Good deliberation

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Deliberating about Bioethics

by Amy Gutmann and Dennis Thompson

If the principles of deliberative democracy were to be more fully realized in the practices of bioethics forums, the decisions the participants reach would be more morally legitimate, public-spirited, mutually respectful, and self-correcting.

THE HASTINGS CENTER REPORT

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Yes, but:

What Is Good
Public Deliberation?

F23: I can understand why you [support the use of surrogate consent], but I think when you get to individual scenarios, you have to really stop and think...Is there going to be a scenario where the risk is so high that we would not as a society ever want to have a surrogate make a decision? . . . Now let me finish. I can see you're trying to answer me, but really think about this...Are we ready as a society to say, "Okay. It's okay to have surrogate consent for a relatively high-risk scenario..." You might be willing to push yourself in a higher risk scenario than you might be as a surrogate.

M20: This is not an argument. This is an exercise from my standpoint. If you and I were married and I was the patient, and there was low risk in research, do you feel that society should let you make that decision if I couldn't?

F23: Yes, yes.

M20: ...Let’s take it up another notch. I’m the Alzheimer’s patient. I cannot make a decision on my own...There is high risk involved in the research...Should society allow you, my wife, to make a decision regarding my participation?

F23: See, that’s where it gets fuzzy for me because... from a societal point of view, ...it would have to be that proper risk-reward ratio, and I think that would be up to societal debate.

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Civil disagreement

Societal point of view

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Societal point of view

Assessing the quality of democratic deliberation: A case study of public deliberation on the ethics of surrogate consent for research

Raymond De Vries[a,*], Aimee Stanczyk[a], Ian F. Wall[a], Rebecca Uhlmann[a], Laura J. Damschroder[b], Scott Y. Kim[a]

A Framework for Assessing the Quality of Democratic Deliberation: Enhancing Deliberation as a Tool For Bioethics

Effect of public deliberation on attitudes toward surrogate consent for dementia research

S.Y.H. Kim, H.M. Kim, D.S. Knopman, et al.
Neurology 2011;77;2097; Published online before print October 5, 2011;

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How Important Is 'Accuracy' of Surrogate Decision-Making for Research Participation?

Scott Y. H. Kim[1,2]*, H. Myra Kim[3], Kerry A. Ryan[1], Paul S. Appelbaum[4], David S. Knopman[5], Laura Damschroder[6], Raymond De Vries[1]

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Assessing quality

- **Structure**
- **Process**
- **Outcomes**

Assessing quality

- **Outcomes**
- **Structure**
- **Process**

1. Outcomes:
Does deliberation DO anything?

Well yes….

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Societal perspective	DD group, % Survey 1 (n = 212)	Survey 2 (n = 173)	Survey 3 (n = 168)	Survey 1 vs 2, *p*	Survey 1 vs 3, *p*
Lumbar puncture					
Definitely not allow	5	1	3	<0.001	<0.01
Probably not allow	9	4	5		
Probably allow	51	19	41		
Definitely allow	33	76	51		
New drug RCT					
Definitely not allow	2	1	2	<0.001	<0.01
Probably not allow	4	2	2		
Probably allow	56	21	43		
Definitely allow	38	76	53		

Societal perspective	DD group, %				
	Survey 1 (n = 212)	Survey 2 (n = 173)	Survey 3 (n = 168)	Survey 1 vs 2, *p*	Survey 1 vs 3, *p*
Vaccine					
Definitely not allow	10	8	7	<0.001	<0.001
Probably not allow	25	13	14		
Probably allow	46	28	45		
Definitely allow	19	51	34		
Gene transfer					
Definitely not allow	18	16	15	<0.001	<0.01
Probably not allow	26	17	18		
Probably allow	39	27	37		
Definitely allow	17	41	30		

Public opinion about return of *incidental findings* from genome sequencing (preliminary findings)

	Survey 1	Survey 2 (post-deliberation)
Percent agreeing with policy to withhold findings regarding adult onset diseases (n=65)	11.0	43.1

$X^2 = 4.71$, $p < 0.001$

So something happens, but…

is it the informed and considered opinion of the (appropriate) public?

2. Structure

- **Who?**
  - …is at the table? [representative]

- **What?**
  - …information is provided? [free from bias]

Information: putting the "informed" in "*informed* and considered public opinion"

- *Learning new information*
- *Understanding and applying information*
- *Use correct information*
- *Use on-site experts*
- *Impact of information on opinions*

Learning new information (SBR)

17-item knowledge questionnaire*

	Mean (95% ci)
Survey 1 (pre DD)	11.5 (± 2.6)
Survey 2 (post DD)	14.5 (± 2.3) $p < 0.001$
Survey 3 (after 1 month)	14.1 (± 2.6) $p < 0.001$)

*Level of knowledge about AD (prevalence, risk factors, course of disease, treatment options), purpose and types of clinical research in AD, ethical regulation of clinical research, and current policy regarding surrogate consent for clinical research.

Information: putting the "informed" in "*informed* and considered public opinion" [qualitative measures]

- *Understanding and applying information*
- *Use correct information*
- *Use on-site experts*
- *Impact of information on opinions*

Surrogate based research:

F39: Requiring research advance directives would be ideal, and more education might bring more people to do that, but in reality, it's a very small percentage as far as how many people actually go through . . . Everybody knows they should have a will. Everybody knows they should have a durable power of attorney, but very few people . . . percentage might have it.

[Using information]

F35: Like if you're donating an organ, you already know exactly what you are going to be doing and you've weighed the ethical question out. I think [the expert] is saying that when it comes to research, you don't know what they're going to be doing, and so you don't know if you would have agreed with it ethically or not.

[Using analogy]

Return of incidental findings:

I don't know . . . I kind of feel like that with all of this, there's so many unknowns and the degree of this or that is so unknown . . . Like why are we causing ourselves all of this stress? Like why don't we wait maybe . . . I mean, I could also argue against what I'm saying too, but maybe we should just wait until we have a lot more information and then like now, just sort of do the pre-decision . . . "Oh, when we get to that point, let's decide this." But for right now, I feel like it's like it could be catastrophic to have these sort of partial, maybes, 'this could happen', 'we don't know'. (ID-02)

[Impact of information on opinion]

We have the right people and they are *informed*, but…

Are we getting the considered opinion of the public?

3. Process

1. Equal participation
2. Respect for the opinions of others
3. The adoption of a societal perspective
4. Reasoned justification of ideas

Equal participation (SBR)

TABLE 6. Number of Words Spoken and Turns Taken by Participants.

	Number of Words Spoken		Number of Turns Taken	
Group #	Range of words spoken	% of words spoken per participant	Range of turns taken	% of turns taken per participant
1 (n=6)	528-3122	5, 9, 11, 20, 27, 27	32-106	9, 9, 10, 17, 25, 29
2 (n=6)	1383-2742	10, 13, 17, 19, 20, 21	31-77	9, 14, 17, 19, 20, 21
3* (n=5)	1443-2855	14, 16, 20, 21, 29	33-104	12, 12, 16, 21, 39
4* (n=5)	1296-3999	10, 13, 20, 26, 31	42-152	8, 16, 20, 26, 29
5* (n=6)	1025-2750	9, 12, 16, 18, 20, 24	51-127	8, 13, 18, 18, 19, 21
6* (n=6)	750-2940	7, 9, 14, 19, 23, 26	47-148	9, 10, 13, 15, 18, 30
7* (n=6)	922-3046	8, 9, 13, 19, 24, 26	49-136	9, 14, 15, 16, 18, 26
8* (n=6)	1180-2994	10, 12, 14, 17, 20, 25	45-118	8, 12, 14, 16, 20, 21
9* (n=7)	296-2903	3, 3, 7, 13, 20, 25, 27	22-129	4, 8, 8, 14, 15, 20, 22
10* (n=6)	713-2703	7, 10, 14, 21, 22, 26	47-148	8, 13, 13, 14, 23, 27
11 (n=6)	564-3421	5, 10, 17, 18, 20, 30	32-106	7, 14, 18, 20, 20, 22
12* (n=6)	1328-3104	10, 13, 13, 20, 21, 23	45-81	12, 15, 15, 16, 17, 22

Respect for the opinions of others
(SBR)

	DD attendees (n = 160), mean (SD)[a]
1. Do you feel that your opinions were respected by your group?	9.4 (1.1)
2. Do you feel you were listened to by your facilitator?	9.7 (0.7)
3. Do you feel that the process that led to your group's responses was fair?	9.7 (0.7)
4. How willing are you to abide by the group's final position, even if you personally have a different view?	8.8 (2.3)

(scale of 1–10 where greater number indicates more positive response **)**

Respect for the opinions of others (counter example)

M21: If your son’s death could result in saving millions of lives, you wouldn’t love those people more than you would love your son in order to give him up for others?

M20: I don’t think I would be willing to offer my son or daughter to save millions, thousands.

M21: My God did that.

M20: Yeah. Well, I’m not God.

The adoption of a societal perspective (SBR)

F44: ...the conclusion that I came away with is that if surrogate...consent does not become acceptable in this area, that there will essentially be no meaningful Alzheimer’s research. It seems like that would be a train wreck for our society. So it seems as though we almost have no choice but to have some form of surrogate consent...

Reasoned justification of ideas (SBR)

F15: I look at the 6 out of 18 persons that have permanent problems. Out of 300 people, 18 developed brain inflammation; 6 of the 18 had permanent problems—seizures, headache, vomiting. To me, that’s a little high risk, and I’m going to go with M14. I don’t think society should allow surrogates to make that decision.

Thinking about deliberation

Nagging questions

Methods in Medical Ethics

SECOND EDITION

CHAPTER II

Sociology

Says who?

And what is the historical situation and social location of that "who"?

*Why now?

Why the shift from expert to public bioethics?

*Whose opinion?

Does deliberation deliver ***public*** opinion?

The ideal:

Expert opinion ⟷ Public opinion

The hope:

Expert opinion ← Public opinion

The real?

Expert opinion → Public opinion

Worth worrying about:

- Self-selection of deliberators
- Bias in the information provided
- Processing of the results

Thank you

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