

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

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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-sort 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:

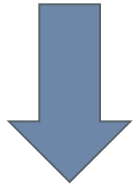
START : general question *'What do you associate with DNA?'*



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:

IN QUARTILES (Q) FOR <u>2016 Q4</u> - <u>2017:</u>	Q4 2016	Q1 2017	Q2 2017	Q3 2017	Q4 2017
MEETINGS PROJECT GROUP					
FINAL VERSION RESEARCH PROTOCOL					
APPROVAL MEDICAL ETHICS COMMITTEE					
EVALUATION INFORMATION VIDEO AND INTERVIEW GUIDE (INFORMATION AFTERNOONS – STK)					
START RECRUITMENT PATIENTS AND ORGANISING FOCUS GROUPS					
FOCUS GROUPS AND ANALYSIS TRANSCRIPTIONS					
PLAN OF ACTION FOR BROAD PUBLIC DEBATE CONCERNING PERSONALISED MEDICINE					

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THANK YOU FOR YOUR ATTENTION!