

The W. W. W. W. of partnership

(Why ? Who ? When ? What ?)

Fondation Paralysie Cérébrale Prize Lecture



Centre of Excellence on Partnership
with Patients and the Public

SCHOOL • LAB • NETWORK



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Disclaimers

No financial contribution from private companies (AB, AC, ERB)

But : we are here to show that a lot of other conflict of interest can be better addressed through partnership and constructive conflictuality than total war.

The CEPPP : patients and health professionals in a **public institution** offering a **methodological support** to leaders of patient engagement projects in :

- Healthcare and services ;
- Healthcare management ;
- Healthcare teaching ;
- Health research.

CEPPP build and sustain the **practice** and the **science** of partnering with patients, professionals and the public.

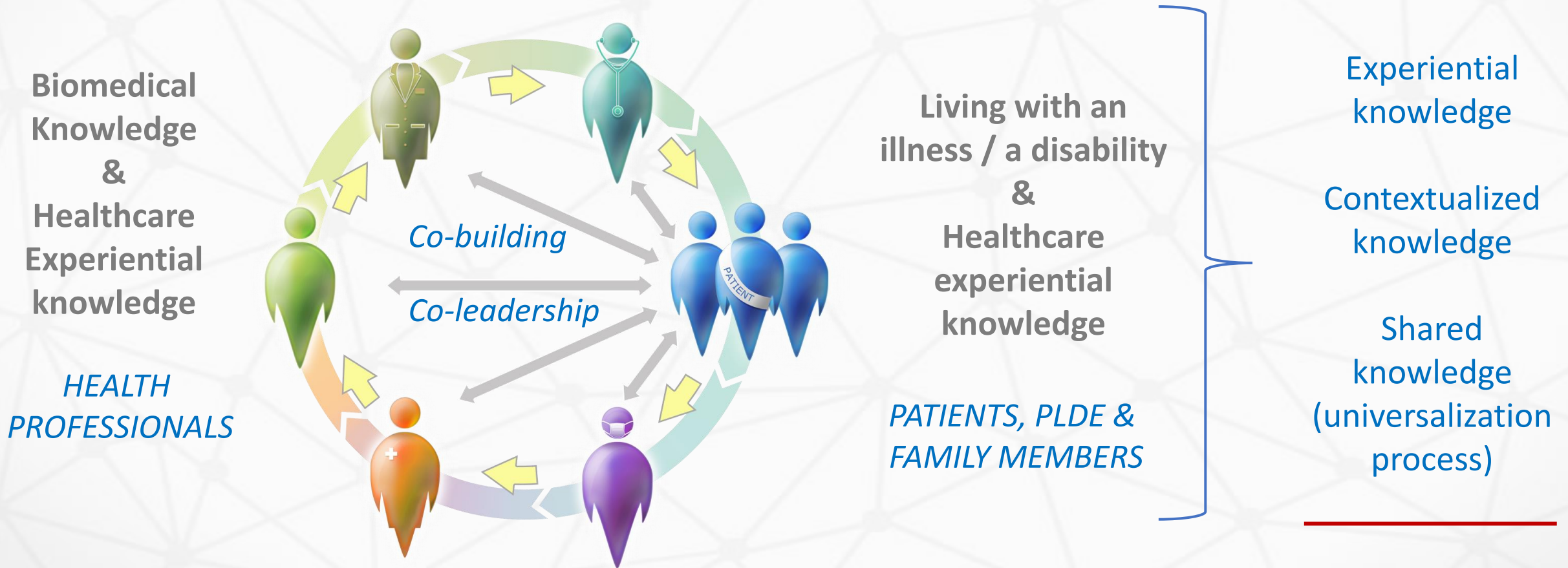




What ?

Move to partnership, to an active cooperation in care.

The « Montreal model »



Acknowledged complementarity and interdependence

Inspired by Olivia Gross's work

Why ?

50% + of western countries' populations live with at least one chronic illness.

50% to 70 % of patients suffering from chronic illnesses are considered non-compliant.

80% of patients search online for health-related information.

Burn-out and **search for meaning** for a significant proportion of healthcare professionals.

With an healthcare system focus on emergencies and acute care but also a curative perspective.

« **A key actor is missing in the innovation process of our struggling health system.** »

- Dean of the faculty of medicine at Université de Montréal (2010)



« MTL model » education model : postulates

Build a common representation of healthcare ecosystem : systemic perspective on formal and informal actors and systems of care to reveal the interdependence of actions in care.

Acknowledge the necessity of an active work on experiential knowledge : to be able to contribute for others.

Adopt a socio-constructive and comprehensive perspective on behaviors to allow partnership : building institutional settings and environments that value cooperative behaviors rather than using only ethical injunctions for professionals.

Competency-based : to recruit patient-as-partners (meso & macro).



What ?

The person living within a disabling environment (PLDE) and their family member(s) of today is/are :

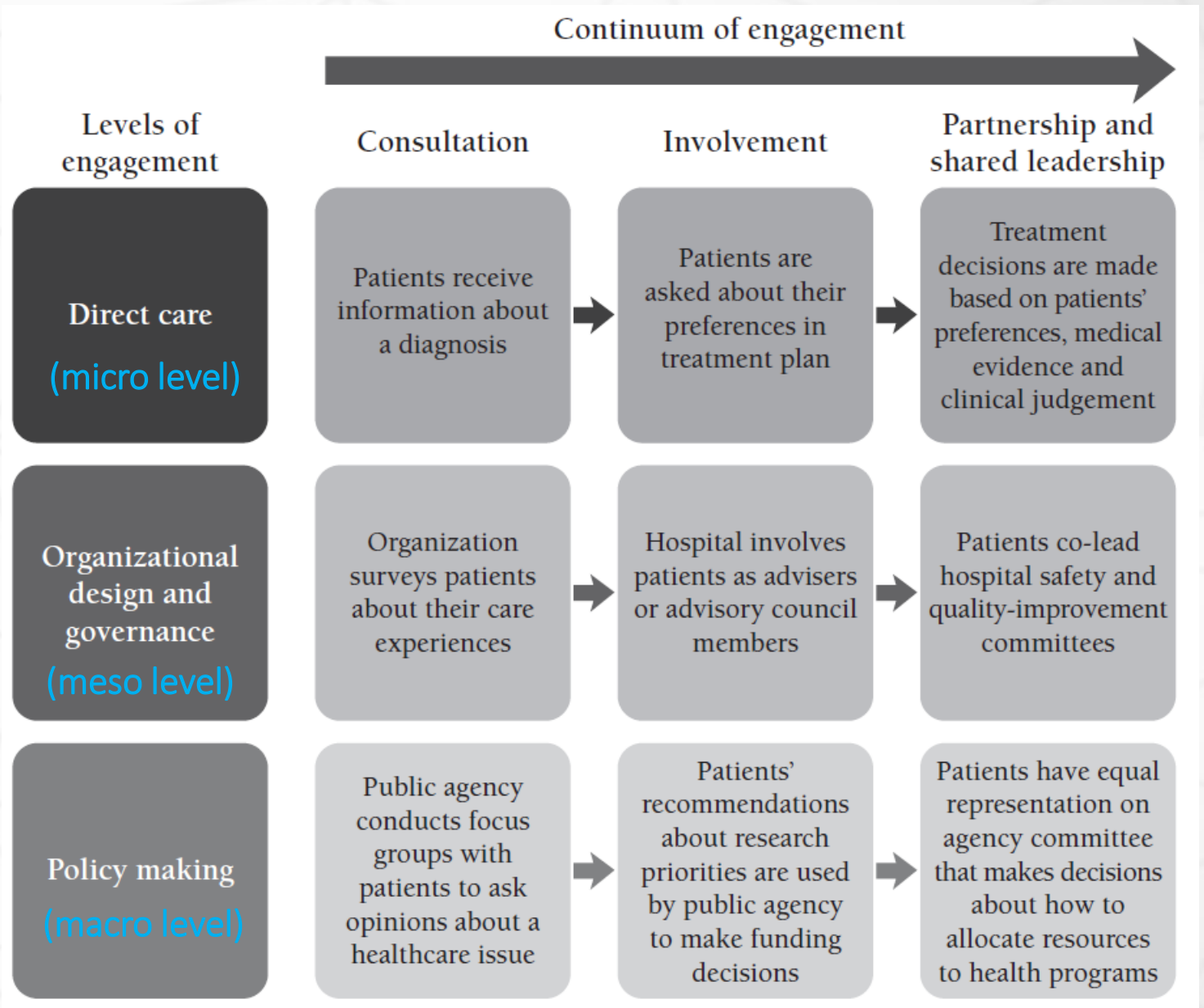
- « ... taken care of... » (patient-centered care)
- Lacking support, space and time to fully understand and make the choices HP ask them.
- Challenging healthcare professionals with new information and questions.
- Do not fully grasp how new healthcare technologies are/will impact their health.
- Not often involved in the development of healthcare's future services and tools.

The PLDE and FM(s) of tomorrow:

- Recognized as a full actor of care.
- Owns their health information.
- Problematize with HP, in relation to their life project, to identify together the questions.
- Better informed and skilled to use information.
- Connected (self-monitoring and management).
- Recognized as legitimate (health democracy) and epistemologically relevant to contribute to health care, research and teaching.

What ?

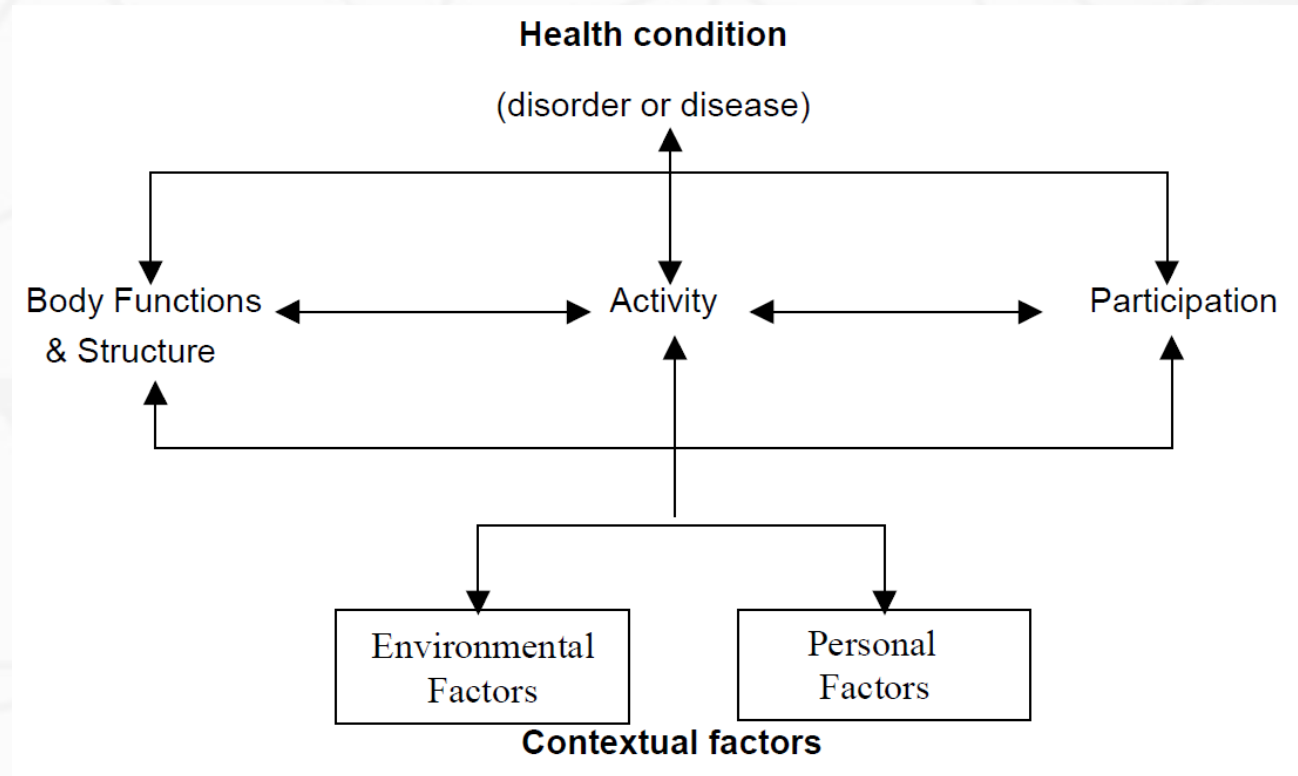
The continuum (degree) + level of engagement.



Why ?

If improvement of participation* is the goal, then :

- The scene is set for partnership (multi-entry scheme).
- The user is at the forefront as he (and his family for a child) are the best judge of his involvement in life situations. **



* WHO 2001; *International classification of functioning, disability and health*

** *Definition of participation as explained in the guide on ICF by WHO*

Who ?

Each person who is **thinking and acting** to take care of himself or someone else = **everybody**.

But its required to make a distinction between :

Patient / PLDE partner of his own care

Family member partner of the care of their child

and

Patient/PLDE/FM-as-teacher

.....**as-resource** (in governance, in quality & security improvement, etc.)

.....**as-researcher**

.....**cooperating with a team of health professionals for the care of others.**



We **ALL** are actors of care,
for ourselves and/or for
someone else.





Dialogue

Elisabet and Alain

How to build conditions for partnership in care ?

**What we learned through experimentations in France and in Canada
and hearing from Elisabet and Alain**

Resources available

- Professionals, PLDE and family members who act (individually or within organizations) as partners in care and with who you can :
 - form **a community of practice** ;
 - be **supported in the implementation** of partnership conditions / capacities (in care, in research, in teaching, etc.) and/or partnership projects ;
 - benefit from partnership experimentations feedback, etc.
- Numerous books, podcasts, videos, etc. on partnership in care.
- University programs on patient partnership (USA, Canada, France, etc.).



What to leave with



Whose needs am I answering ?



Within which temporality am I ? (cure, care,...)



Is it empowering ?



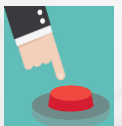
a constant questioning and vigilance
when we are asking ourselves “Where
are we heading ?”



Raise your consciousness about the desires and fears that determined the way you act / react in specific healthcare situations (to raise awareness of their effects).



Facilitate the explicitation of experiential knowledge of children and family members to be able to better mobilising it through care.



Observe and evaluate the presence of those empowering and partnering conditions in your relations of care.





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Let's cooperate !

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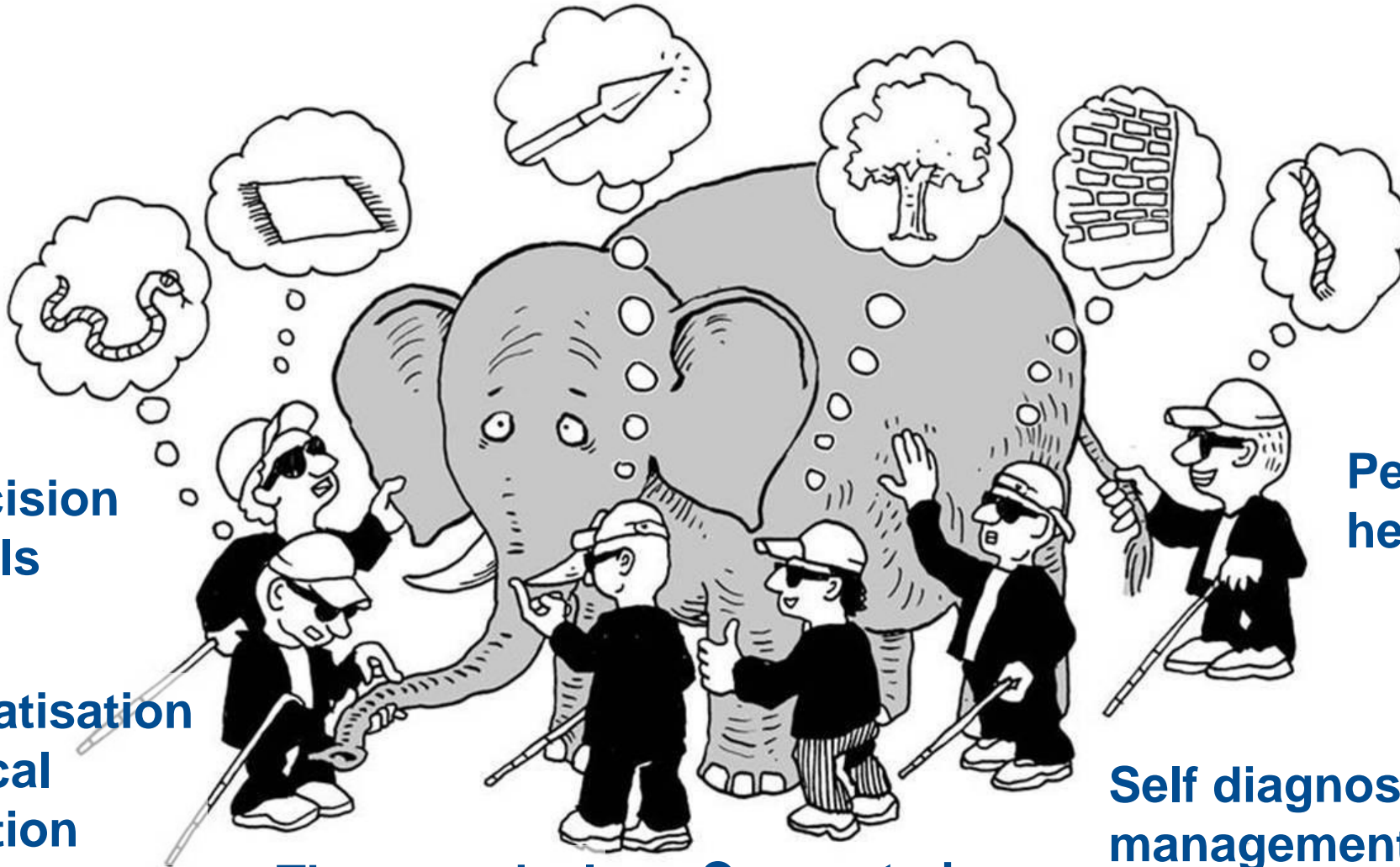
Questions to keep in mind

Partnership in care

- Even with the right intentions, Am I, as a professional / Am I, as a family member / Are we, as partners in care, heading where we should to meet the needs and expectations of the children ?
- How to disintricate intentions, decisions and ways to reach results, according to a variety of point of views ?
- Who should advocate for what ?
- Am I / Are we creating the conditions through which he/she is capable of determining and expressing his/her life project, his/her quality of life priorities and partnering with health actors to integrate those ?



It's time to pool of efforts



Shared-decision making tools

Personalised healthcare

Democratisation of medical information

Self diagnostic / management tools

Therapeutical education

Connected tools



« MTL model » education model : postulates

Competency-based : examples of patient recruitment criteria (meso & macro)

- Demonstrates high level of self-management for his care.
- Reached phase of acceptance of his health problem.
- Can generalize his own experience to other context of care.
- Demonstrate reflective attitude by concrete actions.
- Wants to be involved in training of his peers, students or healthcare providers.

