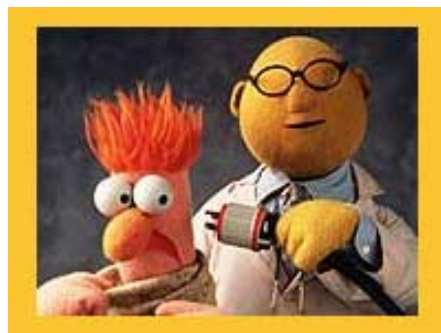


## ETHICAL PERSPECTIVES ON ENGAGING COMMUNITIES IN DEBATES ABOUT NEW TECHNOLOGIES


Annette Braunack-Mayer




"What's the point of consulting the public when they have neither scientific nor ethical expertise?"

Dr Bunsen Honeydew and his assistant Beaker have been voted the UK's favourite screen scientists.


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 **What's the point in consulting the public?**

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- “There is no point in asking the public” because...
- the scientific activity that creates new technology is a private activity, best restricted to discussion between experts.

 **Methods for public engagement**


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- Calls for submissions on draft policies and documents
- ‘Market’ research on public attitudes to human genetic information
- Large scale surveys of opinion and knowledge
- Citizens’ juries
- Consensus conferences
- Qualitative research with interviews and focus groups
- Web-based consultations

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## “Why should we consult the public about new health technologies?”


- To learn what the public don't know, so we can educate them
  - **Deficit model**
- To ensure that the public have enough information to make their own decisions
  - **Informed consent model**
- To shape technology together
  - **Interactive model**

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## The Deficit Model

- The public do not understand new technologies
- Identifying deficits in public knowledge is the basis for education programs which create a public...
  - “ready to participate in decision-making about scientific research from a position of knowledge”.

Levitt M. Public consultation in bioethics. What's the point of asking the public when they have neither scientific nor ethical expertise? *Health Care Analysis* 2003;11:15-25.



Barbara Roche *Tabula Rasa* 2000  
<http://www.artsmia.org/foot-in-the-door/2000entry.cfm>




## The Deficit Model:

### The community doesn't understand new technologies

1. There are bacteria that live from water waste.
  - 83% true
2. Ordinary tomatoes do not contain genes, whereas genetically engineered tomatoes do.
  - 30% true; 35% don't know
3. If people eat genetically modified fruit, their genes could become modified.
  - 48% false
4. Genetically modified animals are always larger than ordinary animals.
  - 36% false


European Commission 1998 *Eurobarometer 52.1 Report.*



## The Deficit Model:

### The community doesn't understand risk


- 'Risk' is understood in a range of ways within the community
- Eg: Community views about the detection of diabetic retinopathy utilising retinal photography in rural and remote areas:
  - Risks tend to be underestimated by patients and health personnel


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## The Deficit Model:

The public can be educated to understand technologies better


- Scientist, policy maker and HTA as 'experts'
- Standardised, structured data collection methods
- Outcomes include greater public comfort with and less disquiet about new technologies




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## The Informed Consent Model


- Parallels an 'informed consent' model of participation in decision-making for patients and research subjects




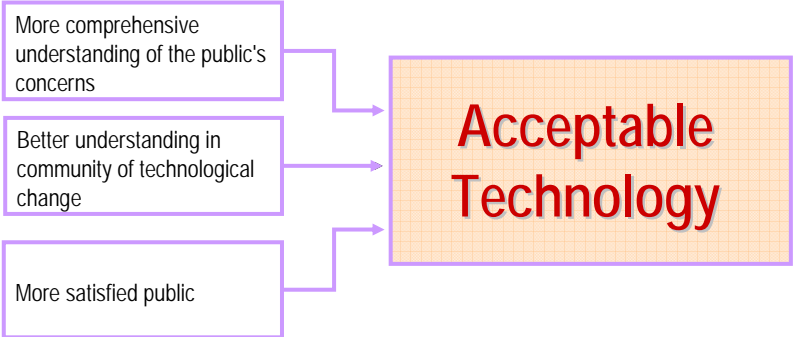
Diane Fenster, Informed Consent  
[http://www.dianefenster.com/informed\\_consent.html](http://www.dianefenster.com/informed_consent.html)

 **The Informed Consent Model**


- Builds on a principlist approach
- Consulting the public about new technologies involves...
  - Provision of information;
  - The exercise of a voluntary choice;
  - Lack of coercion.
- The public are participants in a discussion which seeks to promote understanding and, where possible, to adapt technologies to the community's wishes.
- Uses interviews, focus groups, submissions to inquiries, citizens' juries



 **Justifications for informed consent model (1): Beneficence**





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graph LR; A[More comprehensive understanding of the public's concerns] --> D[Acceptable Technology]; B[Better understanding in community of technological change] --> D; C[More satisfied public] --> D;
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 **Justifications for the Informed Consent Model (2) : Respect for persons**


“It is the privilege and proper condition of a human being, arrived at the maturity of his faculties, to use and interpret experience in his own way.”

John Stuart Mill




 **Problems with the Informed Consent Model**


- Communities who are not willing/able to consider issues
- Communities who cling to 'wrong' beliefs
- Eg, Community views about the detection of diabetic retinopathy utilising retinal photography in rural and remote areas:
  - People don't see themselves as non-compliant

 **The Deficit and Informed Consent Models are essentially individualist**


- Treat the public as groups of individuals
- Individual rights thus have an important role to play in decision-making



The Labyrinth Of Individualism  
[www.exto.nl/gallery/detail/id/103442.html](http://www.exto.nl/gallery/detail/id/103442.html)

 **The individualist approach:**

“I think we've been through a period where too many people have been given to understand that if they have a problem, it's the government's job to cope with it. 'I have a problem, I'll get a grant.' 'I'm homeless, the government must house me.' They're casting their problem on society. And, you know, **there is no such thing as society. There are individual men and women, and there are families...**”




Prime Minister Margaret Thatcher, talking to *Women's Own* magazine, October 31 1987



 New technologies impact on communities,  
as well as on individuals


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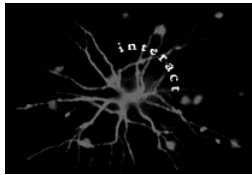


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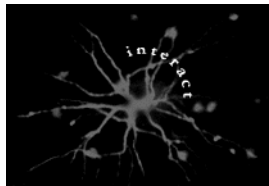
The Deficit and Informed Consent Models are essentially oriented toward the scientific 'expert'




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 **The Interactive Model is a response...** 

- To the 'expert' bias of the Deficit and Informed Consent Models:
  - Emphasises deliberation, discussion and consensus formation
- To the abstractness and individualism of the Deficit and Informed Consent Models:
  - Sees individuals in social context
  - Emphasizes the particularity of each technology and each community

 **The Interactive Model** 

- Emphasises interaction between all stakeholders
  - scientists, policy makers, community members
- Focuses on development of consensus
- Typically uses community consultation approaches
  - Citizens' juries, consensus conferences

 **Proposed outcomes for responses to technology under the Interactive Model**

- The outcome that is the result of participation by all groups is achieved and endorsed by all;
- The outcome must not reflect power differences;
- The outcome must be a result of explicit reflection and deliberation;
- The outcome must be a newly established agreement, developed by all participants.


Reuzel R. Interactive technology assessment. *Poiesis Praxis* 2004; 2:119-137

 **Citizens' juries**

First Australian Consensus Conference on Gene Technology in the food chain ( 1999)  
[www.abc.net.au](http://www.abc.net.au)


The Danish "consensus conference"  
<http://www.loka.org/pubs/techrev.htm>

Designer babies: what do teenagers think  
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## A citizens' jury concerning genetic testing for susceptibility to common diseases

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[www.abc.net.au](http://www.abc.net.au)

- Question:
  - "What conditions should be fulfilled before genetic testing for people susceptible to common diseases becomes available on the NHS?"
- The jury succeeded in helping its jurors to understand the complexities of genetic therapies.

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## A citizens' jury concerning genetic testing for susceptibility to common diseases

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- Yet, there were still difficulties attached to running this jury:
  - Inadequate preparation for jurors
  - Bias toward scientific expertise
  - Lay witness concerns about equality:

"I offered myself as a witness. I would have wished to be used on an equal footing with the professionals, with equal time and equal opportunity for questioning, but more importantly, *not* with special protection for my status..."

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## Conclusions:

- An Australian perspective...

