

# Patient engagement: Focus group experiences

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# Informed consent



“Sharing your data will benefit future patients”

“We may be able to offer you better treatment with less side effects”

“This is cutting edge research”

“We’ve had some success with ...”

“Signing a consent form”

# Informed consent



Competence and Voluntariness  
+  
Information and Understanding

« From the moral viewpoint, informed consent has less to do with the liability of professionals as agents of disclosure and more to do with the autonomous choices of patients and subjects »

Beauchamp & Childress, 2012, Principles of biomedical ethics

Informed consent ~ the eye of the beholder (the patient)

# Competence

Traditionally:

Incapacitated, mentally incompetent, children

For NGS:

Are patients ever capable to make autonomous decisions about such a complex test?

Continuum of competence?

-> Awareness

-> Importance of identifying basic information needs



# Voluntariness

Voluntary ~ free from coercion

Coercion can have many forms

- Financial
- Institutional
- Social pressure



“Sharing your data will benefit future patients”

“We’ve had some success with ...”

# Information



Information provision => neutral

- Neutral  $\neq$  correct/complete
- Neutral = not withholding specific information
- Quid research?

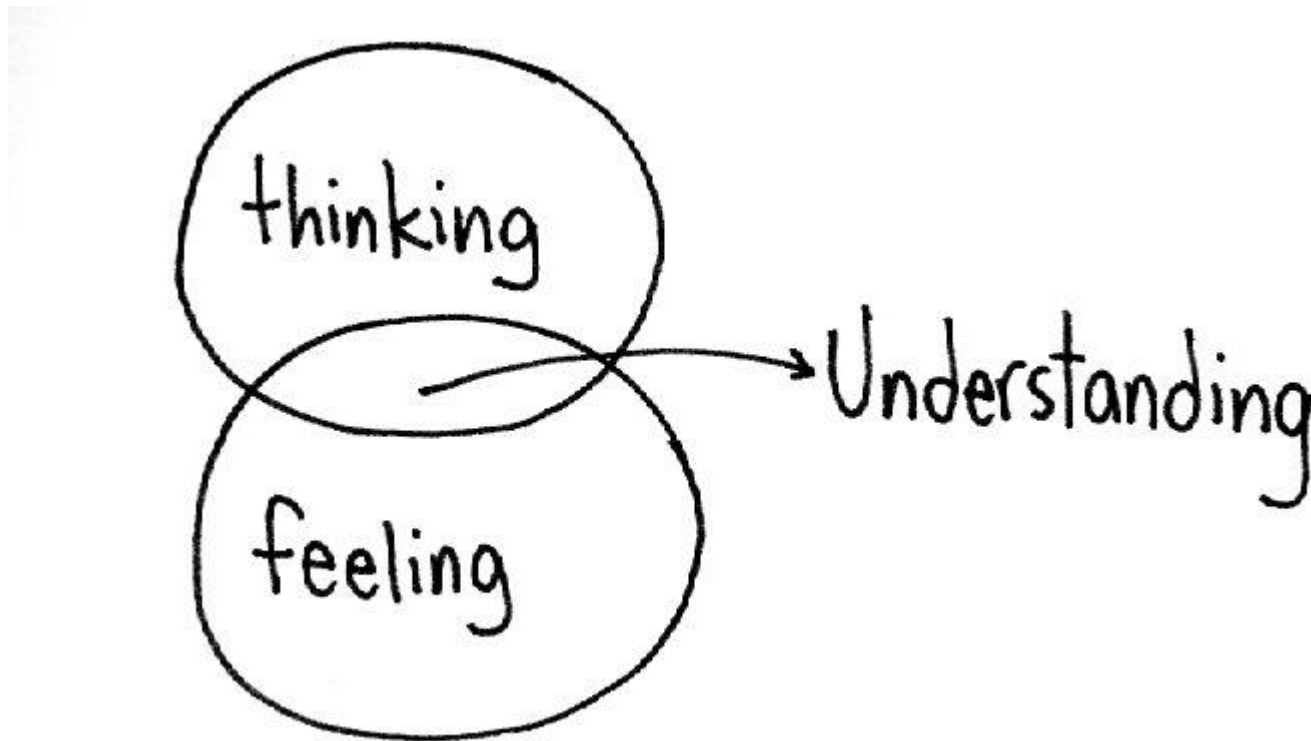
Informed consent form vs oral communication

Subjective standard of consent: what does this particular patient need to know to make an autonomous decision?

# Understanding

## Subjective standard of consent

- Understanding is a unique process





# Focus groups



## Goal

- To include the patients' perspective in policy making
  - To learn from patients' experiences
  - To identify information needs
- To improve all aspects of the informed consent process

# Focus groups

Goal: 10 focus groups with +-60 patients (breast, ovarian, colon, skin or lung cancer)

Currently: 3 test focus groups + 2 focus groups, 38 participants recruited

Recruitment through patient organisations, social media and hospitals, but we can still use your help



# Assertions



Start: a 3 minute introductory video

## A discussion about 8 statements

1. Expectations: optimism, fear, doubt, trust
2. Broad or targeted testing
3. Information provision (counseling)
4. Data sharing
5. Additional findings (VUS -> actionable mutations)
6. Carrier status
7. Relevant results for family members
8. "I have faith in the evolution of the use of genomic data in health care"

# Focus group discussion



Capturing the first impression on a 5 point Likert scale

## Semi structured discussion

- Comparing first impressions
- Initiating discussions
- Sharing thoughts and experiences
- Using active and passive prompts to keep focus

Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
1	2	3	4	5

# Autocorrect?



Discussions about the technical aspects of NGS, even after the information video + first questions, even among patients who already had an NGS test

- Comprehensiveness of the test
- Deterministic view on genomics
- My genes or my tumor's genes?
- Privacy
- Research vs therapeutic practice

The end point of the discussions between patients was sometimes factually incorrect

# Preliminary findings



## Individuals differ

- Illness characteristics
- Not interested – amateur academics
- Thinkers

## Data sharing

- Generally favorable attitudes, sometimes mixed with “I don’t care”
- A minority with very strong views against data sharing

# Concluding remarks



What patients want does not directly transfer to guidelines or ethical principles

- Balance with legal and normative arguments

Including the perspective of the patient is key to tailor implementation of new technologies to their needs

We would not realize it if we were the young fish who does not know he is swimming in water every day



"BUT IF YOU WANT THE REAL LOWDOWN, WE'LL  
NEED SOME OF YOUR DNA."

Questions?

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