

# Ethical challenges and opportunities of pre-natal testing

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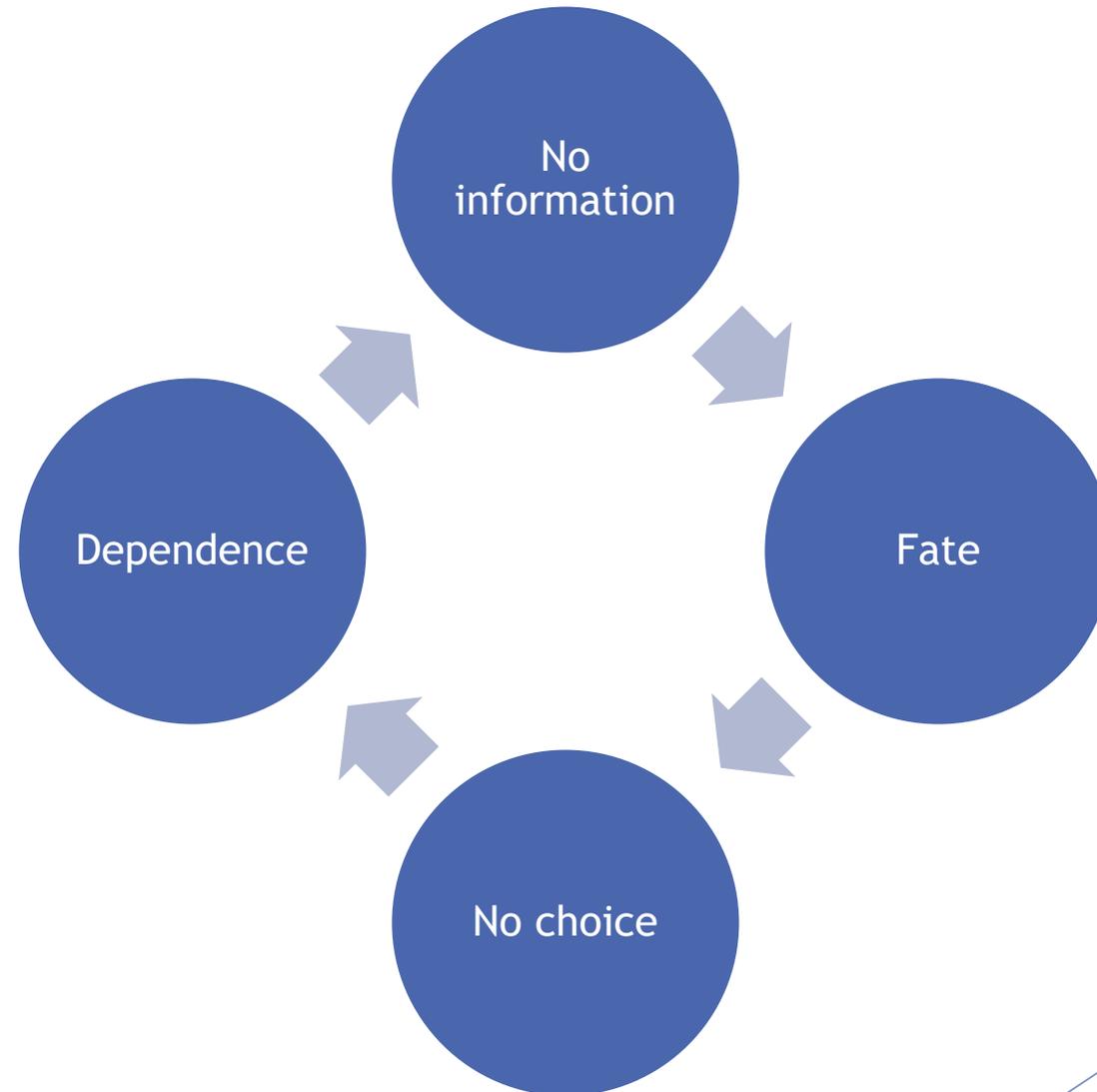
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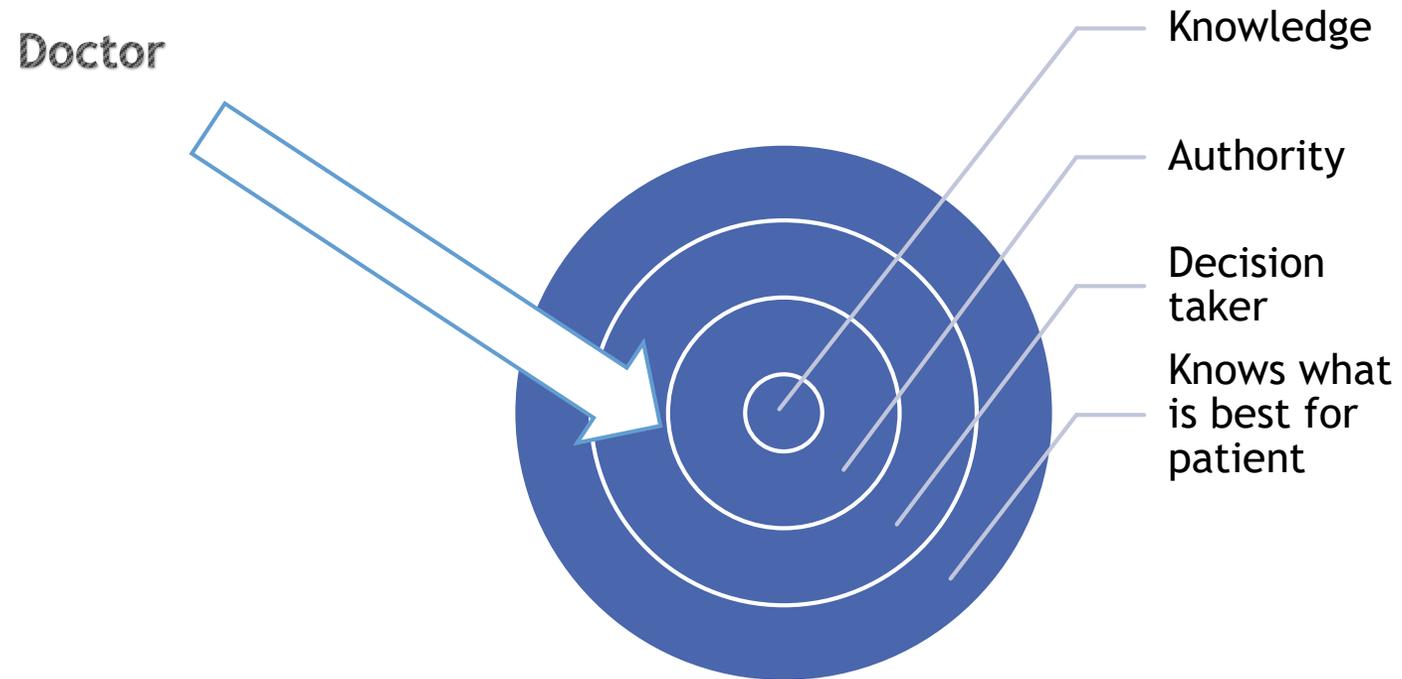
# From fate to modification

Changes in society and healthcare

# Where do we come from



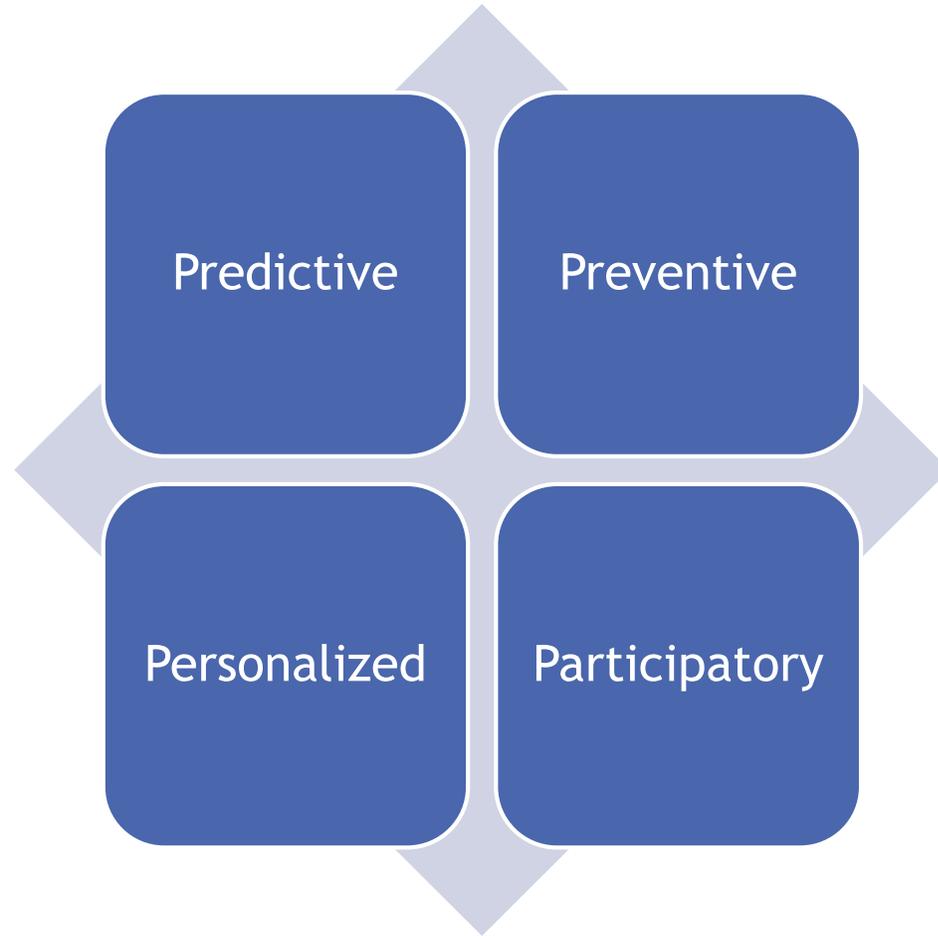
# Doctor-patient relationship Non-symmetrical



# Evolution in society

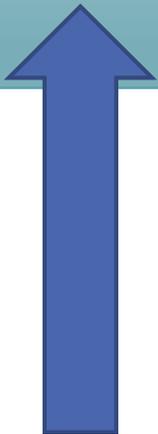
- ▶ Ideal of emancipation and increasing importance of subjectivity
- ▶ Protest against authority and ‘the system’
- ▶ Medical technology allows making decisions on crucial lifespan moments

# Evolution in medicine: P4

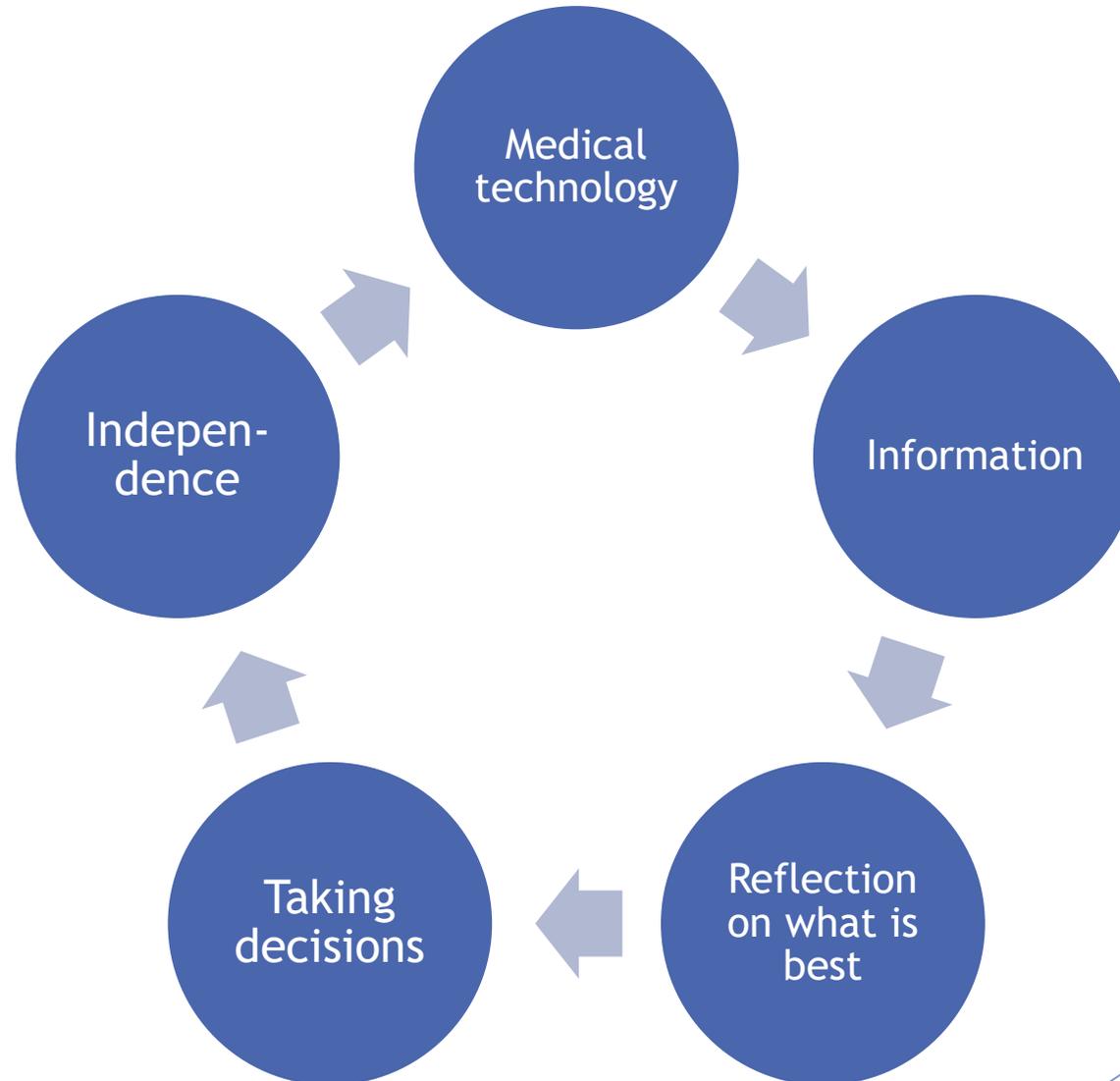


# Ten Have and Gordijn, 2018

‘Personalized medicine promised that medical treatments can be tailored to the specific characteristics of each patient. The new medicine will not only be predictive but also personalized and participatory. It will **empower** individuals to manage their own health and illness.’

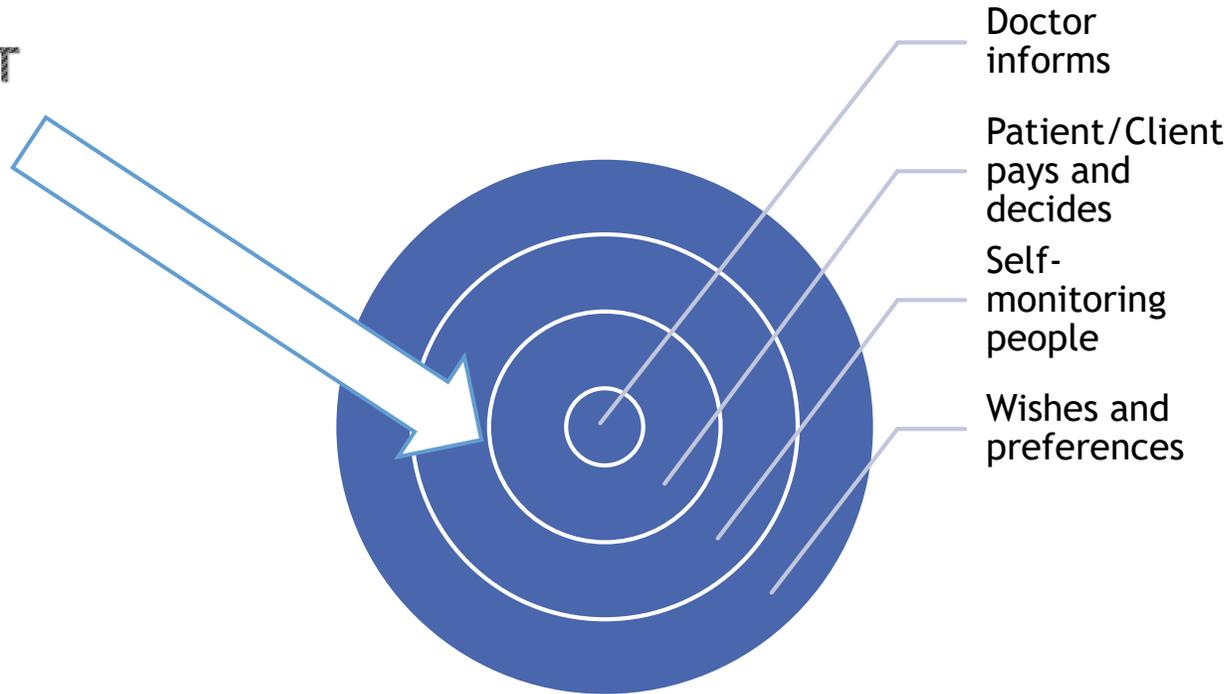


# Where we are: autonomy



# A new non-symmetrical client-doctor relationship?

PATIENT



Maximizing independence for patients/clients

# Ethical issues in pre-natal testing

Making decisions and trying to live with them

# Some key challenges

Health vs risks

Actionability

Severity of illness (and who defines it)

**Parental autonomy (no other criteria)**

# What about (parental) autonomy?

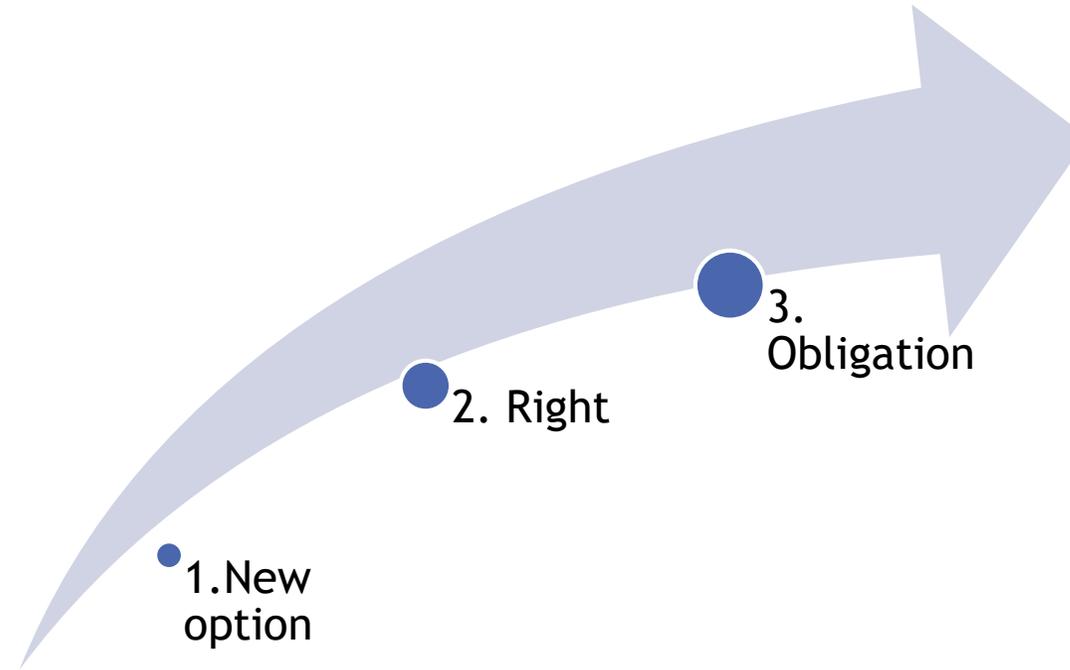
Two major evolutions in medicine:

- ▶ More information
- ▶ Widening of screening options
- ▶ Seems to support autonomy

# But

- ▶ Informed decision making and consent (complexity of data)?
- ▶ Future (time-lapse between prognosis and occurrence of illness)
- ▶ Risks/probabilities: how to live with that?
- ▶ Facilitating reproductive choices includes more than information
- ▶ More information is not the same as more autonomy

# NIP test as a Belgian case study



## Three stages of ethical debates

- ▶ Right to (Non-discrimination)
- ▶ Accessibility and affordability
- ▶ Right turns into obligation: explaining why one does not make use of sth
- ▶ 3rd stage: shift from system responsibility to individual responsibility

# Parental autonomy under pressure

- ▶ How to inform when information is everywhere?
- ▶ Prevention from social pressure
- ▶ Digitalization of healthcare
- ▶ Complexity of results in terms of risks and how to communicate them
- ▶ Widening the scope of testing but how to safeguard reproductive autonomy?

In need of other model

# Shared Decision Making

Symmetry

Reliable  
information

Informed  
choices

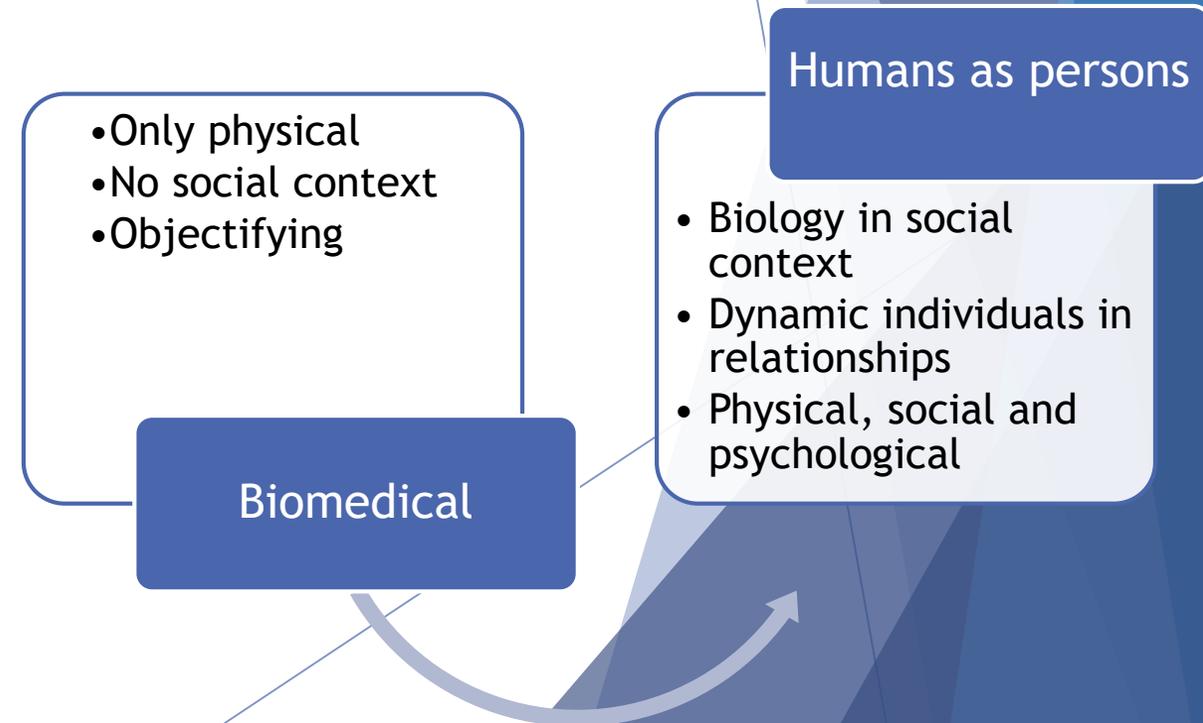
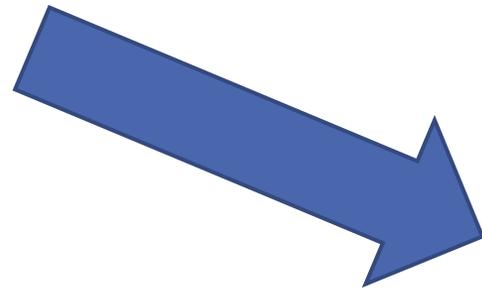
Maximizing benefit for patients

# Shared decision making

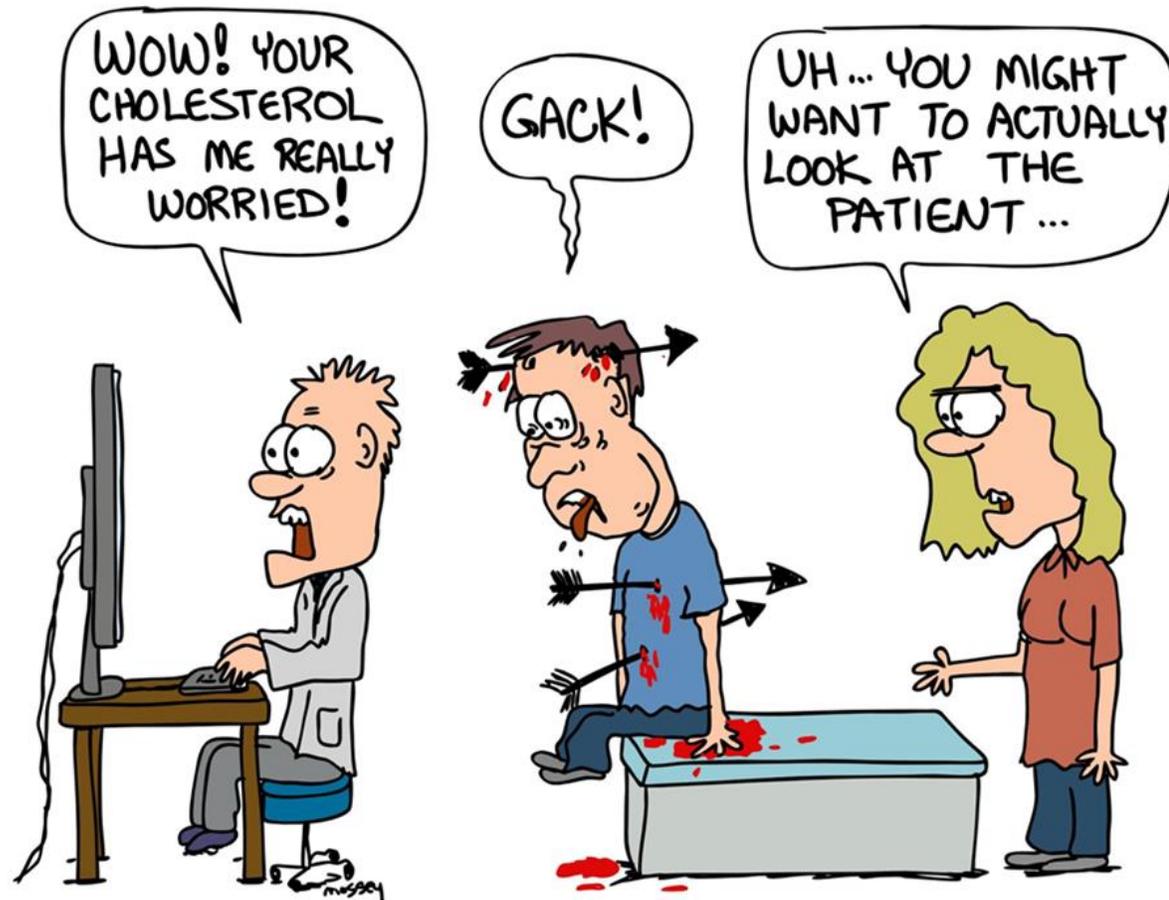
- ▶ Patient and doctor step into a dialogue to take well-informed decisions
- ▶ Both play an active and particular role
- ▶ Doctors have their expertise
- ▶ Patients have their life, personality and preferences

# Conclusions

- ▶ Allowing people in developing capacities
- ▶ Education doctors to support/inform them
- ▶ Safeguard parental autonomy
- ▶ Taking care after decisions being made
- ▶ Organizing care from broad perspective



# Personalized or impersonal? Digitalization is also a challenge



# Literature

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