



Genetics on stage: Public engagement in health policy development on preimplantation genetic diagnosis[☆]

Susan M. Cox^{a,*}, Magdalena Kazubowski-Houston^b, Jeff Nisker^c

^aUniversity of British Columbia, The W. Maurice Young Centre for Applied Ethics, 227-6356 Agricultural Road, Vancouver, BC, Canada V6T 1Z2

^bCultural Studies Program, Trent University, Ontario, Canada

^cSchulich School of Medicine & Dentistry, University of Western Ontario, Ontario, Canada

ARTICLE INFO

Article history:

Available online 21 February 2009

Keywords:

Canada
Health policy development
Theatre
Genetics
Reproduction
Public engagement methods

ABSTRACT

Arts-based approaches to public engagement offer unique advantages over traditional methods of consultation. Here we describe and assess our use of theatre as a method of public engagement in the development of health policy on preimplantation genetic diagnosis, a controversial method for selecting the genetic characteristics of embryos created through in vitro fertilization. Funding from the Canadian Institutes for Health Research and Health Canada supported 16 performances of the play *Orchids* in Vancouver, Toronto, and Montréal and post-performance discussion in English and French (with Hubert Doucet) in 2005. A total of 741 individuals attended. The methods used to assess audience engagement and elicit policy-relevant dialogue included in-theatre observation of audience responses, moderated post-performance large audience discussion and focus groups, audience feedback forms and researcher fieldnotes. Emphasizing process and context over emerging outcomes, we reflect on the distinctive contributions of theatre in stimulating public engagement and the need to utilize multiple methods to adequately assess these contributions. We suggest continued dialogue about the possible uses of theatre in health policy development and conclude that greater clarity is needed with regard to citizens' (as well as specific stakeholders, policy makers' and sponsors') desired outcomes if there is to be a suitably nuanced and reflexive basis for assessing the effectiveness of various strategies for public engagement.

© 2009 Elsevier Ltd. All rights reserved.

Introduction

Engagement with art synthesizes the rational and the emotional, the imaginative and the intuitive. It releases the visionary impulse, bringing an innovative dimension to problem-solving (Wyman, 2004, p. 6).

Since at least the time of Sophocles (497 BC), theatre has offered a vital forum for engaging citizens in dialogue about moral, social and political issues. In bringing to life the tragedies and triumphs that describe the human condition, theatre poses questions about

what is good and just and how we ought to behave as moral beings. Some forms of theatre also engage the imagination to enlarge our capacity to understand and respond to human suffering (Boal, 1998; Johnson, 1993; Nussbaum, 2001).

Theatre has been used to investigate health and social problems, raise public awareness, inform relevant decision-makers; stimulate community activism and social change, and, disseminate research findings in novel and potentially influential ways (Belliveau, 2007; Diamond, 2004; Gray & Sinding, 2002; Mienczakowski, 1995; Stuttaford et al., 2006). Our use of theatre demonstrates the unique advantages of using theatre in the development of health policy. Although other uses of theatre (and many individual plays) have broad policy relevance, this is the first time that theatre has been explicitly used for engaging the public in the development of health policy.

Our use of theatre in the context of developing health policy focuses on preimplantation genetic diagnosis (PGD), a controversial method of assessing the genetic characteristics of embryos created through in vitro fertilization (IVF). The bilingual public engagement exercise we describe involved 16 performances of the play *Orchids* in three Canadian cities in 2005. (Francophone productions also

[☆] We deeply appreciate the collaboration of Hubert Doucet (Director, Groupe de Recherche en Bioéthique, Université de Montréal), research assistants Robyn Bluhm, Natasha Damiano, Margaret Dorazio-Migliore, Celine Durand, Isabelle Ganache, Isabelle Gareau, Heather Greenwood, Holly Longstaff and Marc Toppings and facilitators Katherine Arnold, Evan Adams, Sue McRae, Martin McNeally, and Shawn Winsor. We gratefully acknowledge funding from the Canadian Institutes for Health Research and Health Canada. Cox was also the recipient of a Michael Smith Foundation for Health Research Scholar award.

* Corresponding author. Tel.: +1 604 822 0536; fax: +1 604 822 8627.

E-mail address: suecox@interchange.ubc.ca (S.M. Cox).

involved collaborator Hubert Doucet.) The study was designed to make both substantive and methodological contributions, by engaging ordinary citizens and stakeholders in developing health policy on PGD and by assessing the use of theatre-based methods of public engagement in policy development.

Methods of public engagement

In their typology of strategies for public engagement, Rowe and Frewer (2005) distinguish between public communication, consultation and participation on the basis of the flow of information between the sponsor and members of the public. With public communication, information is conveyed from the sponsor to the public. With public consultation, information is elicited from the public by the sponsor. In public participation, information is exchanged between the public and the sponsor.

The typology contributes to theorizing “what works best when” (Rowe & Frewer, 2005). Nonetheless, it rests on a simplified model of the nature and purpose of communication in public engagement wherein the goal is to maximize the flow of “information” from relevant senders to appropriate receivers (Rowe & Frewer, 2004). This model corresponds with the conduit and/or container metaphors that depict information as ‘stuff’ that is transmitted more or less effectively (Reddy, 1993). Thus it may, if not employed judiciously, deflect attention from the quality, framing and context of delivery of the information. Calling for greater ‘reflexivity’ in the practice of public engagement and a more iterative form of moral learning at all levels, others (Weldon, 2004; Wynne, 2004) suggest a more ethnographic frame for understanding how various methods of public engagement are used and evaluated.

Our stance regarding these competing paradigms is pragmatic. We concur with Abelson et al. (2003); Abelson & Gauvin (2006) that while there is reason to be skeptical about the development of a toolkit prescribing ‘what works best when’ there is also ample reason to proceed with research that enhances governmental as well as scientific accountability for large expenditures of public funds. There is a paucity of rigorous studies evaluating different methods of public participation and much work remains to be done in unpacking notions of effectiveness and establishing general principles for evaluation criteria (Abelson et al., 2003). Understanding the role of context and characterizing specific settings are also important (Rowe & Frewer, 2005) as is greater clarity on citizens’ (as well as sponsors’) desired outcomes.

In what follows, we present our use of theatre and post-performance dialogue. Abelson et al. (2003) identify four components of evaluation that provide a helpful though not comprehensive framework: 1) issues of representation (i.e., legitimacy, inclusiveness versus exclusiveness); 2) process or procedures (i.e., structure, degree of control or input, form of deliberation); 3) information used in the process (i.e., amount, accessibility, framing); and 4) outcomes and/or decisions arising from the process (i.e., improved decisions, achievement of consensus). Given that representativeness/inclusivity is the focus of another article (in preparation) and that policy on PGD is still being formulated, we focus here on the process of post-performance dialogue, the way in which ‘information’ was framed and, other emergent criteria relevant to the effectiveness of the exercise and its translational quality (Horlick-Jones, Rowe, & Walls, 2007).

Public engagement in the development of policy on PGD

Most strategies utilized for citizen participation in policy development are limited by the inability to engage large numbers of citizens and/or provide necessary background information prior to soliciting their opinions (Coleman & Gøtze, 2001; Einsiedel &

Eastlick, 2000; Nisker, Cox, & Kazubowski-Houston, 2006; Nisker, Martin, Bluhm, & Daar, 2006; Rowe & Frewer, 2000). Given these shortcomings, theatre offers unique advantages as an innovative method for engaging citizens as well as stakeholders in health policy development. Theatre can accommodate large numbers of participants. It also has the capacity to cultivate empathy as well as reasoned critique. This is nowhere more urgently needed than in the realm of assisted human reproduction.

About PGD and context for policy development

Preimplantation genetic diagnosis (PGD) was developed in the late 1980s (Handyside et al., 1989) to enable genetic assessment of embryos created through in vitro fertilization (IVF). Genetic material is withdrawn from embryos at the 8-cell stage and, after examination, selected embryos are transferred to the woman’s uterus or frozen for subsequent use (Verlinsky, 1999). PGD thus provides an alternative to the emotional and physical stress of prenatal testing followed by consideration of second trimester genetic abortion.

Several countries regulate possible uses of PGD for: a) selecting embryos that do not carry genetic markers, b) detecting chromosomal anomalies, c) determining the sex of the embryo and/or, d) determining the histocompatibility of an embryo with an existing person. In Canada, there is no legislation, nor professional policy guidelines, that regulate PGD although all activities involving IVF embryos are governed by the *Assisted Human Reproduction (AHR) Act* (2004). PGD is currently offered in several IVF units but only two do the actual genetic testing on site; the others transport the embryos to laboratories in the United States. Worldwide, there is approximately one successful pregnancy in every four PGD cycles with only half leading to a live birth (ESHRE, 2002).

Although regulation of PGD was considered in the development of Canada’s *AHR Act*, there had been insufficient opportunity for input from citizens and stakeholders. Our research was part of a bilingual consultative process on PGD and was jointly funded by the Canadian Institutes of Health Research and Health Canada. During this time, the AHR Implementation Office also initiated a survey-based public consultation on regulation of PGD (Minister of Health, 2005).

Citizen and stakeholder engagement in developing appropriate policy on PGD are important for many reasons. PGD may not be safe, longterm, for those ‘created’ in this way; the range of conditions for which PGD is permitted may expand; there are risks (physical, emotional and financial) for the woman and her partner and significant implications for families, communities and populations. Little is known about what it will mean to children created through PGD and women who become pregnant without using IVF and PGD may be perceived as irresponsible if their child develops a condition that could have been avoided (Brunger & Cox, 2000; Dresser, 2006; Franklin & Roberts, 2006; Hildt, 2002).

Such concerns set a challenging agenda for policy-makers. Their task is compounded by intense political pressure, both for and against easing of restrictions on stem cell and other controversial research requiring access to eggs, sperm and embryos (Beeson & Lippman, 2006; Mykitiuk, Nisker, & Bluhm, 2007). As such, the development of appropriate policy on PGD is widely seen to require the participation of ordinary citizens as well as stakeholders. A key question is how to most effectively tap the wisdom, creativity and experience that ordinary citizens, as well as stakeholders, can bring to bear on pressing social, political and moral questions. As one participant in our research said,

“... we live in a democratic society, a lot of this stuff happens without much engagement... everybody’s crying for it at some level. They want to hear from the public. But how to hear from

the public is a real challenge and what's the way to engage?" (T10)

Research design and methods of assessing engagement

There were three specific study objectives: (1) use theatre and post-performance discussion to engage citizens and stakeholders in policy development on PGD; (2) compare two strategies for post-performance audience discussion (i.e., large audience and focus groups); and (3) evaluate our use of theatre as an innovative method of public engagement in health policy development. By “engagement” we mean bringing citizens together in a forum that facilitates active participation; involving citizens in mutual learning about scientific, clinical, ethical and social considerations; and, stimulating citizens to consider, question and empathize with persons immersed in the issues being considered for policy development.

Theatre can be effective in engaging “citizens of diverse perspectives, emotionally and cognitively, in a manner that promotes their informed opinions on the policy issue under consideration” (Nisker, Cox, et al., 2006; Nisker, Martin, et al., 2006: 269). A play's capacity to engage depends upon the abilities of the playwright who weaves the knowledge and lived experiences of persons interviewed for the script into a compelling story and set of characters, the director whose synergy and vision lifts such knowledge off the page and the actors who embody this knowledge and bring to life the experiences of the central characters. When theatre succeeds, audience members may receive new insight through experiencing the play together and hearing about the lived experiences of other audience members participating in post-performance dialogue.

Our approach takes seriously the imperative that theatre, as an event, provides “the audience with possibilities for rich engagement with the issues, but leaves them free to interpret as they wish” (Gergen & Gergen, 2000: 1030). The possibilities for ‘rich engagement’ coupled with unconstrained interpretation are especially crucial when there are many complex issues to consider and when policy development is at an early stage.

Fig. 1 shows sources of input and interaction from the script-writing stage through to delivery of our report to Health Canada. This figure illustrates opportunities for three-way communication

and education in policy development as governments ask questions and citizens respond, citizens ask questions of and respond to each other, and citizens ask questions and governments respond (Coleman & Gøtze, 2001; Nisker, Cox, et al., 2006; Nisker, Martin, et al., 2006). We also situate ourselves as researchers within this communicative nexus, engaging in dialogue with citizens and government and scrutinizing our own taken-for-granted assumptions as we reflexively assess our role in facilitating public engagement.

Script development and production

The play *Orchids* was written to question the social construction of normalcy and abnormalcy in reproductive and genetic medicine (Nisker, 2001). The storyline is based on the real inevitability that two women carrying a genetic marker for the same condition will meet in an infertility clinic waiting room: one wanting IVF and PGD to avoid having a child with the genetic condition and the other wanting IVF to bypass her blocked fallopian tubes so she can become pregnant and have a child (who may or may not carry the gene for the same condition). The other two lead characters are physician/scientists. The first is enamoured by the potential of genetics while the other is concerned with the effects that embryo selection will have on persons with disabilities. The play is staged as a musical and four additional actors comprise a chorus of IVF laboratory technicians (The full script, as well as a plot summary, is available online in [Supplementary data](#)).

Orchids raises issues relevant to many genetic conditions and forms of disability. Tourette Syndrome (TS) was chosen because its manifestations offer audience members an immediacy of experience in understanding the social challenges of the condition. Although the role of genetics in TS is unclear, TS is like many inherited conditions in that it presents a “spectrum” of manifestations (i.e., motor and vocal tics), varying greatly in kind, frequency and depth. Social responses to persons with TS also vary and the apparently uncontrollable body movements and outbursts associated with the condition often lead to stigmatization (Davis, Davis, & Dowler, 2004).

The play was translated from English into French and each production had different directors, producers and actors. All actors were members of Canadian Actors' Equity. Final casting was done

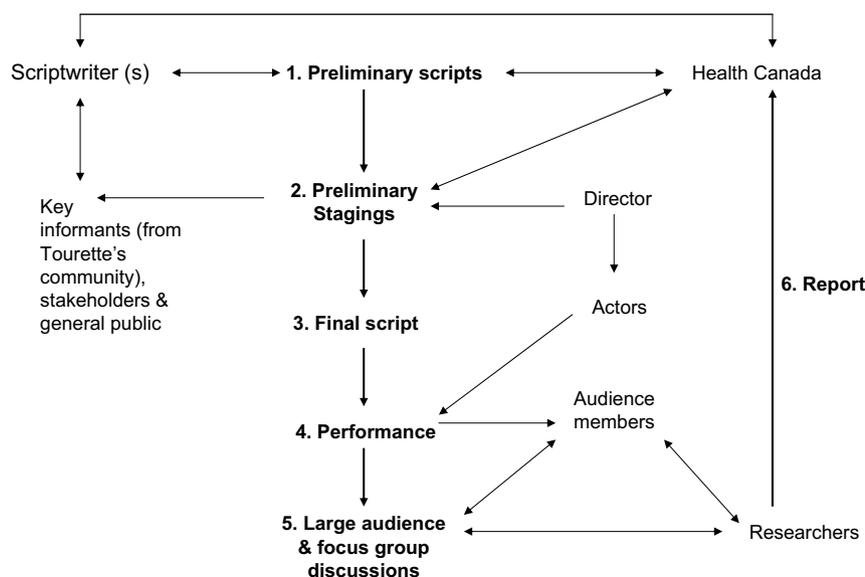


Fig. 1. Input and interaction in process.

by each director as the utility of the production for purposes of policy development rested on ensuring that the central characters were equally compelling and that opposing perspectives on the key policy issues were presented in a balanced way.

A rehearsal and pilot focus group was held one week before the opening of the English language production to evaluate the accessibility of the information in the script and obtain input on dramaturgical aspects of the production.

Performance schedule, venue and accessibility

In fall 2005, four performances of *Orchids* were held in Vancouver, eight in Toronto, and four in Montréal. Venues in the three cities were similar in seating capacity, geographical access, physical characteristics and overall ambience. Each was furnished in a spare, modern style and seated up to 150 people with accommodations for disabled persons. The Vancouver and Toronto performances were in English and Montréal performances in French. There was no charge for admission to any performance. Attendees could reserve tickets through the *Orchids* web site and toll free number or obtain tickets at the door.

Audience recruitment and participation

Recruitment strategies were selected to obtain a diverse audience and attract participants with an interest in PGD, such as persons with disabilities, health care providers, members of non-profit health and disability organizations, scientists, ethicists and health researchers. Recruitment strategies included posters, listings in local entertainment magazines and community newspapers, invitations to journalists interested in covering the arts, health policy and/or medical research, an *Orchids* website with details about the play and research, and email and telephone invitations to relevant personal and professional contacts, non-profit organizations, advocacy groups, selected university departments and public relations offices.

A total of 741 people attended the 16 performances. Most learned about the play through word of mouth or email messages with approximately one third receiving messages from community and institutional list serves. Some decided to see the play spontaneously and did not reserve seats. Table 1 shows the attendance

and rate of audience participation in post-performance discussion in the three cities.

The audience demographics display a bias towards a more female, older, and better educated sample than would be representative of the general or even the theatre-going public. Of the 70% who completed a demographics form provided with the *Orchids* program, 70% were female. The median age range was 30–39 years. Nearly 50% were employed fulltime and 20% were students. Over 30% of respondents were educators and academics, while 13% were health care practitioners and 11% were employed in the arts. 50% held a graduate or professional degree. Most respondents self-identified as “Canadian” but also identified with multiple ethnicities and 10% were Francophone-Canadian/Quebecois. Approximately 33% were married and 40% had one or more children. Many had firsthand experience with a disability or hereditary condition as 15% reported either or both for themselves and/or a family member. Eighteen respondents and their spouses/partners had undergone fertility treatment, and seven had a child as a result of fertility treatment.

Methods for assessing audience engagement

Our research was designed to elicit a wide range of citizen and stakeholder views on PGD. Equally important was the opportunity to understand how the shared experience of seeing the play and participating in post-performance discussion contributed to audience members’ identification of salient issues and perspectives. Multiple methods of data collection and analysis were necessary to address these interwoven research, consultation and evaluation objectives. These included: 1) observation of audience responses recorded as fieldnotes during each performance, 2) audio-taped large audience discussions held in the theatre after each performance, 3) audio-taped focus group discussions held in small breakout rooms after most performances, and 4) written comments from audience members submitted with their demographics form. Fieldnotes prepared by the authors during the research, production and analysis aided reflection on the entire process.

Approval for the study was obtained from the Research Ethics Board for the Review of Non-Medical Research Involving Human Subjects at the University of Western Ontario. Ethical issues related to the use of theatre in health research have been discussed in

Table 1
Attendance and audience participation.

	Vancouver Roundhouse Sept 7–10/2005	Toronto Al Green Sept 13–17/2005	Montréal Bombardier Oct 27–29/2005	Total
Language	English	English	French	
Total Performances	4	8	4	16
Evening	3	5	3	11
Matinee	1	3	1	5
Attendance	205	400	136	741
Range				18–101
Median				39
Demographics Forms Completed	188	250	84	522
Response Rate				70%
Written comments	68	146	47	261
Response Rate ^a				50%
Participants in large audience discussion ^b	71	200	102	373
Range				8–43
Median				30–40
Number of Focus Groups	3	7	1	12
Range				0–2
Median				1
Participants in focus groups	20	41	4	65
Range				4–7
Median				5

^a As percentage of demographics forms completed.

^b Estimated number of participants at mid-point of LAD.

previous studies (Gray & Sinding, 2002; Nisker & Daar, 2006). In our study, it was important to ensure that audience members were aware that their attendance at the play constituted participation in research and in a real health policy exercise.

Before, during and after the performance

Audience members arriving at the theatre were asked to consider participating in either format for post-performance discussion. Before each performance, Susan Cox read aloud an information letter describing the purpose of the research, implied consent and options for voluntary participation. Given the emotional content of the play, a health professional was available to provide support if an audience member became distressed.

During each performance, two (of three English speaking or two French speaking) fieldnote takers observed audience responses, using an agreed upon protocol for notations on auditory aspects, facial expressions, and body language. Use of line numbers in the script permitted fieldnote takers to link audience engagement with specific aspects of the embodied and spoken performance.

Styles of fieldnote taking varied from detached-observational to conversational-reflexive. The following extract describes audience responses to the central scene where Rose tells Heather about terminating a previous pregnancy when prenatal testing yielded a positive result for TS:

Scene 6: ... the audience was extremely silent during this scene, not a lot of moving. In some of the prior scenes ... people would be moving in their seats or making little noises, or coughing, or whatever. ...this was the scene where Heather starts to tic more ... there seemed to be a little more tension in the audience... between both the actors and the audience at that point. (FN3:V3).

Large audience discussions

There was no intermission during the 70 min performance. Immediately after the play, focus group participants convened outside the theatre. The facilitator for the large audience discussion asked remaining participants to use a cordless microphone to record their comments and mention their perspective (e.g., mother of a child with a disability) but not to offer identifying information about themselves or others.

Facilitators were provided with topics for discussion relating to the play and central characters, uses of PGD and the implications for policy, and the use of theatre as a method of public engagement. Styles of facilitation varied according to the facilitator's personality and familiarity with the topics discussed, the size and composition of the audience, and the rapport between facilitator and audience. During the large audience discussions, fieldnote takers recorded observations about changing audience composition, the dynamics of participation, gestures, movements and facial expressions of participants, and commentary on how facilitation styles shaped emergent dialogue.

Focus group discussions

The focus group(s) occurred simultaneously with the large audience discussion. Depending upon the number of pre-identified participants, one or two focus groups were conducted after all performances where there were 30 or more audience members. All focus groups were facilitated by one of the authors or fieldnote takers. An assistant recorded the sequence of speakers. The topics used by facilitators were the same as those used in the large

audience discussion but, given the different setting and dynamics, there were contrasting emphases in the dialogue and interaction.

Data analysis

All large audience discussions and focus groups were transcribed. *Atlas.ti* was used to facilitate coding and analysis in English. Francophone researchers employed *NVivo*. The process of analysis entailed successive reading, annotating and coding of transcripts, fieldnotes and written comments using adapted grounded theory techniques (Charmaz, 2006). To avoid bias, the playwright did not code for substantive themes arising from the initial analysis. All transcripts were available to the core research team to facilitate cross-checking of coding and deeper reflection. Analysis of data from the four French performances was conducted by the Franco-ophone team. After translation of all documents into English, the two teams discussed the findings, comparing emergent themes.

Findings

The research and consultative aims of our study were reflected in findings which centred on participant perspectives on PGD and its regulation and the process of using theatre as a method of public engagement in health policy development.

Perspectives on PGD

Our report to Health Canada focused on what audience members said about PGD and related policy issues, especially the range and complexity of issues arising from scientific "progress" in genetics and assisted human reproduction (Nisker, Cox, et al., 2006). Many expressed concerns particular to PGD were also salient to standard forms of prenatal testing (such as ultrasound). Space permits only a brief overview of the scope of issues raised and diverse viewpoints expressed.

The substantive findings relevant to policy development covered a wide range of topics including availability and circumstances for offering PGD in Canada; criteria determining access to PGD; specific regulatory issues; individual versus social factors shaping the choice to use PGD; and the broader social implications of PGD, reproductive science and genetic testing. A wide range of views was articulated on each of these topics. For example, some participants stated that PGD should not be available at all because of the long term implications for persons with disabilities and the social dangers of striving for perfection in children while others stated that PGD should be widely available and publicly funded, with access based primarily on individual choice. Audience members holding the latter view predominated but qualified their emphasis on individual autonomy and reproductive choice by specifying medically appropriate and/or socially inappropriate uses of PGD. For instance, PGD could legitimately be used to avoid conditions causing "painful death soon after birth" but ought not to be used for conditions that pose "less severe" life challenges.

With regard to the regulation of PGD, many spoke passionately about the implications of attempting to draw a line between acceptable and unacceptable indications for PGD. This concern was also reflected at a meta-level with many speakers addressing the question of who should decide where such a line is drawn, individuals or society at large? There was no emerging consensus but audiences in all three cities reflected deeply on the imbricating responsibilities that citizens have in making individual choices that will have collective effects, and collective choices that will have individual effects. Specific regulatory options (such as whether the AHR Agency should decide on a case by case basis which conditions PGD should or should not be permitted to test for) arose less often.

This permitted extended dialogue free of the constraints imposed by having fixed choice policy options and/or a requirement to come to a premature consensus.

Theatre and public engagement in health policy

Audience members' views on using theatre in the development of health policy also covered a spectrum of topics including the nature of effective public engagement; fairness of the script and its representation; validity and verisimilitude of the script and its performance; representativeness of audience members; and the relevance of the play for policy development.

The majority of participants were impressed with the capacity of *Orchids*, and theatre more generally, to provide information and engage ordinary citizens and stakeholders in a stimulating and policy relevant dialogue. There were many comments on the script and characters as well as disagreement in some audiences about whether the play reflected an inherent bias for or against PGD and if so, whether this mattered since the play provided necessary information and sparked lively discussion. There was also some consternation that an inadequate spectrum of Canadians were being consulted, particularly in that most audiences had a high level of formal education and all performances occurred in relatively affluent urban environments, yet most participants stated that they were deeply engaged by the play and post-performance discussion and wished to see more Canadians involved.

Evaluation of theatre and post-performance discussion

The criteria we adopted for evaluating the effectiveness of theatre as a method of public engagement included: 1) attracting a large and diverse audience; 2) engaging a significant number of audience members in post-performance dialogue; 3) generating informed, thoughtful discussion useful to participants as well as policy makers. Here it is useful to distinguish between participatory, critical and empathic dimensions of audience engagement and the implications of each for the process of facilitating policy-relevant dialogue amongst ordinary citizens as well as other stakeholders.

Dimensions of engagement

Participatory engagement entails the active participation of audience members in the social experience of the play and post-performance dialogue. This involves listening and speaking, while remaining attentive to the responses of others. It may also entail internal dialogue or deliberation, as in the case of the following participant.

I'm kind of a general Joe public...I found the play a really good way of portraying a story and provoking discussion and for the majority of the play I could see both sides but towards the end I was leaning towards being against [PGD]. (large audience discussionV3)

Ideally, participatory engagement enjoins all who are present in dialogue, from ordinary citizen to expert and such engagement may extend well beyond the *durée* of the play.

You know theatre has always done that... you come out of a good play and there's something that's sparked and you go to the bar and you argue about it. (focus group, T11)

There are many challenges for producers as well as researchers who strive to create participatory engagement. Choice of the right venue is crucial in eliminating barriers to participation. A key

consideration must also be how to enable dialogue and hence one must be concerned with everything from acoustics to styles of facilitation.

Critical and/or intellectual engagement involves participants in the co-construction of knowledge about scientific, clinical, ethical and social issues. For some participants, the experience of critical or intellectual engagement demystified scientific knowledge.

This experience probably teaches us all in reflecting that we don't need a degree in genetics or we don't need to be able to understand how cloning works to have an understanding of what the issues are from an ethical perspective. (large audience discussion, T10)

Such engagement involves the flow of information between participant senders and receivers but it is infinitely more complex in that the quality, framing and context of delivery of the information is also crucial to its meaning. The clarity or coherence of information may, as a result, be less important than the opportunity to appreciate complexity and ambiguity. As one man said,

[PGD] was chosen because it is morally ambiguous. I don't think there is a right or a wrong in either of these two characters [Rose and Heather]. (large audience discussion,V5)

Ambiguity may seem less than a laudable outcome in the development of health policy yet here we argue for the importance of avoiding premature closure. Although many policy makers may wish to draw a line between acceptable and unacceptable uses of PGD, many citizens were engaged in formulating a new and critical appreciation for the complexity of the issues.

My overwhelming feeling from the play is I'm in constant conflict. When I watched the play, I just found it amazing how the play brought that out. And when you look at policy, the tricky thing is THAT. How do you put THAT complexity and THAT conflict, which results from these types of issues, into a policy? (Woman, Health Care Professional, large audience discussion, T9)

Empathic engagement emerges with the development of feeling for the experiences of individuals immersed in the situation. Theatre practitioner and theoretician Bertolt Brecht (1898–1956) argued that empathic immersion is incompatible with critical engagement because it immerses audience members in the comforts of illusion and makes them incapable of questioning societal problems and taken-for-granted beliefs (Brecht, 1964). Contrary to Brecht, we take the position that empathy and critical reason can be equally compelling strategies of socially aware theatre. Indeed, the synergy that results is one of the unique strengths of theatre as a method of public engagement, stimulating a deeper sociological appreciation for the reciprocal interactions which pertain between people, social practices and public policies (Mills, 1959).

Empathic engagement may be experienced as an individual phenomenological experience but it is fundamentally relational and involves seeing oneself in the situation of others. Following Artaud (1958), we also note the cathartic potential of emotions arising from the experience of empathy during a performance. As one woman said,

In terms of the characters, I thought being able to see their emotional response to some of the issues was important in helping me decide what I was feeling about the issues. It wouldn't have been quite the same thing to read something or to, I guess, answer questions in a focus group without seeing, ah, the emotional turmoil that all, really all the participants on the stage were going through... (large audience discussion, T7)

Music further enhanced the experience by evoking imagination and personal involvement in the unfolding drama.

Comparison of methods of assessing engagement

Participatory, critical and empathic dimensions of engagement were also important during the post-performance discussions when we compared the two formats for discussion in terms of their power to sustain and build upon audience engagement with the play. We anticipated that participants would prefer one format and that we would discover patterned interactions characteristic of each. For instance, focus groups would by virtue of their smaller size yield greater participant interaction than large audience discussions. We were not, however, initially as attuned to the pivotal importance of utilizing multiple approaches when a project requires both a method of stimulating ongoing engagement and a method of simultaneously assessing that engagement.

Table 2 summarizes our methods for assessing engagement. Comparison of the large audience discussions and focus groups entails consideration of the substantive issues raised, the setting for and dynamics of the emerging dialogue, including the way it is shaped by the perceived expertise of participants who position themselves in relation to the topic (i.e., as ordinary citizens, health care providers or other stakeholders with specific interests) and each other (Tutton, 2007).

The focus group discussions explored fewer issues in greater depth and from a greater range of perspectives. The large audience discussions yielded more issues but participants delved into these issues in less detail and with a narrower range of perspectives represented. These findings are chiefly attributable to three factors. First, speakers in the large audience discussions observed a certain formality wherein they addressed their comments to the facilitator (rather than audience members) who was at the front of the theatre and in control of the microphone. Second, many speakers in the large audience discussions identified themselves as having professional or other expertise (especially in medicine) by announcing their specialty, using specialist jargon, speaking in abstract terms and/or simultaneously questioning yet identifying with the “well-educated” composition of the audience. Those without such expertise were less likely to speak and, when they

did, were more likely to preface their comments with an apology of sorts and/or a heartfelt example of personal experience with illness or disability that asserted other sources of expertise. In contrast, participants in focus groups were less guarded about what they said and how they said it. In some groups, a lack of self-consciousness and casual use of language lead to more overt joking around and, occasionally, the emergence of ‘unpopular’, racist or other perspectives offensive to the facilitator or participants.

A third factor contributing to these differences, is that participants in the large audience discussions tended to introduce their own point-of-view as a discrete perspective rather than as part of a collective response to sustained dialogue. Thus large audience discussions tended to yield a series of individual monologues with most participants speaking only once or twice. Focus groups were, on the whole, characterized by a much higher degree of interaction between participants who spoke more often and frequently interrupted one another as they collectively identified and teased apart important issues.

The different dynamics of these discussion formats have important implications for data analysis and truthful presentation of the findings. As Wilkinson (1998) demonstrates through analysis of focus group dynamics, the practice of presenting isolated quotations from individual participants is often misleading. It fractures the dialogue and severs the substantive issue from its relevant context, negating the role of previous speakers in shaping the topic, emphasis or emergent collective wisdom. This is of paramount importance when assessing deliberative process because the interaction is both stimulus to and means of assessing engagement.

We also received written comments on nearly 50% of the completed demographics forms. It is unknown whether such comments were written with greater frequency by those who did *not* speak during the discussion although it is likely that some respondents found this more private method of response preferable for expressing negative comments and for articulating under-represented or potentially unpopular perspectives.

Another concern was the representativeness of the audience and the need to include a wider cross section of Canadians in policy development. There were some useful suggestions about how to accomplish this within the scope of our project (e.g., hold

Table 2
Comparison of methods for assessing engagement.

Method	Participant observation of audience responses to performance	Large audience discussion	Focus group discussion	Open-ended comments
Format	In-theatre observation and fieldnotes	Facilitated in-theatre discussion	Facilitated small group discussion	Space on demographics form or informal discussion
Medium for recording	Notes written by participant observer	Audio-taped and transcribed (with fieldnotes written by participant observer)	Audio-taped and transcribed (with speaker list kept by assistant)	Comments written by attendee (or noted by observer)
Percent of audience engaged	All attendees	50%	9%	35%
Goals of method	Engagement with performance through actors and collective experience of audience responses	Dialogue involving participants and facilitator, speaking and listening to each other	Dialogue involving participants speaking, listening and responding to each other (more than facilitator)	Short notations about individual responses to play and method of engagement
Strengths of method	Direct experience of ambience, indications of audience engagement and observation of significant moments in performance	Identification of wide range of significant issues, opportunity to question information provided and enhance understanding	Exploration of salient issues, mutual questioning and co-construction of knowledge, and potentially less intimidating format	Private and mostly anonymous opportunity to offer critical or favourable comments that may not otherwise emerge
Weaknesses of method	Difficulty in observing whole theatre, ambience experienced by observer may be localized	Combination of factors may formalize participation of audience members, heighten apparent importance of expertise and/or intimidate some from speaking	More relaxed format may create casual atmosphere where some participants or issues dominate and/or dialogue becomes too personal or possibly offensive	Unclear whether comments are reinforcing points already made in large audience discussion or whether they represent new contributions

performances in smaller communities) and others that suggested the need for a completely different iteration of the project (e.g., creating a DVD).

Conclusions

Although we do not want to suggest there is a single 'best' method for engaging citizens and stakeholders in policy development, our use of theatre demonstrates some advantages over more traditional methods of public engagement. The use of theatre and post-performance discussion facilitates three-way communication (i.e., between citizens, government and researchers). The provision of information remains important but the paradigm for communication emphasizes participants' mutual roles in questioning and co-constructing knowledge through the shared experience of the play and subsequent dialogue. This is possible because socially-aware theatre, when successful, stimulates participatory, critical and empathic forms of engagement wherein audience members are not passive recipients of information. They are equipped to reframe as well as respond to the problems presented, to challenge as well as digest various interpretations of what is right or just, and to formulate as well as choose between existing options for policy development. There is, therefore an enhanced translational quality to the exercise of public engagement (Horlick-Jones et al., 2007).

The context for our use of theatre must be taken into consideration when assessing the potential effectiveness of theatre for other health policy applications. Regulation of PGD in Canada remains in the early stages of the regulatory life cycle. At the time we began this project, there had been no consultation with the public or other stakeholders regarding Canadian regulation of PGD. This called for expanding rather than reducing the scope of issues for consideration in the next phase of policy development. It was also significant that Health Canada launched their survey-based consultation process in conjunction with the completion of our project so we were able to avoid the framing effects of such government documents.

The AHR Agency has now been created and the regulatory process for PGD is scheduled to proceed (Editor, 2007). Public and stakeholder consultations will likely occur on key policy questions such as whether there should be boundaries set to determine which conditions PGD may be used for in Canada and if so, how such boundaries should be set. There are also complex questions related to potential uses of PGD for susceptibility testing, late onset diseases and tissue or HLA typing. If *Orchids* were rewritten to focus on a different genetic condition, it could surface a range of additional policy concerns, for example economic issues related to the cost of dialysis with autosomal dominant polycystic kidney disease (Cox & Starzomski, 2004).

It is too soon to report on how our findings are informing policy development on PGD. Greater clarity is, however, needed with regard to citizens' (as well as sponsors') desired outcomes if there is to be a suitably nuanced basis for assessing the effectiveness of methods of public engagement in health policy development. There is, in particular, much to be gained from developing more inductively a set of criteria for evaluating various methods of public engagement (Rowe & Frewer, 2004). This demands that public participation practitioners give as much attention to summative as formative modes of evaluation and that they scrutinize taken-for-granted assumptions and practices such as excluding non-participants from the process of evaluation.

Having listened carefully to Canadian citizens' hopes and concerns about PGD as well as their experiences of engagement in this complex policy issue, we are grateful for the direction given in identifying both the limitations of our work and the new lacunae it suggests. We recognize that despite our critique of the 'information

flow' paradigm for communication, it remains important to assess pre-existing knowledge of an issue as complex as PGD both to more effectively understand the impact of the play or other intervention and to assess how well it educates and informs. Further, familiarity with the issues under consideration for health policy development must be weighed in determining how to best ensure appropriate levels of knowledge and communicative competence amongst citizens and stakeholders. Such competence is context sensitive. Thus, if one of the desired outcomes of public engagement processes is to encourage lively debate as part of cultivating citizenship, it would be helpful to study alternative formats and other more naturalistic settings for dialogue (e.g., following groups to the bar or a coffee shop) over sustained periods of time.

Appendix 1. Supplementary data

Supplementary data associated with this article can be found, in the online version, at doi:10.1016/j.socscimed.2009.01.044.

References

- Abelson, J., Forest, P.-G., Eyles, J., Smith, P., Martin, E., & Gauvin, F.-P. (2003). Deliberations about deliberative methods: issues in the design and evaluation of public participation processes. *Social Science & Medicine*, 57(2), 239–251.
- Abelson, J., & Gauvin, F.-P. (2006). *Assessing the impacts of public participation: Concepts, evidence and policy implications*. Canadian Policy Research Networks.
- Artaud, A. (1958). *The theater and its double*. New York: Grove Weidenfeld.
- Beeson, D., & Lippman, A. (2006). Egg harvesting for stem cell research: medical risks and ethical problems. *RBM Online*, 13, 1–11.
- Belliveau, G. (2007). Dramatizing the data: an ethnodramatic exploration of a playbuilding process. *Arts and Learning Research Journal*, 23.
- Boal, A. (1998). *Legislative theatre: Using performance to make politics*. London: Routledge.
- Brecht, B. (1964). *Brecht on theatre: The development of an aesthetic*. New York: Hill and Wang.
- Brunger, F., & Cox, S. M. (2000). Ethics and genetics: the need for transparency. In F. Miller, L. Weir, R. Mykitiuk, P. Lee, S. Sherwin, & S. Tudiver (Eds.), *The gender of genetic futures: The Canadian biotechnology strategy, women and health*. Proceedings of a National Strategic Workshop held at York University, February 11–12, 2000 (pp. 27–31), Toronto.
- Charmaz, K. (2006). *Constructing grounded theory: A practical guide through qualitative analysis*. Thousand Oaks: Sage Publications.
- Coleman, S., & Götze, J. (2001). *Bowling together: Online public engagement in policy deliberation*. London: Hansard Society.
- Cox, S. M., & Starzomski, R. C. (2004). Genes and geneticization? The social construction of autosomal dominant polycystic kidney disease. *New Genetics and Society*, 23(2), 133–166.
- Davis, K. K., Davis, J. S., & Dowler, L. (2004). In motion, out of place: the public space(s) of Tourette syndrome. *Social Science & Medicine*, 59(1), 103–112.
- Diamond, D. (2004). *Practicing democracy*. Vancouver, Canada.
- Dresser, R. (2006). Preimplantation genetic diagnosis as medical innovation: reflections from The President's Council on Bioethics. *Fertility and Sterility*, 85(6), 1633–1637.
- Editor. (2007). New reproductive technology board believes expert selection process. *Canadian Medical Association Journal*, 176(5), 611–612.
- Einsiedel, E. F., & Eastlick, D. L. (2000). Consensus conferences as deliberative democracy – a communications perspective. *Science Communication*, 21(4), 323–343.
- ESHRE Preimplantation Genetic Diagnosis Consortium. (2002). 2002 Data collection III. *Human Reproduction*, 17(1), 233–246.
- Franklin, S., & Roberts, C. (2006). *Born and made: An ethnography of preimplantation genetic diagnosis*. Princeton: Princeton University Press.
- Gergen, M. M., & Gergen, K. J. (2000). Qualitative inquiry: tensions and transformations. In N. K. Denzin, & Y. S. Lincoln (Eds.), *The handbook of qualitative research* (pp. 1025–1046). Thousand Oaks, CA: Sage Publications.
- Gray, R., & Sinding, C. (2002). *Standing ovation: Performing social science research about cancer*. Walnut Creek/Lanham/New York/Oxford: AltaMira Press.
- Handyside, A., Pattinson, J., Penketh, R., Delhanty, J., Winston, R., & Tuddenham, E. (1989). Biopsy of human preimplantation embryos and sexing by DNA amplification. *Lancet*, 344, 347–349.
- Hildt, E. (2002). Autonomy and freedom of choice in prenatal genetic diagnosis. *Medicine, Health Care and Philosophy*, 5(1), 65–71.
- Horlick-Jones, T., Rowe, G., & Walls, J. (2007). Citizen engagement processes as information systems: the role of knowledge and the concept of translation quality. *Public Understanding of Science*, 16, 259–278.
- Johnson, M. (1993). *Moral imagination: Implications of cognitive science for ethics*. Chicago: University of Chicago Press.

- Mieczakowski, J. (1995). The theater of ethnography: the reconstruction of ethnography into theater with emancipatory potential. *Qualitative Inquiry*, 1(3), 360–375.
- Mills, C. W. (1959). *The sociological imagination*. New York: Oxford University Press.
- Minister of Health, Canada. (2005). *Issues related to the regulation of pre-implantation genetic diagnosis under the assisted human reproduction act*. A.H.R.I. Office.
- Mykitiuk, R., Niskier, J., & Bluhm, R. (2007). The Canadian assisted human reproduction act: protecting women's health while potentially allowing human somatic cell nuclear transfer into non-human oocytes. *American Journal of Bioethics*, 7(2), 71–73.
- Niskier, J. A. (2001). Orchids: not necessarily a gospel. In J. Murray (Ed.), *Mappa mundi: Mapping culture/mapping the world* (pp. 61–109). Windsor, Ontario: University of Windsor Press.
- Niskier, J., Cox, S. M., & Kazubowski-Houston, M. (2006). *Citizen deliberation on preimplantation genetic diagnosis*. Ottawa: Health Canada.
- Niskier, J., & Daar, A. S. (2006). Moral presentation of genetics-based narratives for public understanding of genetic science and its implications. *Public Understanding of Science*, 15(1), 113–123.
- Niskier, J., Martin, D. K., Bluhm, R., & Daar, A. S. (2006). Theatre as a public engagement tool for health-policy development. *Health Policy*, 78, 258–271.
- Nussbaum, M. (2001). *Upheavals of thought: The intelligence of the emotions*. Cambridge: Cambridge University Press.
- Reddy, M. J. (1993). The conduit metaphor—a case of frame conflict in our language about language. In A. Ortony (Ed.), *Metaphor and thought* (pp. 164–201). Cambridge: Cambridge University Press.
- Rowe, G., & Frewer, L. J. (2000). Public participation methods: a framework for evaluation. *Science Technology Human Values*, 25(1), 3–29.
- Rowe, G., & Frewer, L. J. (2004). Evaluating public-participation exercises: a research agenda. *Science Technology Human Values*, 29(4), 512–556.
- Rowe, G., & Frewer, L. J. (2005). A typology of public engagement mechanisms. *Science Technology Human Values*, 30(2), 251–290.
- Stuttaford, M., Bryanston, C., Hundt, G. L., Connor, M., Thorogood, M., & Tollman, S. (2006). Use of applied theatre in health research dissemination and data validation: a pilot study from South Africa. *Health (London)*, 10(1), 31–45.
- Tutton, R. (2007). Constructing participation in genetic databases: citizenship, governance, and ambivalence. *Science Technology Human Values*, 32(2), 172–195.
- Verlinsky, Y. (1999). Preimplantation diagnosis: an alternative to prenatal diagnosis of genetic and chromosomal disorders. *Journal of Assisted Reproduction and Genetics*, 16(4).
- Weldon, S. (2004). *Public engagement in genetics: A review of current practice in the UK*. Institute for Environment, Philosophy and Public Policy, Lancaster University.
- Wilkinson, S. (1998). Focus groups in feminist research: power, interaction, and the co-construction of meaning. *Women's Studies International Forum*, 21(1), 111–125.
- Wyman, M. (2004). *The defiant imagination: Why culture matters*. Vancouver: Douglas & McIntyre.
- Wynne, B. (2004). *Preface to public engagement in genetics: A review of current practice in the UK*. Institute for Environment, Philosophy and Public Policy, Lancaster University.