Medicines: what about the risks?
-The patient's point of view-

Anneleen Lintermans, Vlaams Patiëntenplatform

Sophie Ingels, LUSS

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- **Presentation VPP and LUSS**

- What does pharmacovigilance mean to patients?

- How to become a real actor as patient and prevent risks?
  - Patient's empowerment
  - Need for reliable, complete and understandable information

- Adverse events reporting

Vlaams Patiëntenplatform vzw

What?

- Independent platform

- 112 patient organisations

- Patients advocacy

Goal?

- Accessible care for everyone

- Active participation of patients

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LUSS
Fédération francophone d'associations des patients et de proches

LUSS is the independant francophone federation of the patients' and relatives' associations.

LUSS is currently federating more than 90 associations.

She is working for an open access to the health and care services of quality for everyone and highlights the active participation of patients to health politics.

3 MAIN POINTS:

- SUPPORT ASSOCIATIONS
    Meet the associations' requirements allowing them to ensure their missions.

- TRAIN AND INFORM
    Develop the analysis and comprehension of health politics.

- PARTICIPATE TO HEALTH POLITICS
    LUSS is reconized as an officiel representant of the patients'point of view and is currently assuming 19 mandates.

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What does pharmacovigilance mean to patients?

- Risks associated with medicines = weak knowledge

- … Consequences of that ignorance:

  - « It is a natural medication, it is safe! »

  - « I take very few medicines, I don't risk anything !»

  - « A relative takes this medicine. It is helping him, therefore it will help me! »

  - Confusion about the « medicine status »:
    - The real stakes of medicines are unclear
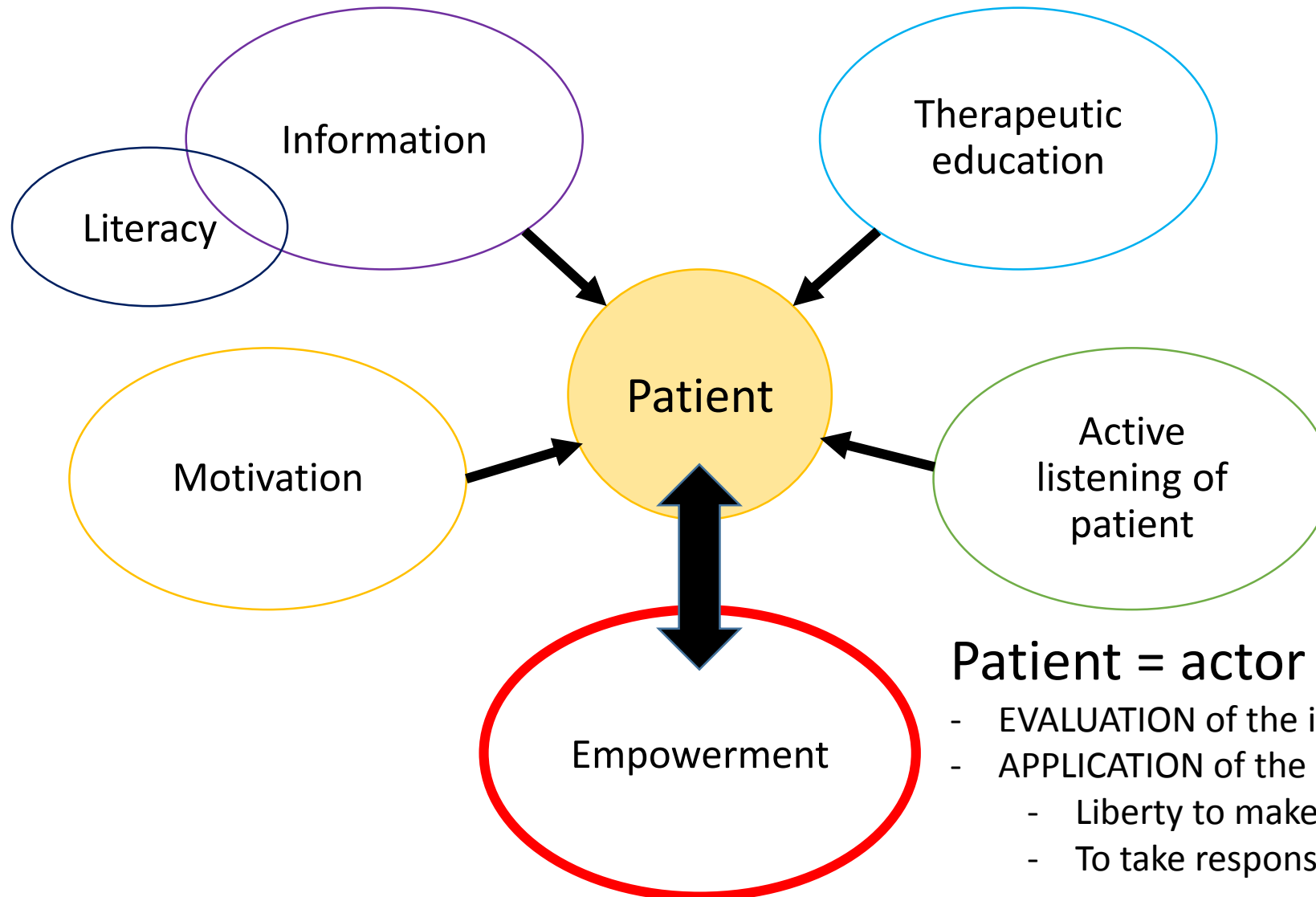   - Confusion with food supplements

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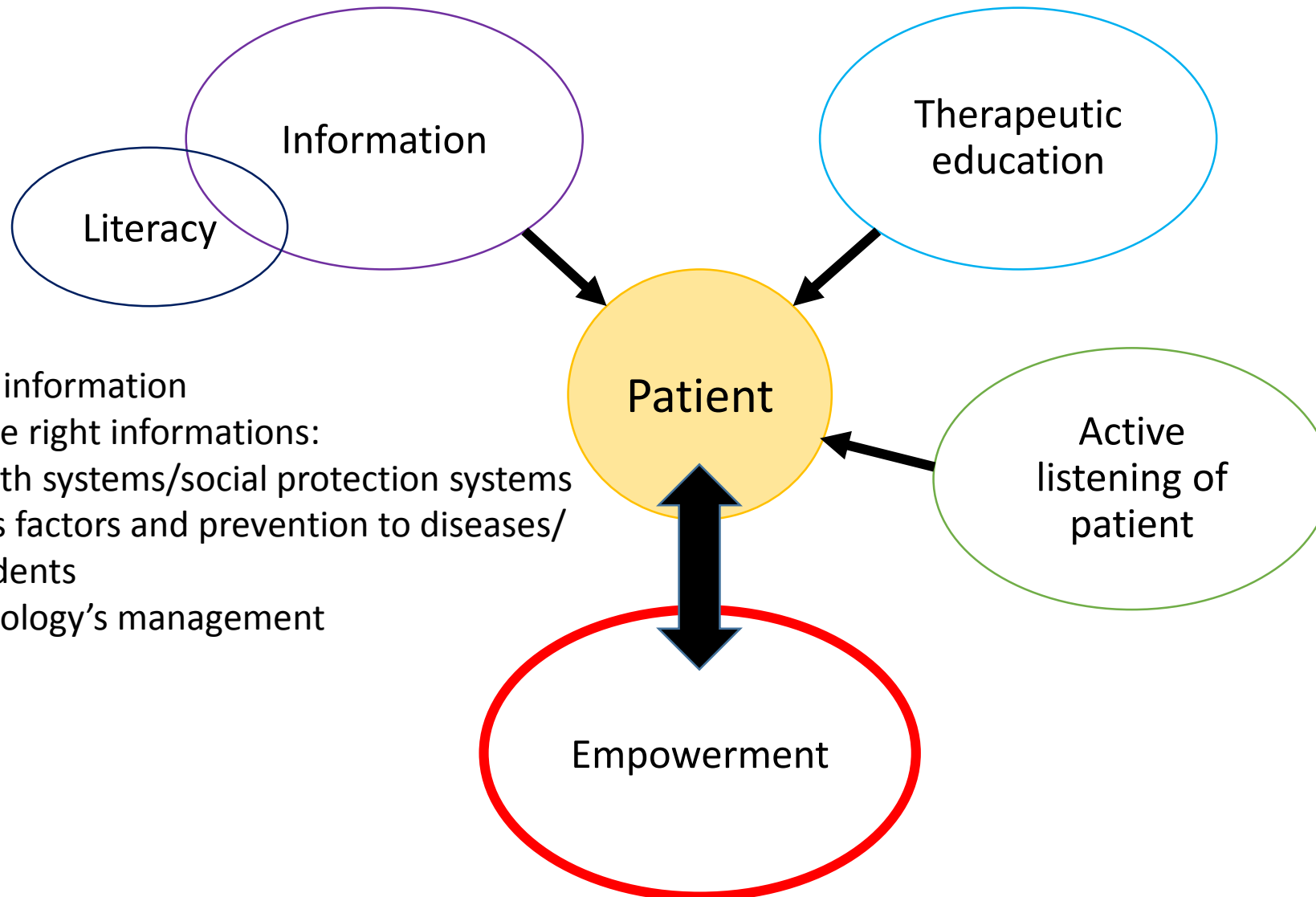# How to become a real actor as patient and prevent risks?

Patient = actor of his disease
- EVALUATION of the information
- APPLICATION of the information
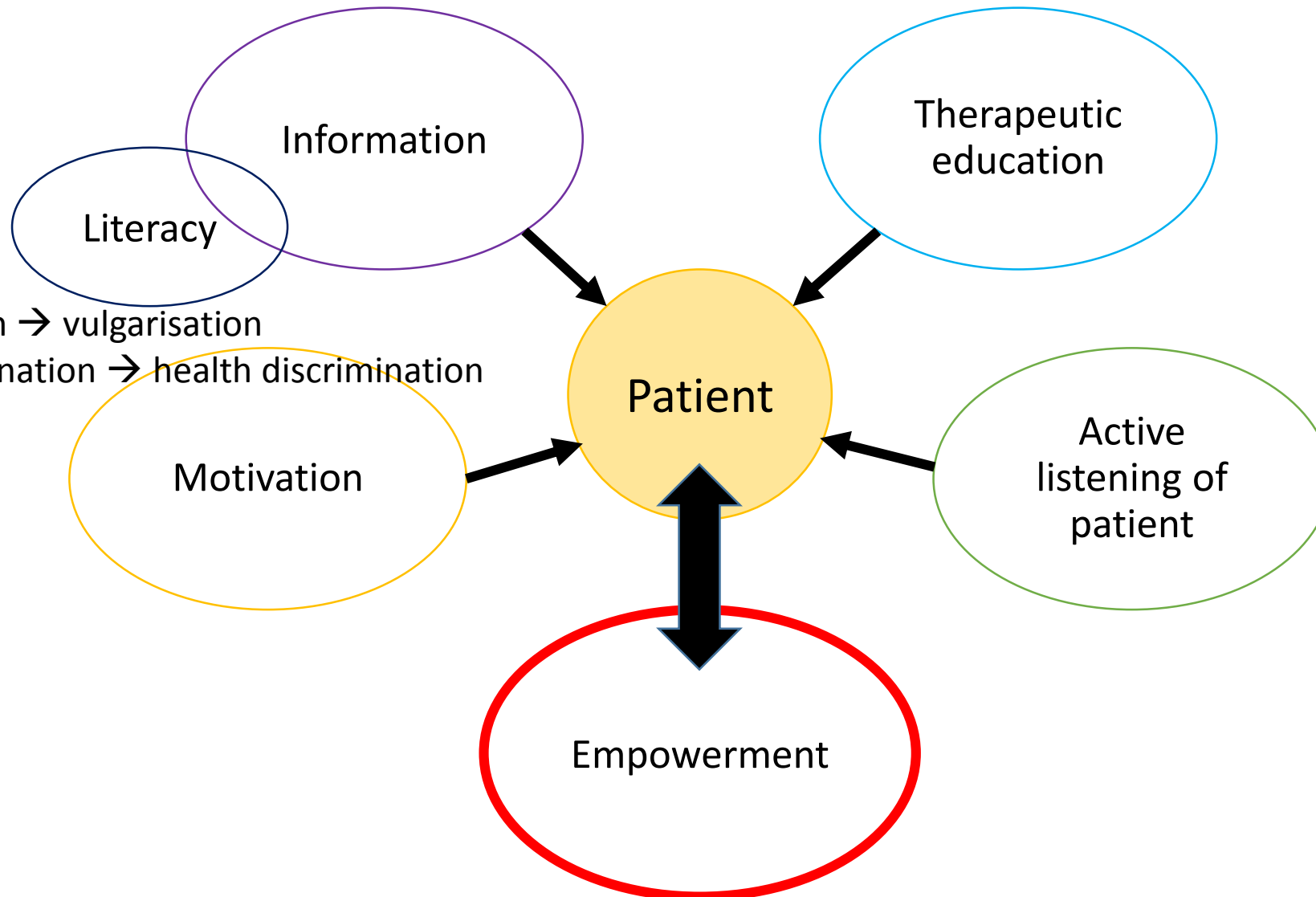 - Liberty to make choices/decisions
  - To take responsability

How to become a real actor as patient and prevent risks?

Information

Literacy

Therapeutic education

Patient

Active listening of patient

ACCESSING :
- Research information
- Obtain the right informations:
    - Health systems/social protection systems
    - Risks factors and prevention to diseases/ accidents
    - Pathology's management
    - …

Empowerment

How to become a real actor as patient and prevent risks?

- Medical jargon → vulgarisation
- Social discrimination → health discrimination

How to become a real actor as patient and prevent risks?

- Information: Some concrete examples from a patient's perspective

  - Capacity to make a distinction between medicines <-> food supplements
    - Unclear:
      - Cfr media advertisements!
      - Pharmacy: supermarket
        - too much choices
        - Mix of paraphamacy + medicines + food supplements → contributes to confusion
    - Clear: logos « This is a medicine », « This is a food supplement », …

  - « Two act consultation »
    - 1st consultation: Diagnostic information → patient doesn't pay any attention to what is following
    - 2nd consultation: patient is more open to manage himself information

© Can Stock Photo

How to become a real actor as patient and prevent risks?

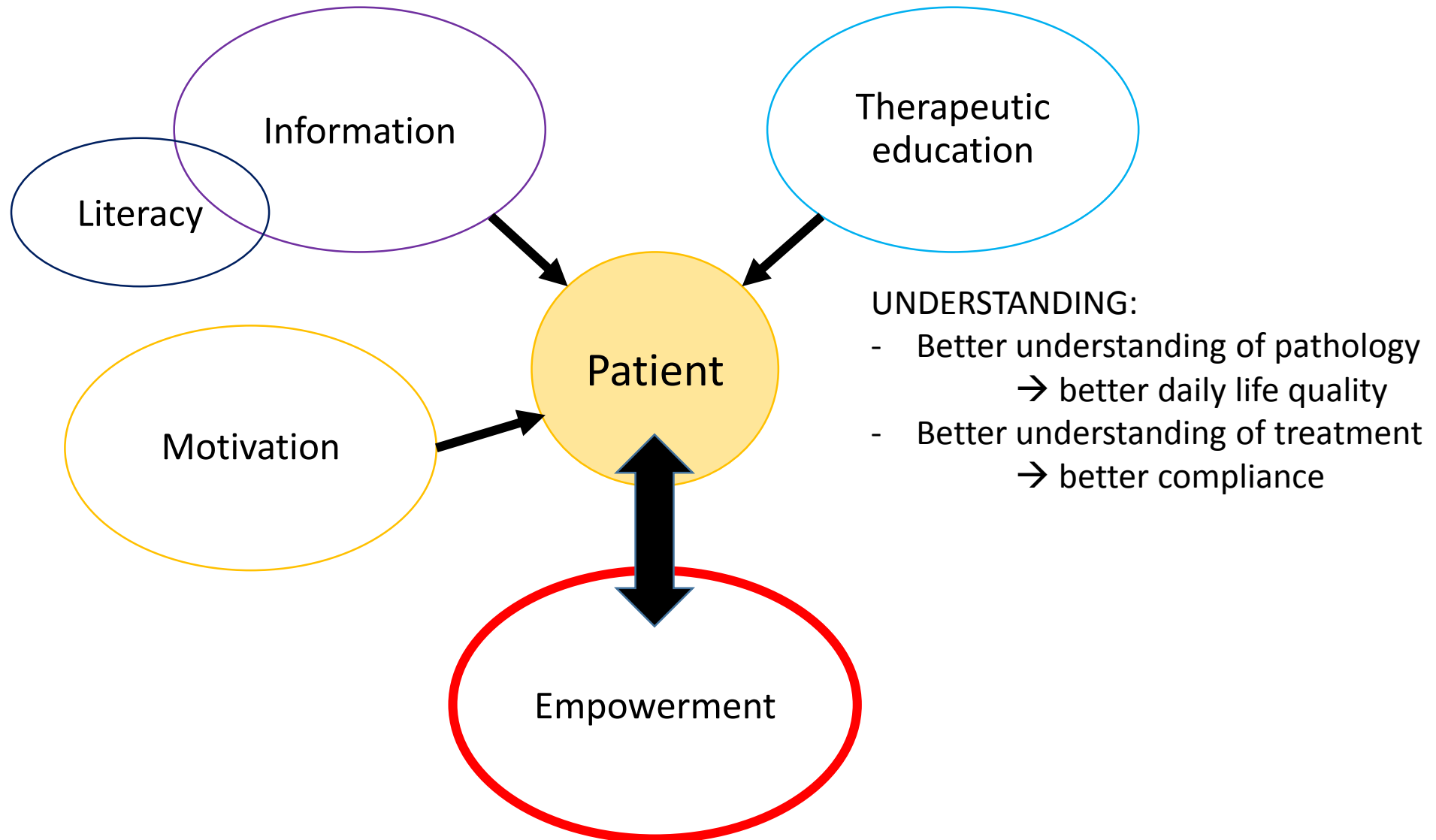- Information: Some concrete examples from a patient's perspective

Institutions network
- Who is doing what?
  - INAMI
  - Mutualities
  - AFMPS/FAGG
  - Politics
  - …
  → have a better global view of my health's actors

How to become a real actor as patient and prevent risks?

Literacy

Information

Therapeutic education

Motivation

Patient

Empowerment

UNDERSTANDING:
- Better understanding of pathology
    → better daily life quality
- Better understanding of treatment
    → better compliance

How to become a real actor as patient and prevent risks?

- Therapeutic education: Some concrete examples from a patient's perspective

  - Enable patients to have a clear and accessible information
    on the optimal use of medicines:
    - Pictures, cartoons
    - Web links with tutorials

  - Get spontaneous information about the benefit/risk ratio of the treatment
    - Patient = actor of his disease → to make considered choices concerning the treatment

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How to become a real actor as patient and prevent risks?

Patient leaflet

- Improve readability and comprehensability
    - Most important information at the top
    - Larger font & use of colour
    - Visual aids e.g. Valproate
    - Avoid difficult medical terms
    - More comprehensive description of AEs
    - Turned black triangle: campaign for the public

- Additional leaflet with more personalized information?

How to become a real actor as patient and prevent risks?

- Advertising
  - Irrational > rational drug use
  - misleading information
  - Influences prescribing behaviour physicians

- Abundance of information on the internet
  - difficult to find correct and reliable information

How to become a real actor as patient and prevent risks?

- Therapeutic advantage compared to other medicines?
- Effectiveness (benefit/risk ratio)
- Adverse events? What is known?
- Alternatives (also non-medical interventions)
- Experiences
- Health tips

> *health literacy*

How to become a real actor as patient and prevent risks?

Reliable information sources

- ➢ sensibilisation to the public
- ➢ more transparancy and direct communication

  - FAMHP
    - more patient-friendly (eg. interactive leaflets)
    - access to registration reports medicines
    - access to pharmacovigilance data: adjustments leaflets, risk/benefit ratio, suspension

  - Eudravigilance
    - more patient-friendly
    - content + causality of reports

  - gezondheid en wetenschap (CEBAM)

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- **Adverse events reporting**

Reporting of adverse drug reactions

- Healthcare professionals

  insufficient reporting

- Patients

  adds valuable information

  - earlier signal detection
  - actual experience
  - enhance the capture of impact on QoL
  - unknown or other AEs

health literacy

Reporting of adverse drug reactions

Improvement patient reporting

- Sensibilisation of pharmacovigilance

- Reporting form
  - Online reporting
  - Patient-specific form
  - Feedback regarding use and QoL
  - Other media tools

- Transparancy

- Direct reporting by patients in clinical trials (phase II)

More information

Vlaams Patiëntenplatform
Groenveldstraat 15
3001 Heverlee
Tel: 016 23 05 26

www.vlaamspatientenplatform.be

info@vlaamspatientenplatform.be

LUSS
Avenue Sergent Vrithoff 123
5000 Namur
Tel: 081 56 67 70

www.luss.be
luss@luss.be