Patient participation - ‘Attitudes and information needs of cancer patients regarding NGS technology applications: a focus group study’

SYMPOSIUM ‘Next generation sequencing’ technology in routine analysis in the Belgian healthcare system – 25-10-2016
Katrien Moens
Background - Context

• **Relevance:**
  • generally: value of patient participation
  • see Roadbook 2016-2020 action 8 ‘ethical and legal aspects concerning NGS data usage’ – informed consent process
  • problem setting - current practice
  • predicted impact (~ results)
Objectives

• **Aim:**
  - to explore the attitudes and information needs of **cancer patients** regarding NGS technology applications

• **Specific objectives:** explore …
  1. meaning of DNA tests
  2. expectations regarding NGS tests in general and specific NGS test results
  3. information needs with regard to NGS tests
Methodology (1)

- **Qualitative** research design:
  - focus groups: observer + moderator – homogenous group of patients - in French and Flemish speaking part of BE
  - recruitment strategies: KOTK, STK, VPP, LUSS and ComPerMed
  - introductory information video
  - Q-s ort procedure: rating of statements on Likert scale
  - **quality control**: project group with representatives from academia, practice, government, patient groups and patients.
Methodology (2)

Illustration process of group interviewing:
START : general question ‘What do you associate with DNA?’

Information video: information on what is DNA and what is NGS?

Q-sort: statement ratings: first individually and then discussion in group

Debriefing – end of focus group.
### Planning

- **Activities planned/3 months for 2016 – 2017:**

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THANK YOU FOR YOUR ATTENTION!