



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



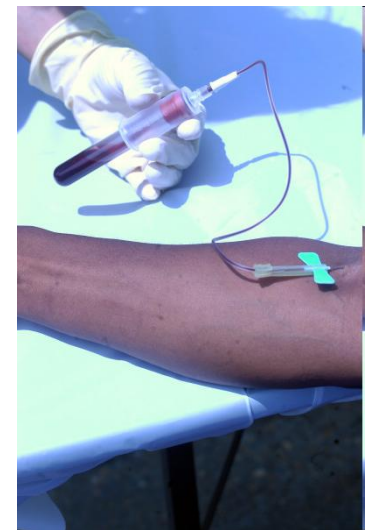
Reasons

- 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

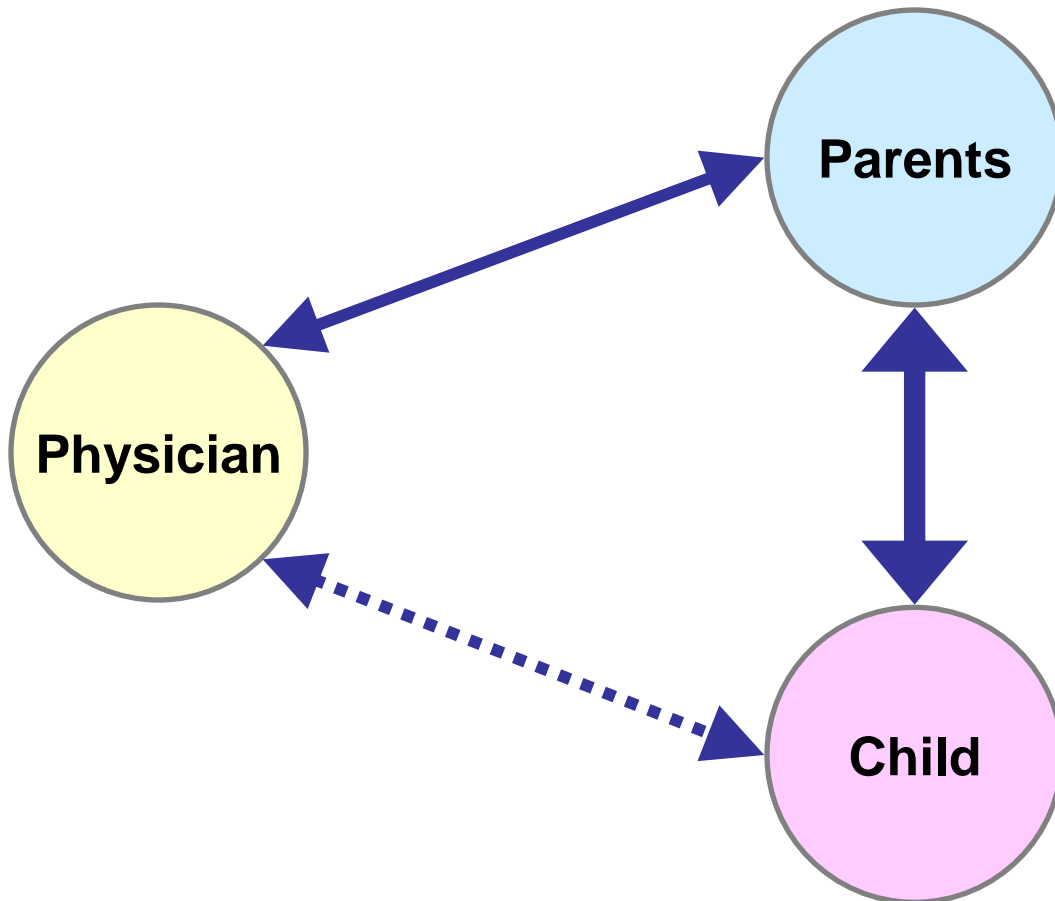


Second consultation:

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

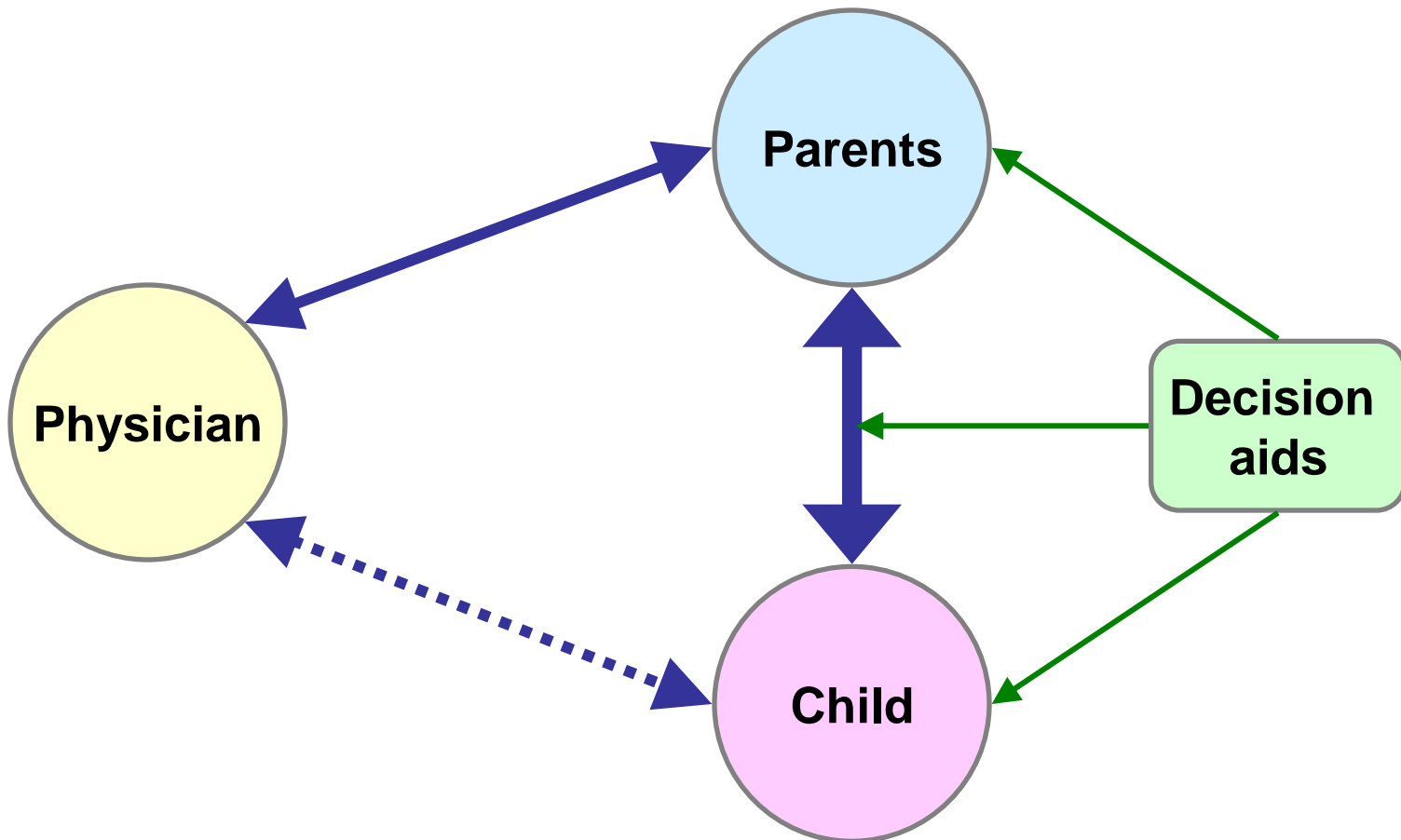


Decision situation – do they understand?



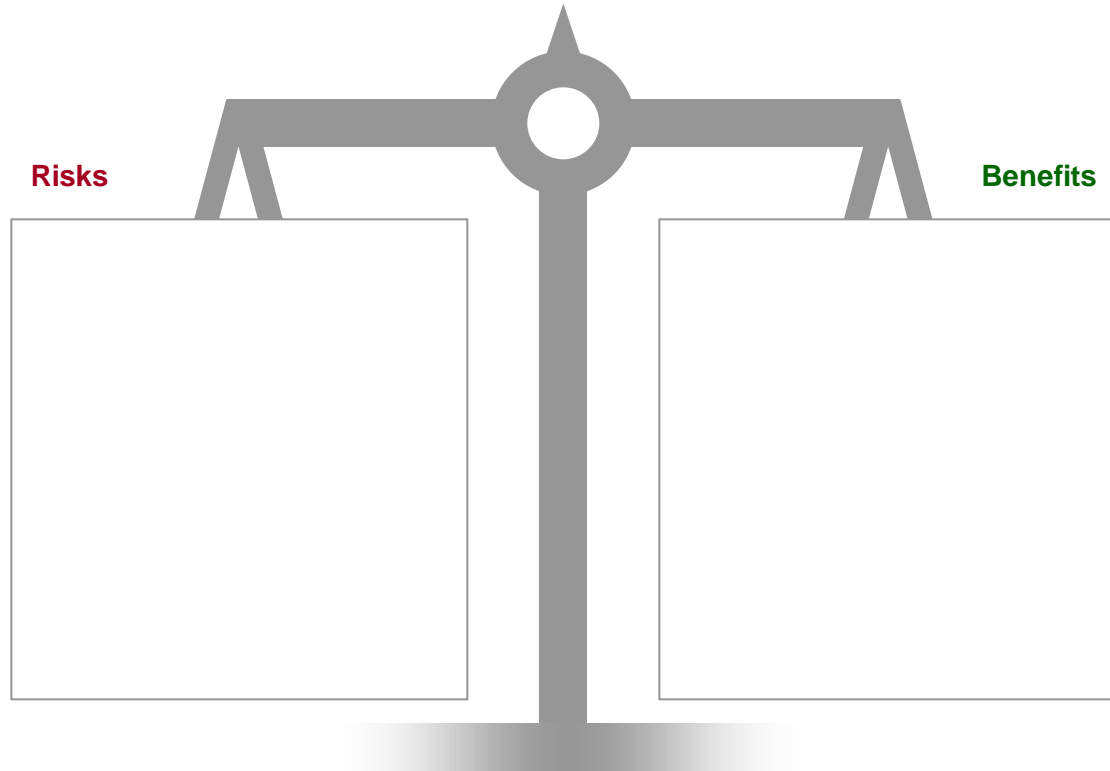
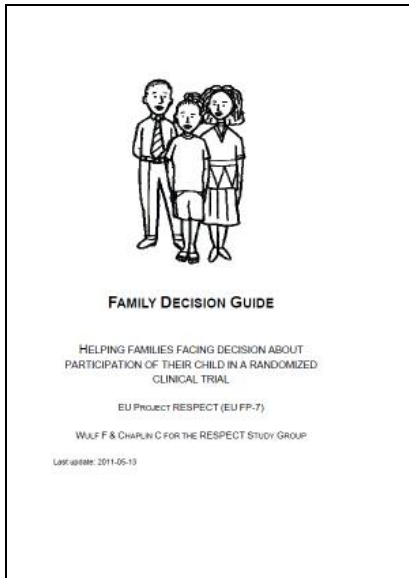


Decision situation – decision aid (1)



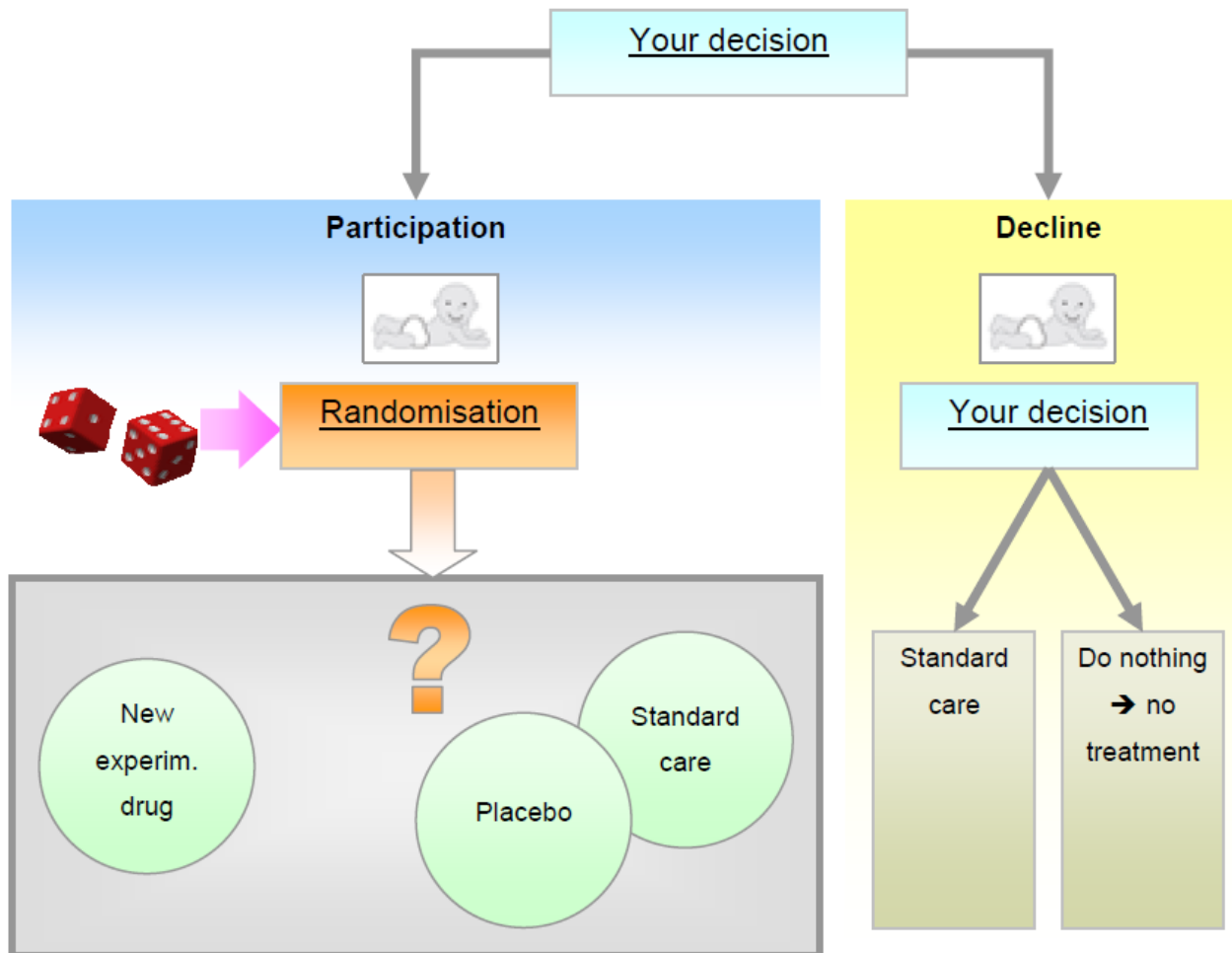


Decision situation – decision aid (2)





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 |