

The Need for Evidence AND Values-Informed Policy Making—The Case for Public Engagement

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The Wake Up Call

- “Your CDC research is Dead on Arrival”
- Dx:
 - Despite good data, other issues involved
 - It’s not only about the facts

Policy Dysfunction Is Pervasive

- Vaccine—Autism issue
- Public Health—Obesity, Screening
- Science—Climate change, new technologies
- Government—Multiple issues

New Realities

- Loss of trust for authority
- Highest levels of education
- Increased access to internet information
- Ability to organize via the internet
- Increased capacity and interest in having more control
- Bottom line: Paternalism is out, participation is in.

For the Future...

- We need to try more “letting-go” in a new “letting-go world”

» Adapted from remarks by Walker Smith at a CDC/NCHM conference.

Potential Solution

A new social contract between science and society

“...reliable knowledge can only become socially robust if society sees the process of knowledge production as transparent and participative. ..

The old image of science working anonymously will no longer suffice...

Rather, a reciprocity is required in which not only does the public understand how science works, but, equally science understands how its publics work.”

Michael Gibbons, Nature, 1999

Potential Solution

“Simply protesting the incursion of value considerations into the conduct and use of science confirms the old adage that insanity is doing the same thing over and over again and expecting a different outcome. ..

Let’s try some diplomacy and discussion and see how that goes for a change.”

Alan Leshner, AAAS, Science Editorial entitled “When Science Meets Society”, February 11, 2005

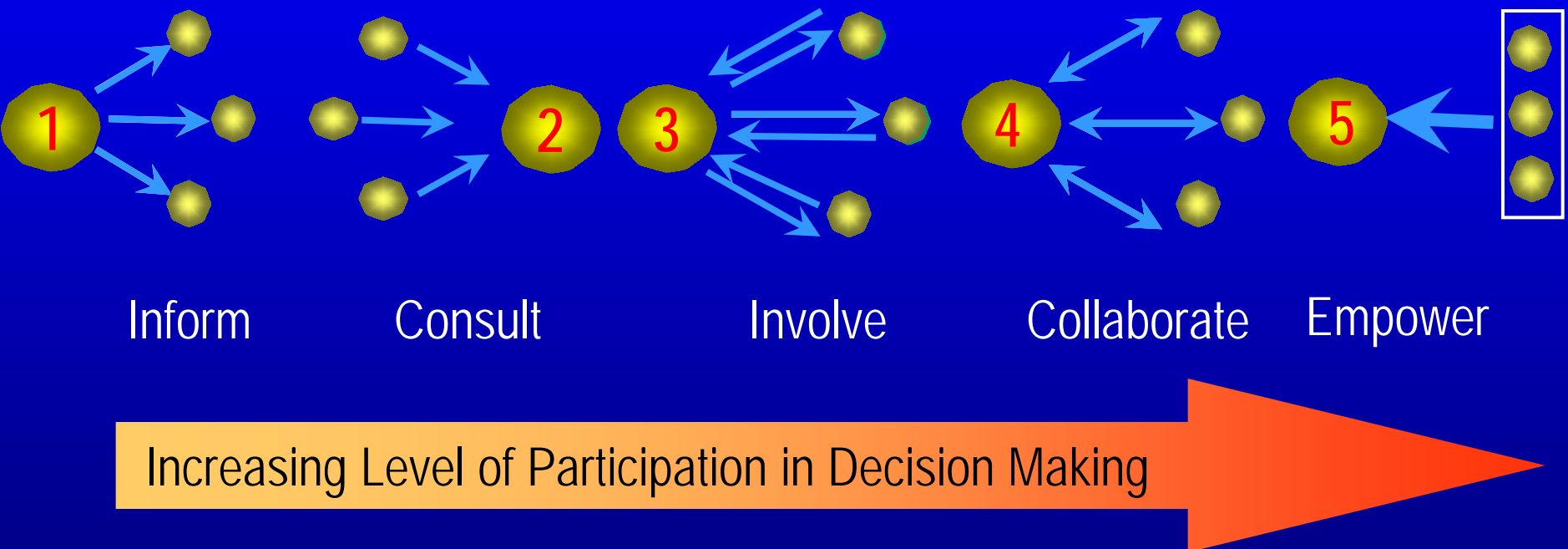
The Challenge

- A fundamental challenge in the 21st century is integrating science and democracy since knowledge alone or power alone are not sufficient to make public decisions that last.
- Truth must speak to Power, but also
- Power must speak to Truth

New Logic Model for Science Policy

- Goal: Sound and supportable science policies
- Such policy decisions require both facts and values be considered
- Scientists contribute expert knowledge---citizens possess and contribute our core public values
- Interacting together on policy work builds relationships
- Trust is part of relationships
- Trust promotes achievement of supportable policy agreements

The Key: Understanding The Levels of Public Participation



What is Public Engagement

- The practice by which decision-makers very actively involve members of the public-at-large and representatives of stakeholder organizations in group dialogue and deliberation sessions to better inform and potentially shape pending decisions.

What is Public Engagement

- At the clinical level, the model is shared-decision making, patient-centered care in medicine
- At the group level, the model is evidence and values informed policy making, citizen-centered policy in a democracy

Why Engage The Public?

Three Rationales

- Normative
- Substantive
- Instrumental

- (Adapted from “Understanding Risk: Informing Decisions in a Democratic Society” from the National Academy of Sciences)

Summary of the Evidence

- “When done well, public participation improves the quality and legitimacy of a decision and builds the capacity of all involved to engage in the policy process...”

» US National Research Council, 2008

Summary of the Evidence

- “Public participation should be fully incorporated into environmental assessment and decision-making processes, and it should be recognized by government agencies and other organizers of the processes as a requisite of effective action, not merely a formal procedural requirement.”

» US National Research Council, 2008

When Public Engagement?

“When you need to ask, not persuade.”

- In public engagement, having the answer is a learning disability!

Model for Public Engagement

- 1) Focus on undecided policy choices involving both facts and values
- 2) Balanced information from credible sources
- 3) Inclusion of both stakeholders and citizens-at-large
- 4) Linkage to the government decision making process and decision makers

Model for Public Engagement

- 5) Neutral facilitation,
- 6) Frank dialogue and genuine deliberation
- 7) Synthesis of the results into the “societal perspective”
- 8) Feedback to the participants

Model Specifics

- 4+ geographic areas represented
- 100 citizens representative of the population by age, race, and sex in each area (N=400)
- Day long dialogue and deliberation events
- Stakeholder representatives from key sectors affected (N=30-40)
- Two day long meetings for stakeholders before and after the citizens meetings

The Public Engagement Project on Pandemic Influenza

- Purpose: To rank order goals/objectives for a pandemic influenza vaccination program
- Question: Who first to vaccinate against pandemic influenza when vaccine supplies are limited at the outset of a pandemic?

Citizens-At-Large In Four Regions

- Southern US— Georgia—100+
- Northern US— Massachusetts—40+
- Mid-West US— Nebraska—80+
- Western US— Oregon—30+

The Competing Goals

- Give everyone an equal chance
- First come, first served
- Protect those with the most life left
- Select those most likely to die
- Assure public safety
- Maintain emergency or life saving services

The Competing Goals

- Protect key leaders of society
- Protect those who provide services which keep society running
- Give vaccine to other countries
- Protect those who provide homeland security and military personnel
- Assure vaccine production

Results Produced

- #1 Assure the functioning of society
- #2 Reduce individual deaths and hospitalizations due to influenza
- Use the minimum number of doses necessary to accomplish #1 before moving to #2
- Lower priority goals—lottery, first come, first served, vaccination of children
- Experts gave more weight to #2

HHS Secretary Leavitt

2008 National Guidance on Influenza

“This guidance is the result of a deliberative democratic process. All interested parties took part in the dialogue; we are confident that this document represents the best of shared responsibility and decision-making” (HHS, 2008).

Conclusions

- Public engagement is possible and useful on a difficult decision involving values tradeoffs
- In this case, the “collective wisdom” placed greater weight on assuring the functioning of society than did expert advisory groups.

Favorite Quote

“When big things are at stake, the danger of error is great. Therefore, many should discuss and clarify the matter together so the correct way may be found.”

- Shotoku Taishi, first Buddhist emperor, **604 AD**

For the Future...

“ We need to move from the leader as the hero, to the leader as the host.”

-Margaret Wheatley

On Democracy

- “To speak today of the defense of democracy as if we were defending something which we knew and had possessed for many decades or centuries is self-deception...we should be nearer the mark ...if we spoke of the need not to defend democracy but to create it.
- Richard Swift, Author of the No Nonsense Guide to Democracy

Extra Slides

Six Common Sins Leading To Public Engagement Failure

- 1. Program is entirely process driven—checklist approach rather than defining purpose and promise
- 2. Program does not begin until after the decision is made
- 3. Program is not integrated into the decision process—runs parallel and not synchronized

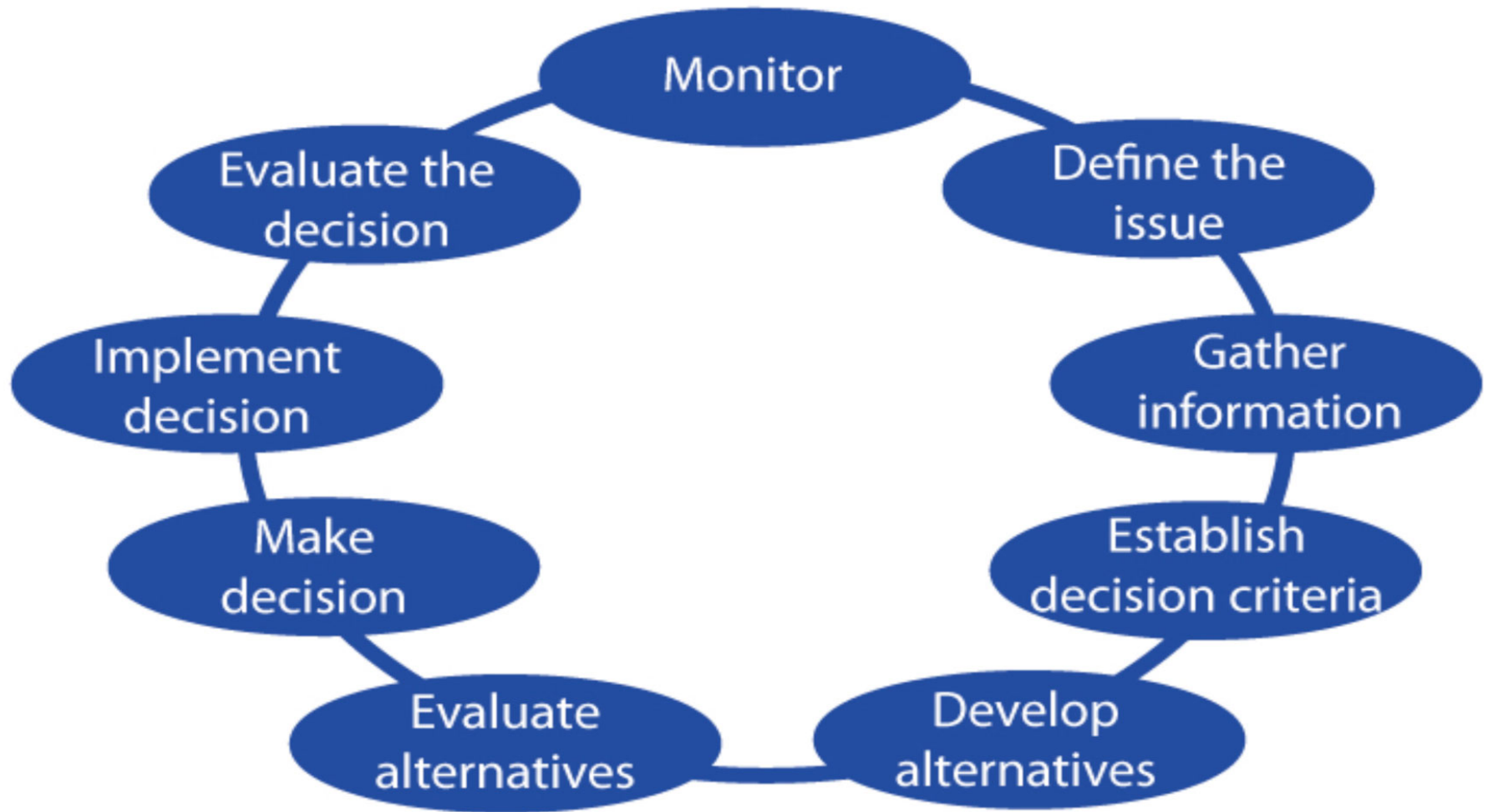
Six Common Sins Leading To Public Engagement Failure

- 4. Public not adequately informed
- 5. There is a disconnect on organizational commitment to public engagement—public is overpromised and ends up bitter toward the process
- 6. There is a lack of broad participation

Sponsor “Safety” Or “Readiness” Test

- Do we share the values?
- Do we have a decision to share?
- Do we have clear objectives?
- Do we have commitments from decision makers?
- Do we have a model to use?
- Do we have the skills to implement?

The Nine Step Decision Making Lifecycle



The appropriate time for public involvement in the decision making process will depend on the issue and the type of information needed to inform each stage. All decision making must consider the timeframe to make a decision and the important choices about who to involve and when.

Critique From A Friend

- My problem has to do NOT with the need for public input but in the ease with which we unwittingly create forums for the injection of non-scientific irrationality under the guise of democracy...in modern times, ... there seems always to be a strong undercurrent of antiauthoritarianism (science having taken on the role of authority). In essence, public input now typically comes with a healthy dose of pseudoscientific twaddle that lies thankfully dormant until it gets legitimized by a pluralistic process...(cont...)

Critique From A Friend

- ...In my opinion, in times like this we need less democracy and more scientific authoritarianism (e.g., Institute of Medicine, Surgeon General). The non-scientific public is too easily misled because it doesn't have, and will probably never have, the skills to distinguish between science and pseudo-science.
- Source: Name withheld

Causal Theories

- It's a communication problem-

“Say it better, simpler, and they will get it!”

- It's an education problem—

“If they knew what we know, they would agree with us”

- It's a media problem

“Journalists only want to create sensation”

- It's an incentives problem

“Faculty get promoted for grants and publications not
utilization of data

Causal Theories

- It's a political problem

“Decision makers are not evidence based”

- It's an advocacy problem

“Scientists need to get more involved”

- It's an ideology problem

“it's about beliefs, and people don't change their beliefs easily.”

- It's a money problem

“Companies hide or deny data to protect their interests”

Consequences of Dysfunction

- Inaction on social problems
- Lack of legitimacy for policies
- Missed opportunities for social progress
- Ineffective policies
- Wasted resources
- Lessened individual and social agency

Potential Solution

“People never care how much you know---until they know how much you care.”

- John C. Maxwell, (1947-) American author and speaker on leadership

Potential Solution

- “To pursue participatory science is more easily proposed than achieved. Once science enters a realm of direct democracy, it becomes imbued with the failings as well as the triumphs of democracy...What is less well understood is how to incorporate deliberative and inclusive procedures into the scientific discourse.”
 - Tim O’Riordan and Anthony McMichael, Dealing with Scientific Uncertainties, in Environmental Change, Climate, and Health, Editors Pim Martens and Anthony McMichael, 2002

RESULT
(Substantive)

PROCESS
(procedural)



EMOTION
(Psychological)

Short Definitions

- It is shared-decision making
- It is co-creation of an outcome
- It is collaborative problem-solving
- It is mutual learning
- It is joint fact-finding
- It's participation not just consultation

When Public Engagement?

When we value public wisdom

When values compete

When controversy can be
expected

When solutions require buy-in
from multiple actors

Projects To Date

- 1. Vaccine priorities I for pandemic flu--2005
- 2. Community control measures for pandemic flu--2006
- 3. CDC goals selection--2006
- 4. Vaccine priorities II--2008
- 5. Identification of at risk populations for pandemic influenza---2008

Projects to Date

- 6. Six State Demonstration Projects on Pandemic Influenza Policy, 2008-09
- 7. Priorities for the National Vaccine Plan, 2009
- 8. Criteria and Priorities for the CDC Vaccine Safety Research Agenda, 2009
- 9. Target Level of Preparedness for the H1N1 Mass Vaccination Program, 2009
- 10. Components of a National Vaccine Safety System, 2009-10

Principles of Public Engagement

- 1. Both the desire for advice + the decision on the table are real.
- 2. Both adequate time to deliberate + clarity of purpose are provided.
- 3. Both knowledge of facts + attachment to values underlie the choices to be made.

Principles of Public Engagement

- 4. Both active agency staff + sufficient resources are committed to the process.
- 5. Both impartial citizens-at-large + partisan stakeholders participate.
- 6. Both a critical mass + diverse group of persons participate.

Principles of Public Engagement

- 7. Both unbiased information + neutral facilitation are provided.
- 8. Both genuine dialogue + thoughtful deliberation occur.
- 9. Best option is chosen + and agreed-upon
- 10. Public's advice receives "serious consideration" + participants obtain candid feedback about the decision

Stakeholders with recognized interests (N=35)

- Health Professionals
- Federal Government Agencies
- Industry
- Consumer Advocates
- State Government
- Minority Groups

Next Up!

SCIENCE PRIVATIZATION!

EVERYONE WILL BE ENTITLED TO SET UP THEIR OWN PERSONAL SCIENCE FACTS!

THOSE SPECIES
CAN JUST MOVE
TO SOME OTHER
HABITAT!

BEING
GAY IS
JUST A
LIFESTYLE
CHOICE!

MERCURY
POISONING
IS NOT
REALLY
SUCH A BIG
PROBLEM!

EVOLUTION
NEVER DID
HAPPEN!
NOT IN MY
FAMILY
ANYWAY!

THERE IS
NO EVIDENCE
FOR GLOBAL
WARMING!



TOLES

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WILL REAL SCIENCE
STILL BE THERE
WHEN YOU NEED IT? —

Triangle of Satisfaction Model of Conflict Analysis

Three distinct types of interests must be satisfied for successful problem solving.

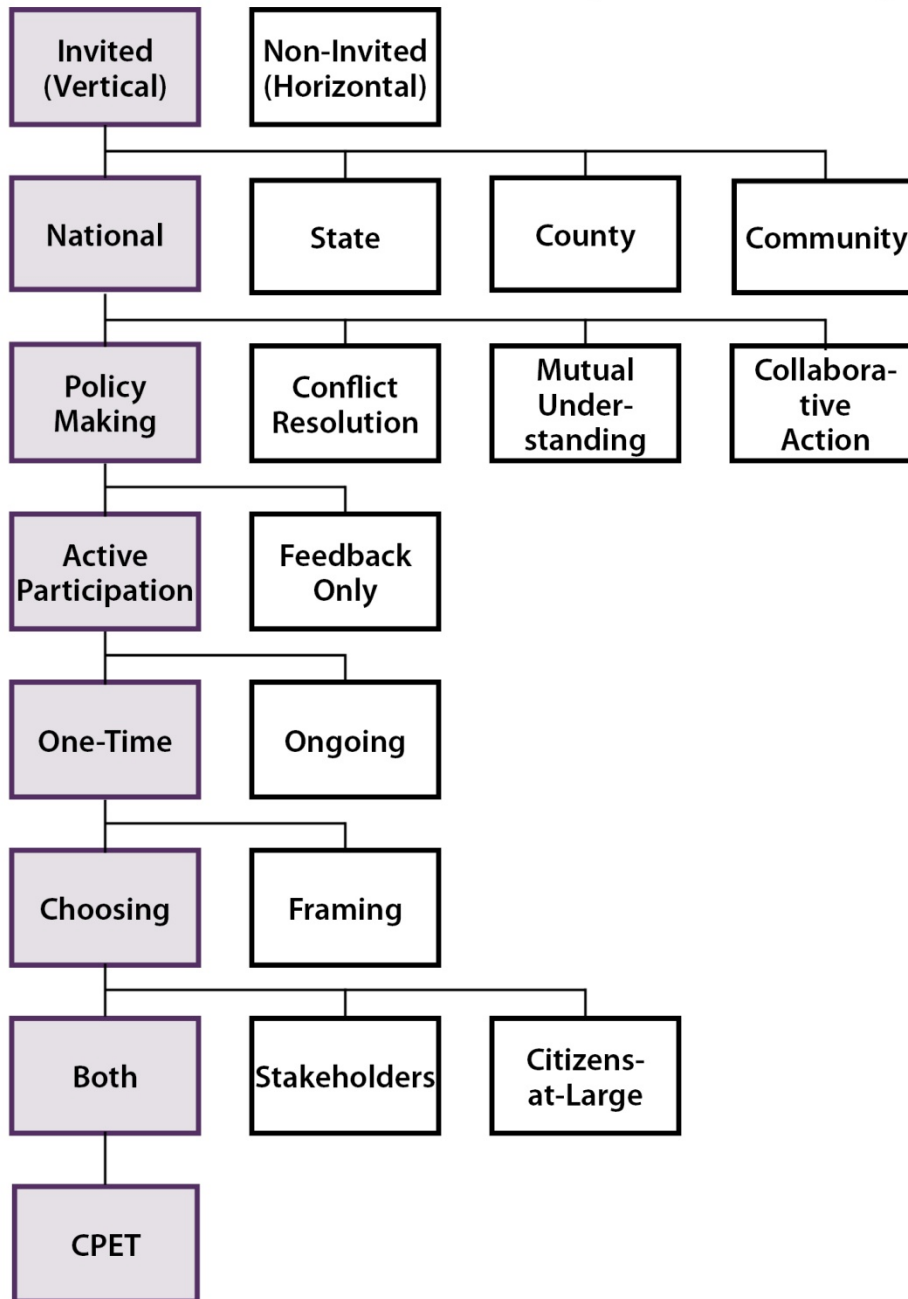
1. Results or substantive considerations
2. Process or procedural interests of participants
3. Persons or psychological interests of participants

What Public Engagement Is Not

It's NOT:

- **Public education or communication**
one way transfer of information
- **Advertising**
persuasion, selling a product or seeking behavior change
- **Public relations**
selling a policy position, persuasion

Considerations in Planning a Public Engagement Process for Policy Making



1. Who is organizing this?

2. At what level is this being organized?

3. What is the purpose?

4. What type of interaction is desired?

5. How frequently will interaction occur?

6. What decision work is being requested?

7. What publics will participate?

8. What technique will be used?