



# How do families make the decision to participate?

RESPECT

Dissemination meeting Brussels

25.05.2011



## Situation:

- Diagnosis
- Feelings
- Uncertainty
- Children



# Decision situation – benefits & reasons

## Benefits

- Get help
- Important others
- Get information
- Help others



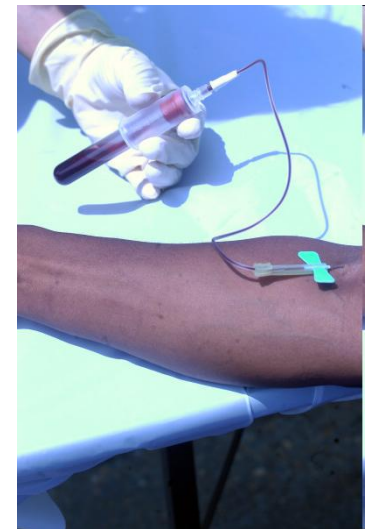
## Reasons

- Direct personal benefit
- Attention / meet others
- Better knowledge
- „Giving back“
- Social pressure



# Decision situation – risks & burdens

- Risks:
  - perceived risk of new / untested / unlicensed medication,
  - perceived risk of trial design and
  - perceived safety of the study in general
- Burdens:
  - frequent clinic visits,
  - travel arrangements and
  - amount of time used
  - drawing blood samples



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# Decision situation – process

## First consultation:

- Disclosure of the diagnosis
- Get the information material
- Get the decision aid brochures



## At home:

- Read the information material provided
- Work with the decision aid – take down notes and questions you'd like to ask at the following second consultation

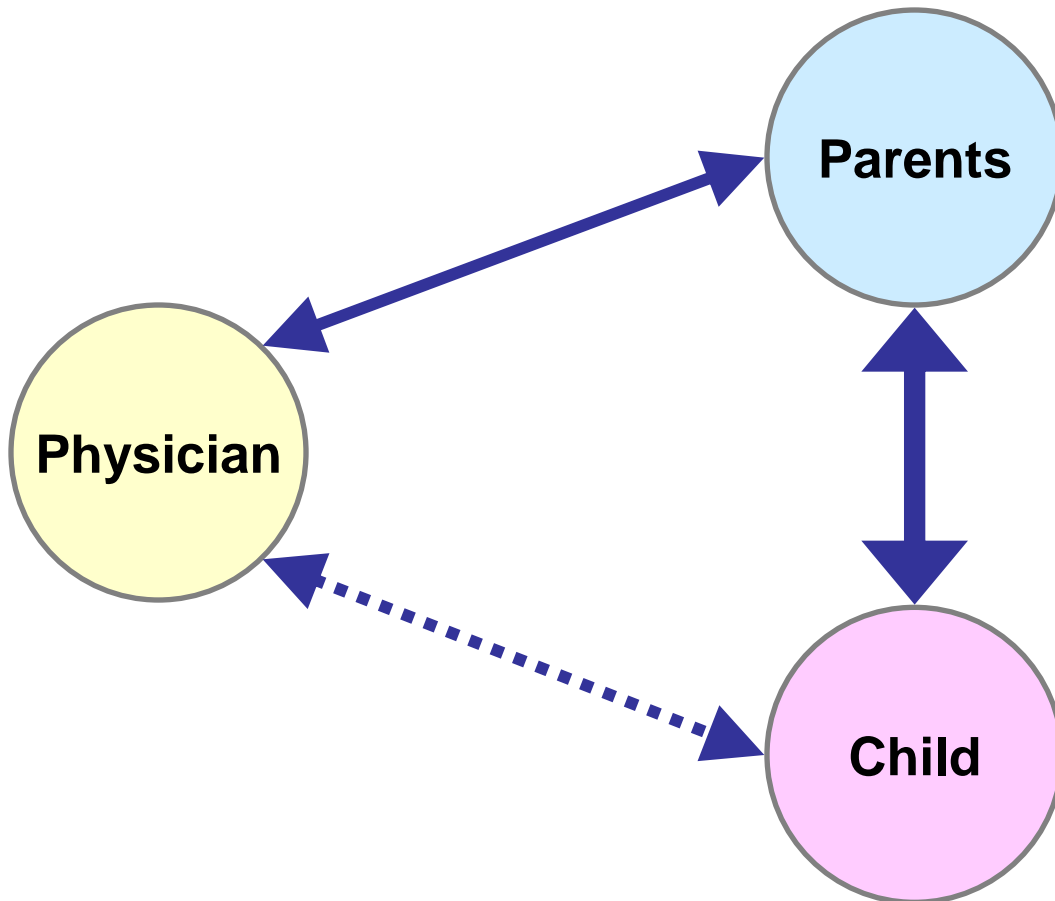


## Second consultation:

- Ask the questions you wrote down before
- Discuss / address other open issues
- Give or decline consent or assent (your child)

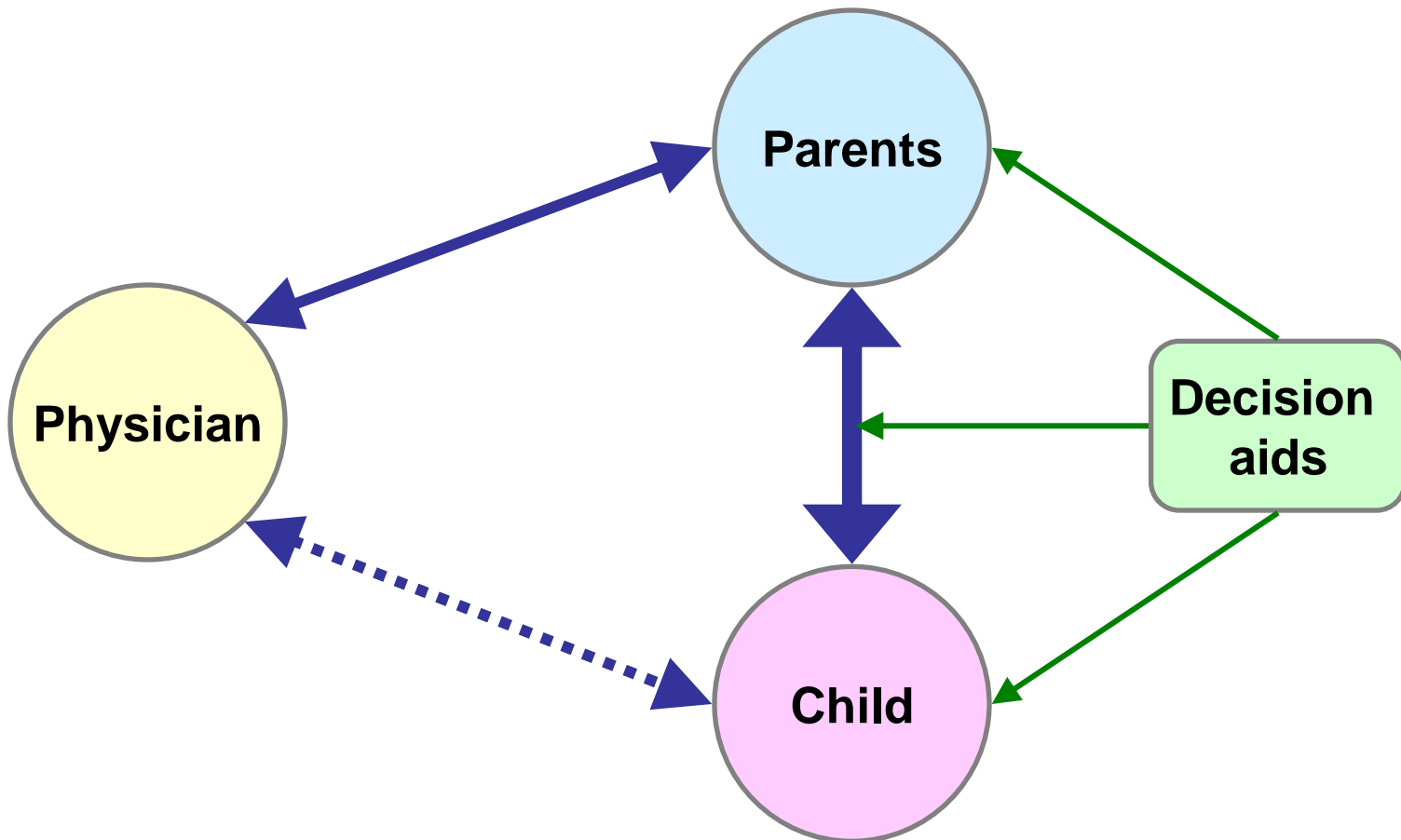


# Decision situation – do they understand?



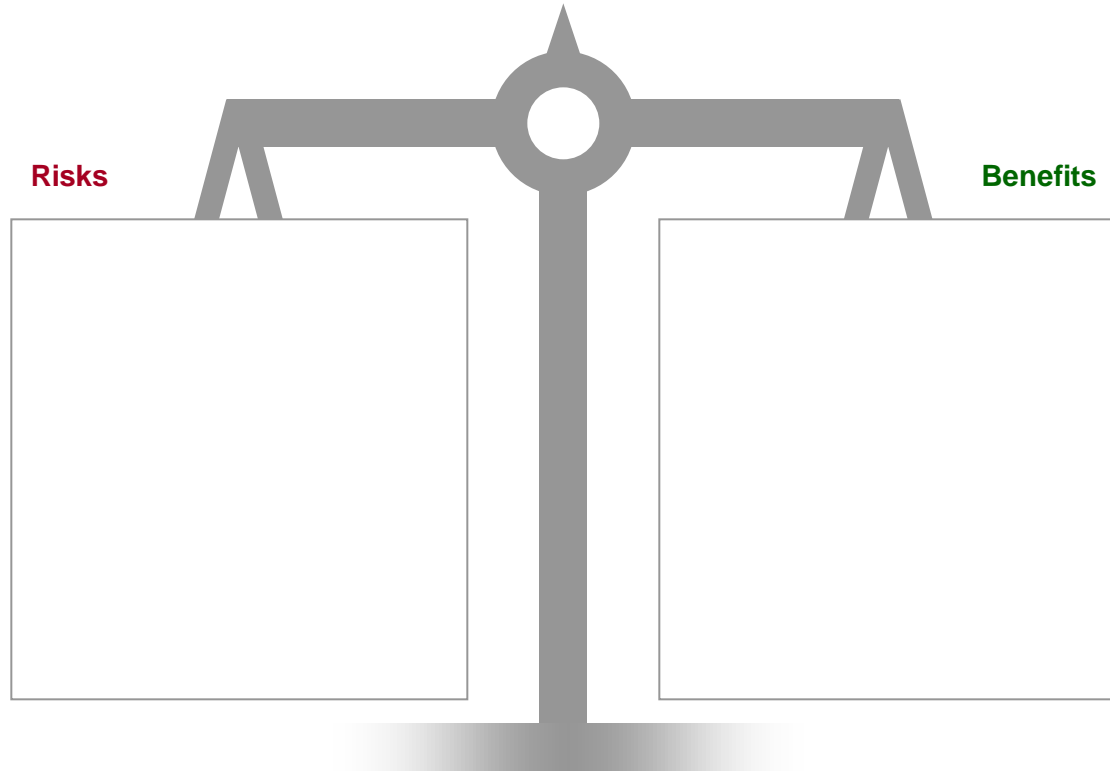
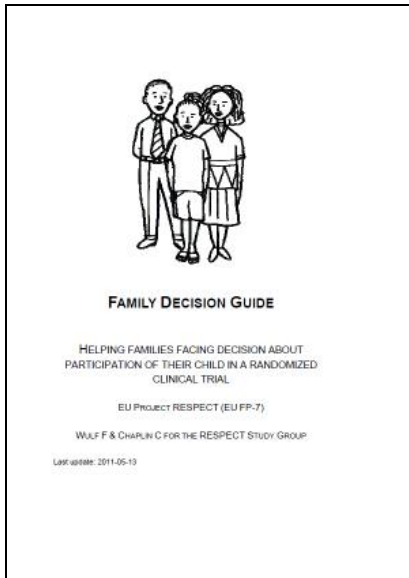


# Decision situation – decision aid (1)



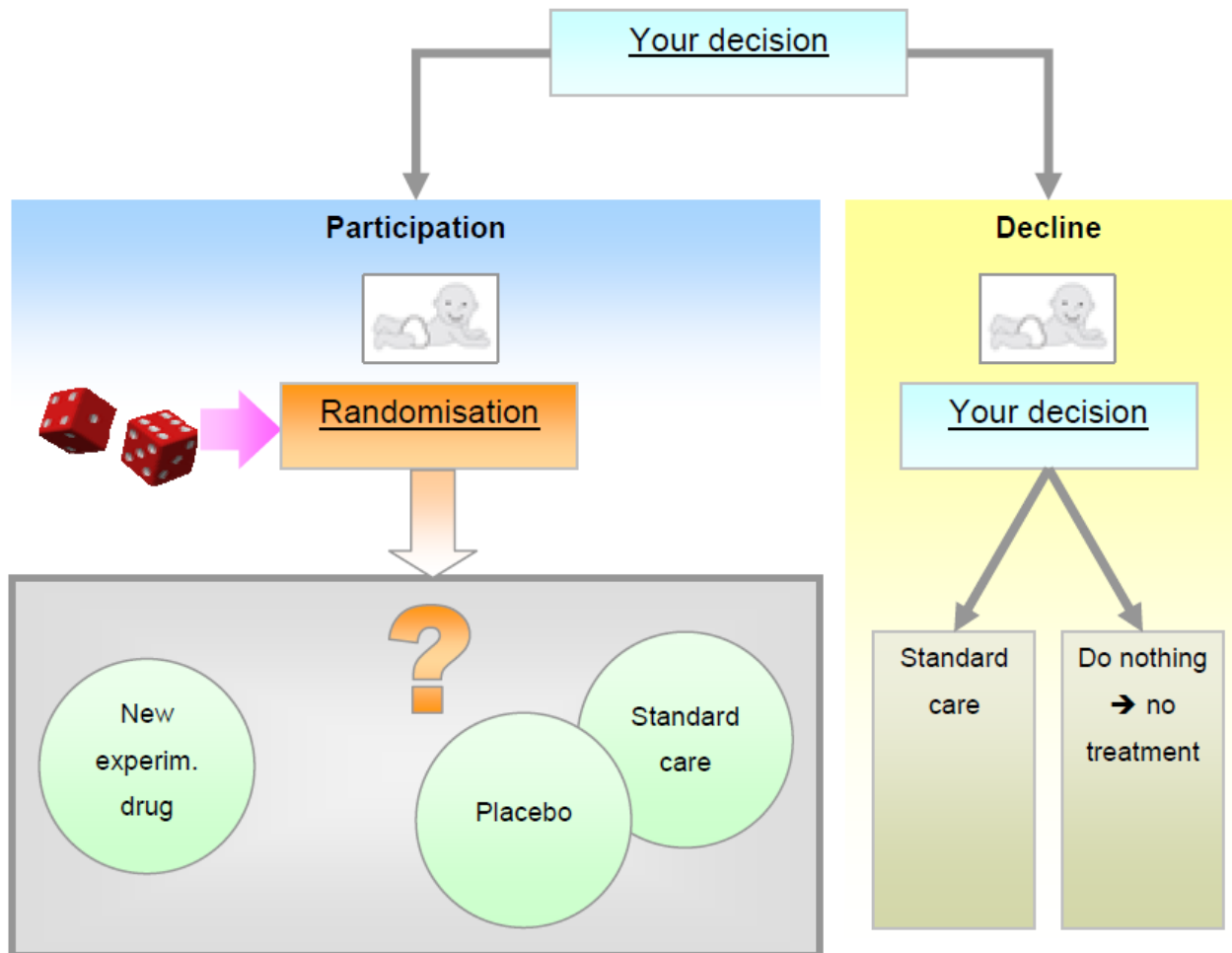


# Decision situation – decision aid (2)





# Decision situation – decision aid (3)





# Conclusion

**Empower families in the decision situation about their children's future health**

- Signing the consent form is not enough
- Decision aids can help:
  - understand risks and benefits better,
  - understand important research concepts,
  - empower to question and discuss fears, needs & concerns and
  - **establish a mutual conversation situation**



RESPECT  
patient needs



**Thank you!**



# Preliminary results from the pilot study

	Participate	Decline	n=37
University	11	9	20
Industry	4	13	17