligence, sporting ability or attractiveness. They set a number of questions about specific issues pertaining to genetics and reproductive decision making as well as asking people to outline their hopes and fears for the future.

Given that today’s young people will be the first generation to make use of new reproductive technologies we felt it was important that their voices be heard in this debate and should inform the HGC consultation. Preliminary research at Techniquest, the science discovery centre in Cardiff, using focus groups across Wales demonstrated that within the area of genetics and reproductive decision making the subject of designer babies is one which young people are familiar with, can relate to, and consider a key issue in the genetics and reproductive decision-making debate.

Young people are more likely to engage with an issue the more immediate it is.\textsuperscript{14–16} Curtis \textit{et al.}\textsuperscript{17} argues that methods for effective consultation with young people on health issues are improving. Every approach must be flexible and age-appropriate so we decided to gather the views of young people aged 16–19 in Wales in a Citizens’ Jury on the question ‘Designer babies: what choices should we be able to make?’ The aim of this paper was to describe the Young People’s Citizens’ Jury on Designer Babies in Wales, and to offer some reflections on what they considered to be acceptable public policy in this area.

Method

Citizens’ Juries are an important way of facilitating informed debate into the policy-making process. Modelled on the juries used in legal
trials, a Citizens’ Jury typically meets for a period of 3–5 days during which jurors are presented with an issue, have a chance to examine evidence, interrogate expert witnesses, debate all aspects of the topic and present a decision on the policy question posed. A Citizens’ Jury differs from a legal trial in that much more interaction amongst jurors, and particularly between jurors and witnesses, takes place in a Citizens’ Jury. Jurors engage in group work and discussions and have considerable opportunity to cross-examine witnesses after they have presented their evidence. The Jury then deliberates over the evidence together and a number of recommendations are agreed with the help of a trained moderator. A Citizens’ Jury is based on the premise that ordinary people given enough opportunity, time, support and resources are eminently capable of arriving at decisions about complex policy matters. Citizens’ Juries have been used in the UK to tackle a variety of subjects, including inter alia, housing, insurance, hospital closure and genetically modified foods. They were used in Wales for the first time in 1997 to explore the public’s attitudes to genetic testing for common disorders in the National Health Service (NHS).  

Recruitment

Trying to get 16 young people to form a Citizens’ Jury involved a variety of innovative methodological approaches. We were keen to ensure the Jury was diverse so we wanted jurors to broadly represent the Welsh population aged 16–19 which meant that two-thirds were to be in full-time education. Recruiting young people still at school was relatively easy; attracting those no longer in full-time education required a variety of different approaches, often working with young people’s groups and organizations as intermediaries, to ensure the quota of one-third required. In the event, four of the 14 jurors were not in full-time education.

Flyers about the project were given out to students visiting Techniquest as part of their A-level courses, and were posted to all schools on Techniquest’s database, employers in the Cardiff area, colleagues in local universities, nurseries and after-school clubs. It was a challenge to get marginalized young people involved in an extended deliberative process, so key workers in organizations such as Sure Start, Barnardos and Tros Gynol (for children in care) were also targeted. Wales has a relatively well-developed infrastructure for young people’s participation in public policy making. Wales was the first of the UK countries to establish a Children’s Commissioner, reflecting many years of work by Children in Wales (representatives from which moderated the Jury) and others to ensure that the UN Declaration of the Rights of the Child shapes the policy framework for children and young people in Wales. This national structure complements a well-developed local infrastructure, with each local authority in Wales sponsoring its own children’s and young people’s forum drawn from School Councils and other young people’s bodies, and ultimately linked to the Wales Youth Parliament and Funky Dragon, a Welsh Assembly-sponsored Internet forum for young people. All of these organizations were also given information about the Jury and asked to advertise a series of pre-Jury meetings.

Participants

Two pre-Jury meetings were held in Techniquest on Saturday mornings in July 2004. The purpose of these meetings was to explain to the young people who had expressed an interest in being a juror what the process of a Citizens’ Jury involved and to elicit from them a firm commitment that they wanted to be considered as a juror. At this meeting they were told the project would take up 3½ days of their time and that they would be paid a daily rate of £50 per day plus travel expenses. A total of 37 young people registered after these pre-meetings and from this list a stratified random sample of 16 people was chosen to give broadly equal numbers of males and females in the Jury, of which one-third were outside the formal school system. Two people (both male) dropped out the morning the Jury commenced. A demographic breakdown of the Jury (n = 14) is given in Table 1.
Preparation

The establishment of a steering group is often the key to the success and legitimacy of the project. This Citizens’ Jury was formally guided by a steering committee, composed of academics, clinicians, policy makers, patient representatives and young people, who met three times between January and August 2004. We were concerned about providing unbiased information to the Jury and consulted the steering committee about the choice of witnesses. We were advised on types of witness for each session and offered suitable names; in addition, the young people at the pre-meetings had requested that some witness evidence be given by people with direct personal experience of genetics and reproductive decision making. A range of young people was also consulted at every stage of the process. For example, their opinions on the terminology and topics were sought in focus groups; they were represented at steering committee meetings; others reviewed some of the written and visual evidence that was presented to the Jury, and were asked for their opinions about everything from the venue, to the type of food that should be served.

Process

The Citizens’ Jury ran for 3½ days in September 2004 and was moderated by two trained facilitators from Children in Wales with experience in engaging young people. The first half day focused on establishing trust, laying down ground rules, developing a common sense of purpose, ensuring everyone understood the process and encouraging the young people to develop some ownership of the Jury. One session was devoted entirely to the science of genetics and reproductive technologies; this was requested in the planning discussions with young people. Information was provided in a variety of different ways, such as video clips, newspaper articles and games, in order to make it as interesting and as interactive as possible.

The Citizens’ Jury was divided into three stages, relating to three of the main potential uses of the technology: (1) to prevent inherited diseases, (2) to save the life of an existing child with a serious medical condition (saviour siblings), and (3) for non-medical reasons such as sex selection. The Jury listened to 12 expert witnesses each speaking for approximately 15 min. Witnesses included clinicians, academics, researchers, policy makers and advisors, as well as individuals with direct personal experience of the issues as patients/service users and their families. Witness presentations moved between those that focused on general principles and were intended to be adversarial to the case studies delivered by ordinary people presenting personal testimonies on how the issues had affected them and their families. Each witness was briefed in advance with guidelines about talking to young people (produced by the moderators) and asked to submit their argument in written form in a couple of paragraphs so that jurors could assimilate the main arguments in advance of their session.

Table 1 Demographic breakdown of Jury

<table>
<thead>
<tr>
<th>Category</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>8</td>
</tr>
<tr>
<td>Male</td>
<td>6</td>
</tr>
<tr>
<td>Ages</td>
<td></td>
</tr>
<tr>
<td>16</td>
<td>3</td>
</tr>
<tr>
<td>17</td>
<td>6</td>
</tr>
<tr>
<td>18</td>
<td>3</td>
</tr>
<tr>
<td>19</td>
<td>2</td>
</tr>
<tr>
<td>In full-time education</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>10</td>
</tr>
<tr>
<td>No</td>
<td>4</td>
</tr>
<tr>
<td>Welsh speaking</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>2</td>
</tr>
<tr>
<td>No</td>
<td>12</td>
</tr>
<tr>
<td>Were parents</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>2</td>
</tr>
<tr>
<td>No</td>
<td>12</td>
</tr>
<tr>
<td>Registered disabled</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>2</td>
</tr>
<tr>
<td>No</td>
<td>12</td>
</tr>
<tr>
<td>Religion</td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>7</td>
</tr>
<tr>
<td>Christian (unspecified)</td>
<td>3</td>
</tr>
<tr>
<td>Roman Catholic</td>
<td>2</td>
</tr>
<tr>
<td>Hindu</td>
<td>1</td>
</tr>
<tr>
<td>Muslim</td>
<td>1</td>
</tr>
</tbody>
</table>

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were also open to members of the public to ensure the process was transparent, and there were a number of observers every day. The jurors questioned the witnesses directly, immediately following their presentation. Approximately a third of the total time was devoted to discussions and other interaction amongst the jurors themselves.

Every witness presentation was tape-recorded and videoed, as were the discussions between witnesses and jurors and between jurors themselves. Other methods used to gather data included hand-held video cameras used by jurors; juror diaries; pre- and post-Jury questionnaires and individual interviews with jurors 1 month after the event. Data analysis involved compiling summary statistics and using thematic categories for the qualitative data.

Results

Participants discussed general concerns in relation to the three main applications of designer baby technology, compiled a verdict of their main recommendations, and outlined many of their hopes and fears for the future.

Inherited conditions

This was the least controversial of the three applications. A majority of the Jury believed that potential parents should be able to choose to make use of assisted reproductive techniques to prevent inherited conditions from being passed on and to prevent serious suffering. The Jury also supported the idea that at least one attempt should be available free-of-charge to all on the NHS, just like any other health service in the UK. The Jury was almost evenly divided on whether permission should depend on the severity of the condition. For some, it was important to prevent parents from designing babies for ‘frivolous’ reasons; for others the judgement of the parents concerned was the determining factor. One girl claimed ‘No-one should be allowed to consciously pass on a genetic condition to the next generation if the condition can be stopped’ with a young man arguing the opposite ‘No-one in the UK should be allowed to scan and remove illness as illness is an important part of society… if we remove illness where do we end, removing everything we believe to be undesirable’. A minority of the Jury (n = 2) believed that such technologies were an unacceptable interference with human life, regardless of the severity of the genetic disease. It was felt that these techniques would inevitably undermine the uniqueness of each individual, and encourage the idea that some people are inherently better than others.

Saviour siblings

A majority of the Jury also supported the principle of designing babies for the purpose of curing existing children with serious medical conditions – ‘saviour siblings’. It was felt that parents were unlikely to discriminate in any adverse way between their children on the basis that they were or were not designed for a particular purpose:

It is the type of parent you are, if you are going to design a baby and you are going to go to that trouble to save the child then you will love that child as much.

Again the majority felt that given this is essentially a health service, it should be available on the NHS. The minority who opposed this particular application of designer babies perceived that designing a baby for the benefit of another undermines the dignity of the one who has been designed – ‘…it should be loved … not just for its parts’.

Sex selection

This was the most controversial of the possible applications. The majority of the Jury was opposed to designing babies for a non-medical reason such as selecting the sex of a future child (10/14, with 3 Don’t Know). Whilst the relief of suffering – either of the designed baby or a sibling – may be sufficient justification for interfering with natural processes, to do this for other reasons (such as family balancing) is to imply
that the designed child is a possession of the parent. Acceptance of designer baby technology in this area therefore appeared to be contingent upon perceived utility. Only one person actively supported sex selection and she argued:

As a parent I have had two caesarean births, and I have had two girls. I would love to have a little boy to finish my family … It should be allowed definitely.

The verdict

The Jury’s verdict was compiled on the third full day by using a series of votes to reflect discussions on the main topics (see Table 2).*

Regulation

There was much discussion on how regulatory principles should be applied in this area. All the jurors supported the existence of some form of regulatory regime in the UK. They felt that the regulator should set and enforce quality of care standards for each clinic, and that each application to ‘design’ a baby should be considered individually by the regulator (by applying standard rules) to allow for exceptional cases. Jurors were particularly concerned that all applicants should receive a fair and swift hearing from the regulator, and that their individual circumstances should be fully explored before a decision is made. Jurors were concerned with ‘welfare of the child’ arguments and claimed that regulation must endeavour to ensure that parents are unlikely to abuse or in any way discriminate against the designed child. Most believed the age of the parents was not a relevant factor on its own for decision making. Finally, there was broad agreement that it would be impractical to prevent potential parents from travelling abroad to avail of ‘fertility tourism’ in order to avoid UK regulation.

Two other key issues emerged from the group discussion. First of all, the majority of the Jury felt that policy-making bodies – and in particular the Human Fertilisation and Embryology Authority (HFEA) – should be more representative of people who will be affected most by policy developed in this area. Thus, they argued that the HFEA should include some members within their age range, i.e. under 20. Secondly, at the end of the process the Jury decided that the term ‘designer babies’ was not a useful description for the processes that were currently being

*Video clips of witness presentations and a full copy of the Jury’s Verdict can be downloaded from http://www.wgp.cf.ac.uk/CitizensJury.htm
utilized, as it creates a false impression about what is actually happening. The majority felt that these processes were much better described as ‘embryo selection’.

Main concerns

Some of the hopes and fears as summarized by the jurors are listed in Table 3. The following excerpt gives a flavour of how some of the discussions between participants were conducted and illustrates some of the wider social and ethical issues that were considered when debating different aspects of embryo selection:

Male2: …and not just use you … I think Saviour Siblings are great as long as you don’t do that, what you said there, give it away. That is just like abusing it.

M4: If you don’t want a baby you can help, you look after the best interests of that baby by putting it up for adoption.

Female1: Then the mother may lose the sick child and gives the other one up for adoption and is now left with…

F2: I think it should be allowed … I think if they have the disease to have another child.

M2: I can understand giving the baby up for adoption if you didn’t want it in the first place, but you did want the child because you paid to have it.

M5: A baby is to love, not just to have stems [stem cells] out of.

M2: We have seen the mother having the baby, using the stem cells and keeping those for another baby.

F2: People should have the choice.

F3: It is the type of parent you are, if you are going to design a baby and you are going to go to that trouble to save the child then you will love that child as much.

M2: Do you know what annoys me the most, if it was someone like Tony Blair, and he had a disabled child and he needed to do something about it, he would get away with it, he could do it and I think it is unfair. Everybody has the right, no matter what.

F1: You are not allowed to do that. You are not allowed to bring a child into the world and then kill it.

M4: You are not going to be able to do that.

Table 3 Jurors’ hopes and fears

<table>
<thead>
<tr>
<th>Hopes</th>
<th>Fears</th>
</tr>
</thead>
<tbody>
<tr>
<td>In an ideal future I hope that designer baby technology will allow people to:</td>
<td>If things go wrong the following might happen:</td>
</tr>
<tr>
<td>Be able to have children, if they so wished</td>
<td>People would design babies for selfish reasons, i.e. not to prevent illness or suffering</td>
</tr>
<tr>
<td>Make informed reproductive choices, free from all outside pressure</td>
<td>Eugenics might come to dominate policy</td>
</tr>
<tr>
<td>Have equal rights and opportunities in life, regardless of personal impairment</td>
<td>Saviour siblings who failed to save might be rejected</td>
</tr>
<tr>
<td>Avoid the suffering of children with inherited conditions</td>
<td>Accidental damage might be caused to designed babies</td>
</tr>
<tr>
<td>Live longer, healthier lives</td>
<td>There could be future imbalance between the sexes</td>
</tr>
<tr>
<td>Stay together as families for longer if the tensions sometimes caused by serious inherited conditions could be avoided</td>
<td>An obsession with the quest for perfection would arise</td>
</tr>
<tr>
<td>Have advance knowledge of their unborn child’s health, and be prepared</td>
<td>There would be increased social pressures to design</td>
</tr>
<tr>
<td>Have access to designer baby technology where appropriate, regardless of cost or where they live</td>
<td>There could be prejudice and discrimination against non-designed babies</td>
</tr>
</tbody>
</table>
The impact of the process

It is not possible in the UK to carry out research on how the evidence (or the rest of the process) impacts on the views of jurors engaged in criminal or other legal proceedings. Fortunately, this restriction does not apply to Citizens’ Juries. The detailed analysis of the transcripts and other material chronicles the various arguments advanced by the jurors in their discussions, and records their verdicts on the various witnesses. There are many examples of jurors changing their minds on specific issues, and sometimes of changing them back again. Taking all the possible applications of designer baby technology together, at the end of the Jury, most jurors (11 of 14) strongly agreed or tended to agree that designer baby technology would be useful for society; but also that it would be risky (12 of 14). The perceived risk related almost entirely to ‘misuse’ of the technology rather than to any inherent clinical dangers, for example creating babies for frivolous reasons, or systematic attempts to impose certain options on would-be parents.

Jurors were more evenly divided on whether the use of such technology was morally acceptable (five agreed, six disagreed), and should be encouraged (seven agreed, four did not). When asked to respond to the statement ‘I would seriously consider designing my own babies in the future’, six agreed and seven disagreed. In general, the process seems to have made jurors more optimistic about the future use of designer baby technology. At the end of the preparatory half day, and again at the end of the Jury, jurors were asked to respond to the question: ‘Are you generally optimistic or pessimistic about the future use of designer baby technology?’. The results are shown in Table 4.

On being a juror

Jurors were also invited to keep diaries as the Jury progressed. These are some of the quotes from those diaries illustrating what participants felt about the process:

<table>
<thead>
<tr>
<th>Table 4 Jurors’ views on the future use of designer baby technology</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
<tr>
<td>Very optimistic</td>
</tr>
<tr>
<td>1</td>
</tr>
<tr>
<td>2</td>
</tr>
<tr>
<td>3</td>
</tr>
<tr>
<td>4</td>
</tr>
<tr>
<td>5</td>
</tr>
<tr>
<td>6</td>
</tr>
<tr>
<td>Very pessimistic</td>
</tr>
<tr>
<td>7</td>
</tr>
<tr>
<td>Don’t know/no response</td>
</tr>
</tbody>
</table>

I was nervous at first, but once involved within the group, I felt a part of a team

It’s been a rollercoaster of a ride these past few days, but very interesting

It was good to talk properly as a whole about every topic discussed throughout. There are so many different points of view and it is good that we are not all the same

My opinion has totally changed both ways from neutral. The witnesses and knowledge I have acquired has enabled me to make my final decision

At first I was concerned that designer babies would take over and that it would get out of hand, however after these 3 days I’ve noticed that because the issues themselves are so sensitive and in the limelight, human instinct would never take us that far

Dissemination

One week after the Jury concluded their deliberations a celebration evening was held for jurors, their families, the press and other invited guests at which their recommendations were discussed and people were given the opportunity to ask jurors questions both about the process and how they arrived at their conclusions. In November 2004 some jurors then presented their verdict at the Welsh Assembly Government to the Health and Social Affairs Committee. In December 2004 some jurors also presented to
the Genetics and Reproductive Decision Making sub-group of the HGC in London, and in February 2005 to the HFEA.

There was extensive regional and local coverage of the project on TV, radio and in the newspapers, and considerable interest in the methodology from public organizations struggling with their responsibility to engage young people in their decision-making processes.

Discussion

A Citizens’ Jury is a method which can engage young people in a meaningful way. Our participants had valuable and interesting things to say about designer babies and they demonstrated that they could move beyond their individual opinions and make recommendations that they felt were best for society as a whole. They used everyday experience to think about genetics and reproductive decision making, and the possibility of harm was often rebutted with positive personal experiences. On many issues these young people were able to reach agreement about fundamental values as a result of debate and discussion, although in many cases, and as Table 2 suggests, they also reached different conclusions about the practical implications to be drawn from those values, and on their relative weighting.

As a research project, this Citizens’ Jury has yielded fascinating data. The values, priorities and epistemological premises of the jurors were thrown into sharp contrast by the many emotional and intellectual challenges of the topic, and the intensity of the process. Considering some of the challenges that had to be overcome; for example, arranging childcare, organizing lifts to Cardiff, and overcoming disabilities, all participants showed huge commitment to the process. In fact, at the end of the Jury everyone said they would have participated regardless of the money they received.

There is much literature about the extent to which citizens are competent to question the knowledge claims of specialists in complex decision-making processes. Although we did not rigorously test knowledge at the end of this project, none of the jurors felt that they had insufficient knowledge to contribute to discussions; the rationale for the introductory sessions explaining genetics and reproductive technologies was to allow jurors to concentrate on the social and ethical issues. Nor was there any evidence that these young people experience the so-called ‘authority effect’ – the inevitable deferral to experts – at any time. This had been a concern before the Jury took place, and formed a key element of the briefs given to the moderators and the witnesses. That the problem was largely avoided is perhaps due in part to careful preparation, both of the jurors themselves with the moderators re-iterating throughout that it was the responsibility of the Jury to make its own decisions, and in relation to planning the evidence as most viewpoints were contested by opposing witnesses. It may also have had much to do with the essential independence of mind of the particular jurors involved, many of whom were more inclined to dispute arguments rather than accept them passively.

New ‘genetic citizens’ should not only be informed but also have the right and the duty to be active in decision making about the use of genetic technologies and genetic information. Genetics has recently received a big policy push in the UK. Genetics and reproductive decision making are difficult subjects, combining cutting-edge science and technology with complex ethical and legal issues, making it an area where a substantial element of reflection and interactivity is required for robust lay views to emerge. It is also an area in which the views of young people – themselves on the threshold of making reproductive decisions – are particularly relevant, representing as they do the generation which will be first to access significant new reproductive technologies and relevant genetic information.

Citizen deliberation is a prominent theme in health policy literature. The usefulness of a Citizens’ Jury is that it emphasizes citizens’ rational deliberation rather than gut instinct or the immediate preferences of a consumer – the Jury reaches judgements rather than registering...
attitudes. Kashefi and Mort argue that the major weakness of the Citizens’ Jury model is that it simply extracts ‘the public view’ without any built-in mechanisms for follow-up, scrutiny or accountability. Another limitation is the cost involved – this Citizens’ Jury cost £25 000 (excluding staff time). Different versions of the Citizens’ Jury are evolving. In some versions the Jury’s verdict is presented to sponsors or commissioners for consideration, who may be contracted to respond to the Jury’s recommendations within a set period. This Citizens’ Jury fell victim to this criticism as there was no immediate decision to be made and no commissioning body to report to; however it did provide a useful input into the deliberations of key policy-making bodies (in the case of the Human Genetics Commission, feeding into a specific consultation) and the impact on jurors themselves was immense. The views of these young people were an important addition to what is usually a debate amongst experts and committed lobbying groups that privileges those with scientific and linguistic capabilities. All of us with an interest in genetics and reproductive decision making need to ensure we listen to their voices.

Acknowledgements

Thanks to all the young people who participated in every stage of this project. They are too numerous to mention by name but every contribution was gratefully received. Thanks to the steering group who regularly gave of their time to discuss matters of process or content. Particular thanks go to the two moderators from Children in Wales – Sean O’Neill and Mike Lewis – and to staff at Techniquest, University of Glamorgan and the Wales Gene Park for assistance with administrative tasks. This project was funded by the Wellcome Trust (ref: 074657/Z/04/Z).

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