

Faculteit der Aard- en Levenswetenschappen

Engaging stakeholders and society

Introduction to interactions and strategies

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Society & GENOMICS 
Centre for Society and Genomics

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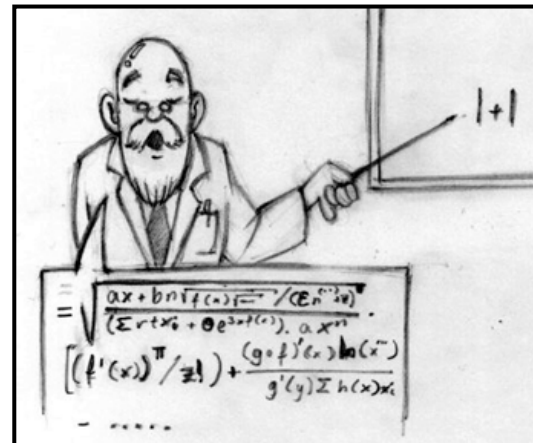
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Issues addressed in this lecture

- **A Brief History of Public Engagement (PE):** from a *one-way flow* of info, to *democratic way* of decision making
- **An Example of PE:** biobanks and the ‘public’
- **Why PE?:** motivations to engage the ‘public’
- **What is PE?:** definitions and characteristics
- **How to do PE?:** approaches and methods
- **PE, deliberation and dialogue:** the substantial argument
- **PE: difficulties?:** normative and substantial level

A Brief History of PE: the eighties

- PE is relatively young – since early 1980s
- Science & Technology (S&T) developments triggered expectations and concerns in society
- Reduced levels of (unconditional) support: Public demanded a voice in S&T
- Declining public support for S&T worried powerful S&T actors
- Rise of 'PUS'



A Brief History of PE: the nineties

- ‘PUS’ heavily criticized by STS and Science Communication scholars
- Refutation of the ‘deficit model’

increased scientific literacy did not increase public acceptance

- Shift from public education and persuasion, to two-way communication
- S&T decision making should *actively engage the public*



An Example of PE (1)

Biobanks and the publics

Austrian-Dutch project with CSG

Research objective

to investigate attitudes towards biobanks among the general public, and to find out about their willingness and reasons for participating in biobank research in order to improve biobank governance in The Netherlands and Austria

An example of PE (2)

Relevant issues:

- Consenting to goals and scope of the research
- Protection of privacy
- Accessibility of the data
- Ownership of data
- Internationalization
- Commercialization

An example of PE (3)

- Explore how various publics perceive biobanks
- Focus group discussions and societal expert groups in Austria and Netherlands, In NL:
 - 6 FGDs with mixed lay publics (45, North Holland, Friesland)
 - 2 FGDs with Lifelines participants (21, Friesland)
 - 4 FGDs with patients (AMC, UMCG) → still to be held

An example of PE (4)

Structure of FGDs:

- Knowledge on biobanks
- Advantages and disadvantages of biobanks
- Biobank issues : privacy, consent to goal and scope, accessibility, ownership, internationalization, commercialisation
- Governance of biobanks
- Intentions to participate/ possible improvements

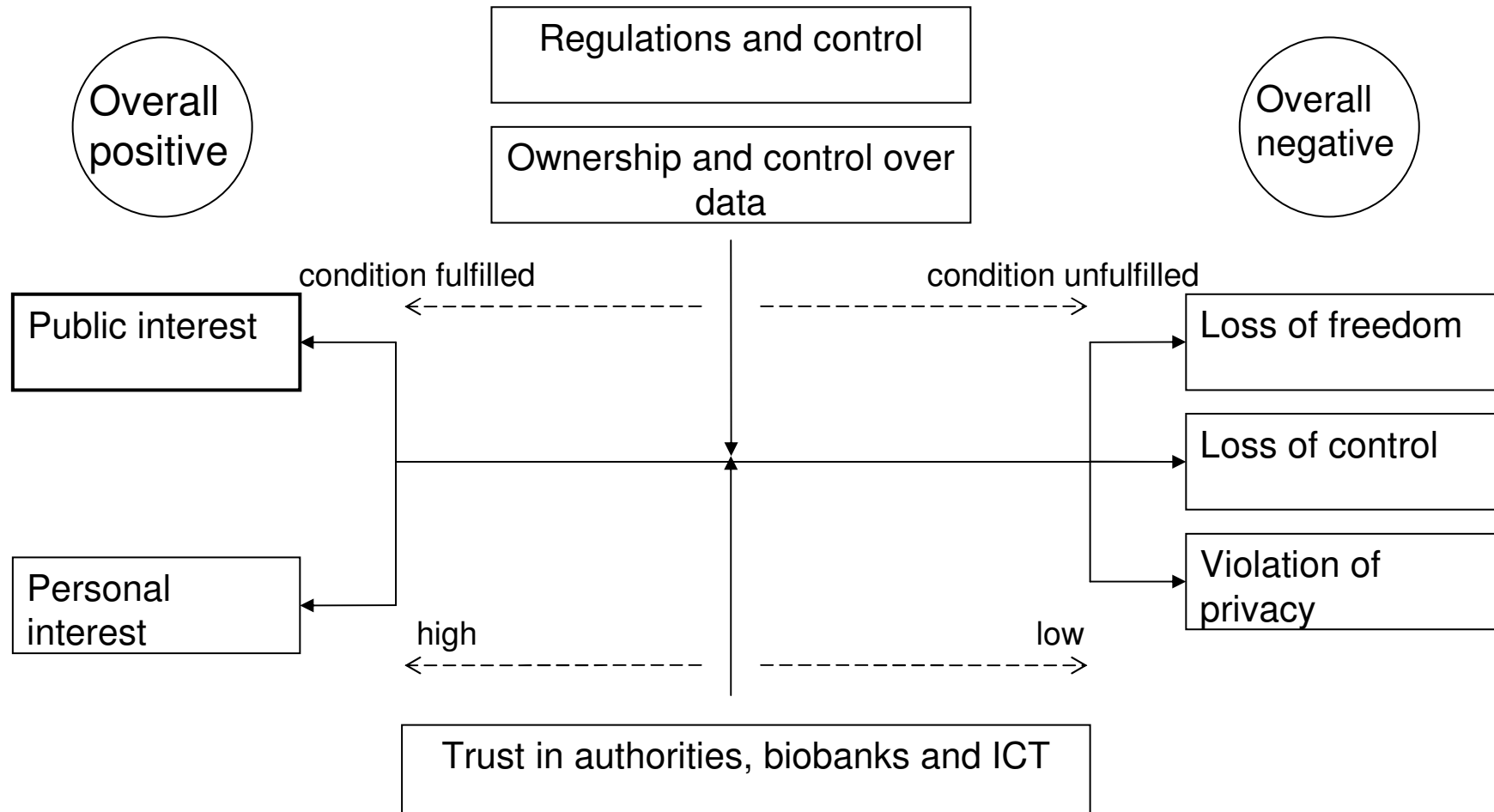
An example of PE (5)

- Little knowledge on biobanks
- Advantages of biobank:
 - Mixed lay publics: public interest
 - Biobank (Lifelines) participants: public interest and personal benefit
- Disadvantages of biobanks:
 - Mixed lay publics: threats to privacy
 - Biobank (Lifelines) participants: possible negative findings

An example of PE (6)

- Issues according to mixed lay publics
 - Privacy, consenting to research goals and scope, and commercialization most important
 - Mostly positive towards participation
- Issues according to biobank participants
 - Commercialization most important
 - Very few other concerns

An example of PE (7)



An example of PE (8)

- Governance has to deal with
 - Control over data by participants
 - Privacy and access to data
- No clear idea who should be responsible
 - No self regulation of biobanks
 - Many hesitant towards gov't regulation
- No clear suggestions for how to regulate and control

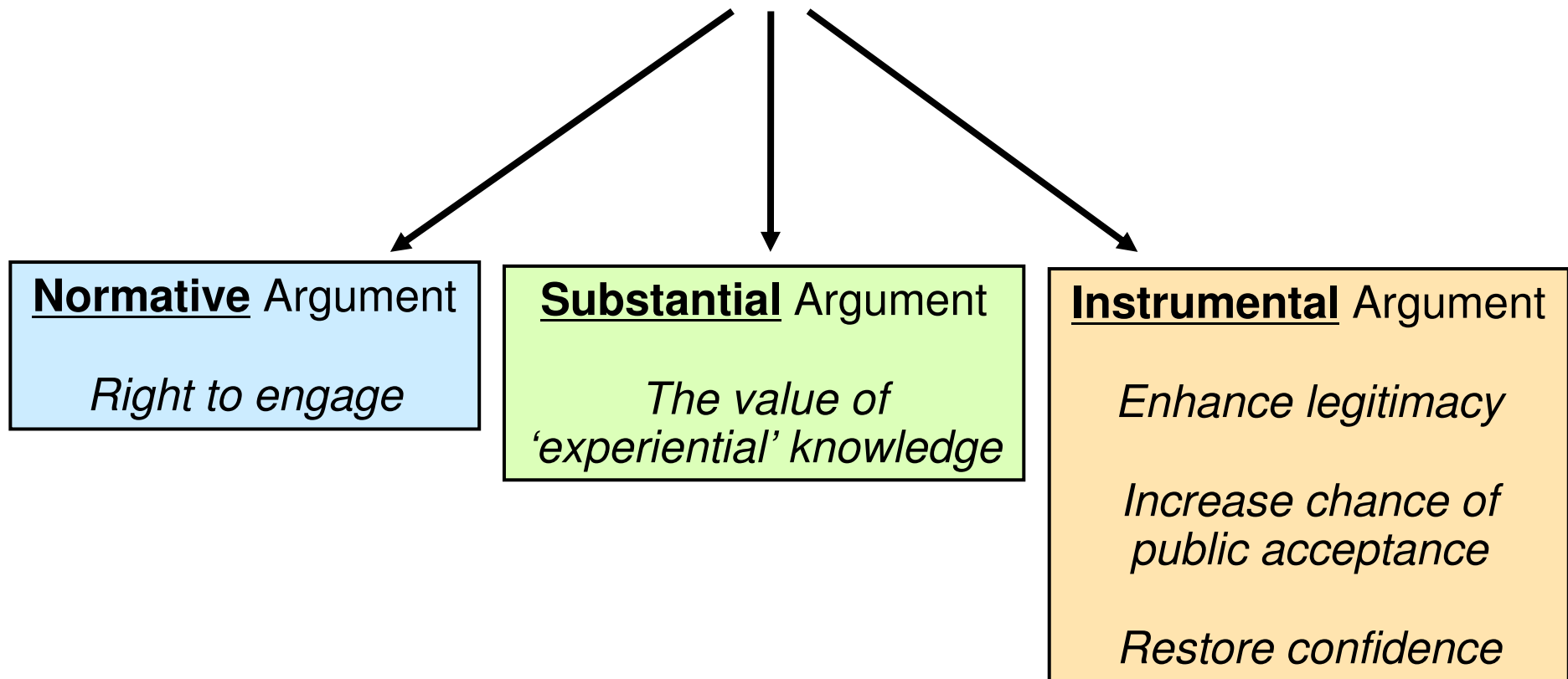
An example of PE (9)

- Focus group participants able to discuss various biobank issues
- Participation in biobank research appears strongly trust based
- Unstable perceptions based on peripheral cues, may easily be influenced by external factors

- Biobanks should take public perceptions into account in order to prevent shift in attitudes and lack of participation in biobanks
- Results give input for eurobarometer
 - Research on European level

Why PE?

“Decision making on S&T should *actively engage the public*”



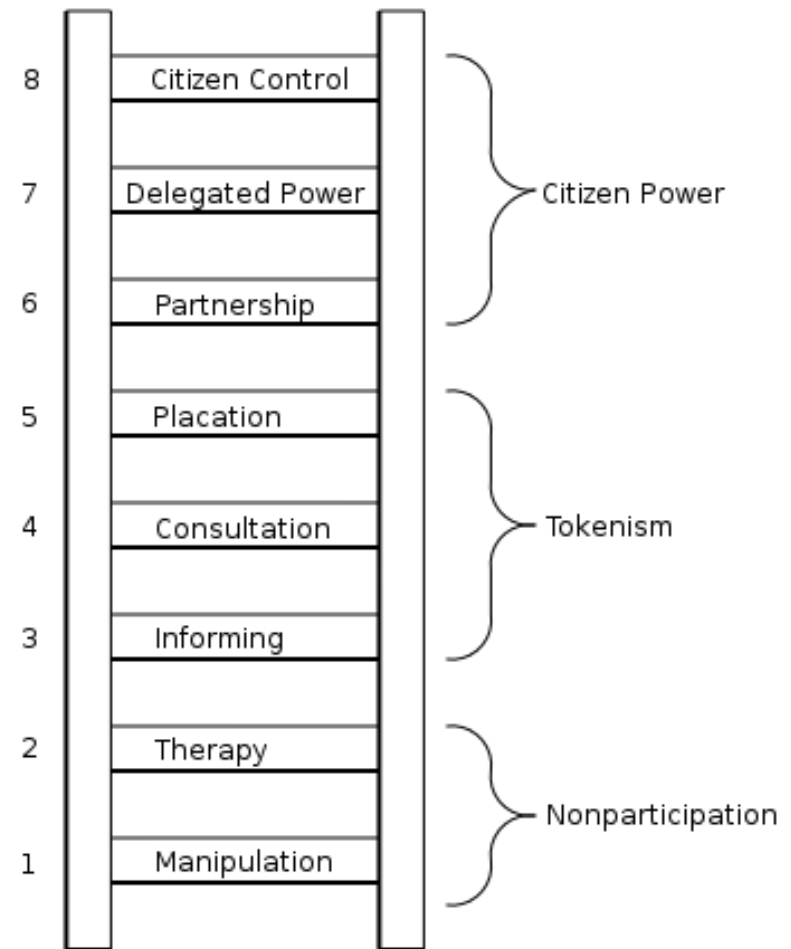
What is PE? *Who do we engage?*

- ‘Public’, or ‘publics’?
- Common categories: public \approx citizens
(demographic divisions: age, gender, ethnicity)
- PE in S&T: other categories more appropriate
(interest, relationship, ...) \rightarrow stakeholders
- *Lay people* \neq *illiterate* citizens
- Individuals, or representatives



What is PE? *Degree of engagement*

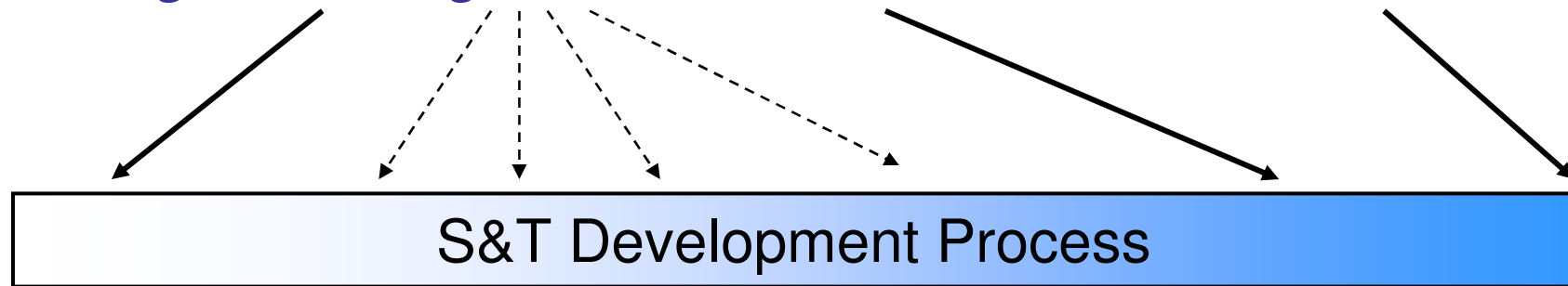
- Different levels of control
- Participation Ladder
- Past 15 years: climbing the ladder



What is PE? *Timing*

- PE in S&T: possible in all phases:

From *agenda setting* to research *evaluation* and result *dissemination*



- Upstream Engagement: scientific research
- Downstream Engagement: near market introduction
- Timing is difficult: Collingridge dilemma

How to do PE?

- Many participatory methods
- Broad distinction on basis of stakeholders involved:

Public:

Elicit Needs and Wishes

*Consultation techniques:
Interviews, questionnaires,
focus groups, citizen juries, etc.*

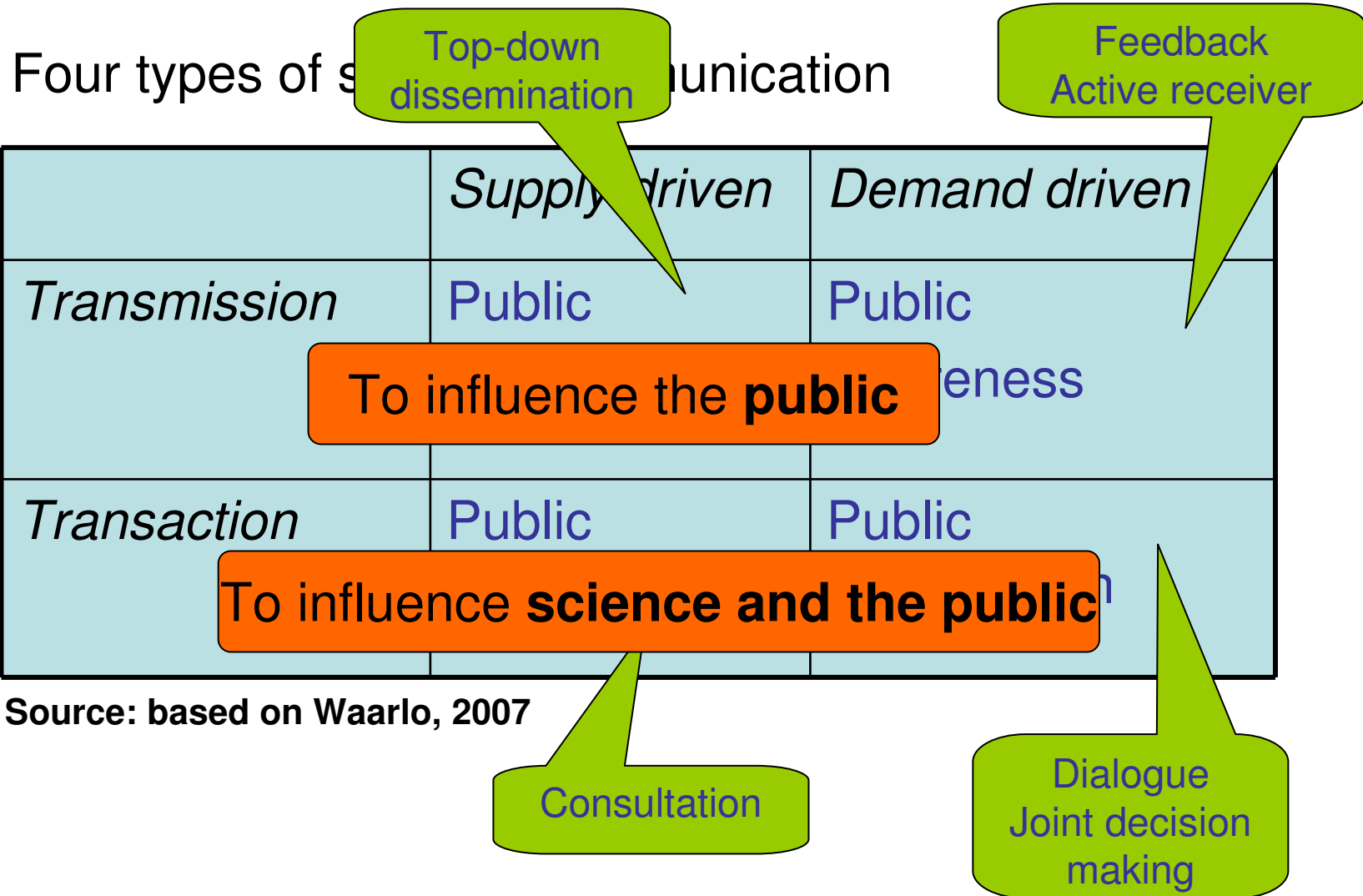
Multiple Stakeholders (incl. experts):

***Exchange Needs and Wishes and
explore options for Mutual Learning***

*CTA, Interactive Policy-making:
deliberation and dialogue*

- Integrated use of multiple methods

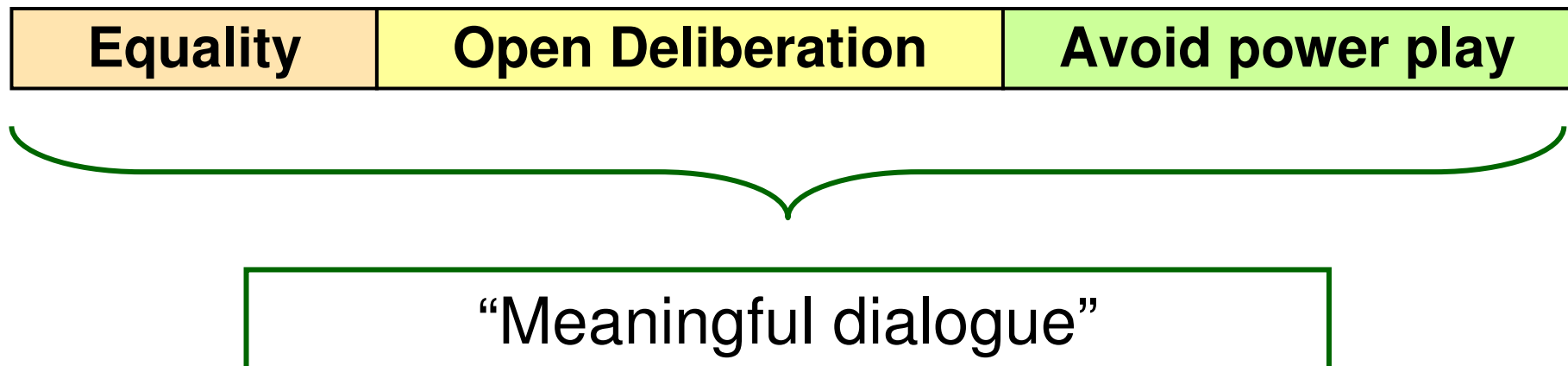
How to do PE?



Source: based on Waarlo, 2007

How to do PE?

- PE particularly meaningful if it enables *Deliberation*, which requires a *Dialogue*
- *Jurgen Habermas (1981):*



- Deliberation *between public and experts* provides opportunities to realize the *substantial* argument

How to do PE?

Interactive Learning and Action approach

1. Preparation and exploration
 2. In-depth study:
 - a. assessing problems and needs
 - b. identifying research optionsfrom different perspectives separately
 3. Integration of different perspectives
 4. Agenda setting and action planning
 5. Implementation of program –learning cycles
- Iterative and flexible – not chronological blue print

Framing

Consultation &
Opinion
development

Dialogue



PE: Difficulties? Normative level

- Normative legitimacy of PE:

Science-Ethics divide

- Separation between science and ethics induces a *dualism* about the topics of discussion
- Experts bring in the ‘facts’, the public brings in ‘practical knowledge, values and concerns’:

Hard facts – soft values

- This distinction is pitfall: reinforces inequalities, reduces effectiveness of PE

PE: Difficulties? Substantial level

- Counteract **asymmetrical dominance** of knowledge between different participants
- Avoid **masking inequalities**
- Be alert of **subtle ways of exclusion** by careful preparation
- Go beyond value conflict identification: aim at finding (substantial / procedural) solutions via **value reflection** and **mutual learning**.