



Centre of Excellence on Partnership  
with Patients and the Public

SCHOOL • LAB • NETWORK



Partnership School

## Module 101 – Fundamentals of Patient Partnership

Engaging experiential knowledge of living with illness  
in order to co-build the health ecosystem

#PatientPartner

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and the public (CEPPP)

in collaboration with the Collaboration and Patient Partnership Unit (University of Montreal)

# AGENDA

1. What do we mean by “partnership with patients and the public”?
2. A new model of care for a new environment
3. Some basic principles
4. Our approach to social transformation



# I. What do we mean by “partnership with patients and the public”?



## (SI) PATIENT ENGAGEMENT: A BURGEONING FIELD

- Definition from the website of the Canada Institutes for Health Research (CIHR):
  - “Patient engagement occurs when patients meaningfully and actively collaborate in the governance, priority setting, and conduct of research, as well as in summarizing, distributing, sharing, and applying its resulting knowledge.” (<http://www.cihr-irsc.gc.ca/e/45851.html>, viewed May 17, 2017)

## (S2) PATIENT PARTNERSHIP: GOING ONE STEP FURTHER

- “The patient-as-partner approach is rooted in such initiatives yet takes a significant step forward into the realm of true partnership in care, where the patient is considered a caregiver of herself and, as such, a genuine member of the treatment team, endowed with competencies and limitations just like any other member of the team. This approach aims to develop the patient’s competency in care instead of merely taking into account her personal experience.” (Karazivan et al., 2015)

## (S3) CASE STUDIES: PARTNERSHIPS OR NOT?

### Case 1: Isabelle

- Meets separately with the health professionals caring for her.
- The professionals meet to discuss her health status, without her being present.
- Her physician decides which medication she should take, the dosage and the route of administration.

### Case 2: Sylvie

- Meets all the health professionals on her team at the same time.
- Is actively involved as a member of the team as it prepares an intervention plan.
- Whenever the health professionals meet, she or a family caregiver she has designated is present.
- With the help of her physician, she makes a selection from among the proposed medications and treatments.





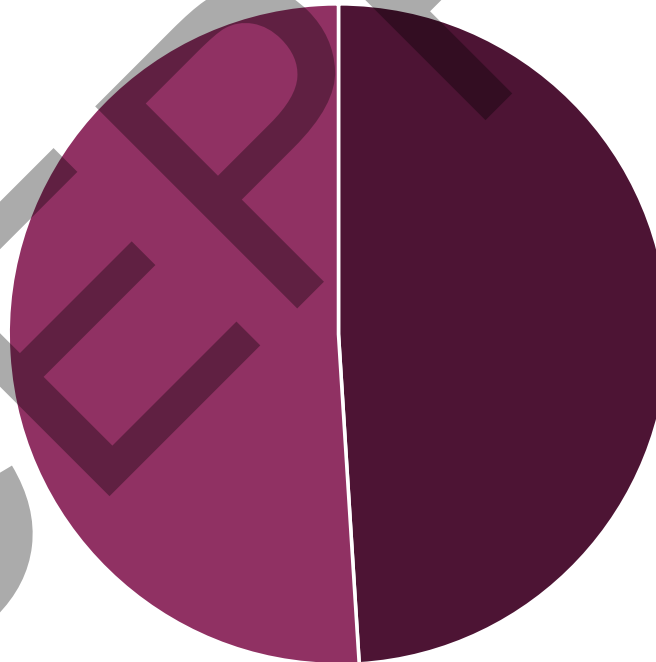
## **2. A new model of care for a new environment**



## (S4) THE INCREASINGLY CHRONIC NATURE OF ILLNESS

- Over 15 million Canadians live with chronic illnesses (Statistics Canada, 2012).

- Personnes atteintes de maladies chroniques
- Personnes non atteintes de maladie chronique



49%



## (S5) DIFFERENCES BETWEEN ACUTE CARE AND CHRONIC CARE

### Acute care

- We treat a person's body.
- We focus on healing, on the elimination of illness.
- The patient follows her prescription.

### Chronic care

- We treat the entire person, with her history, family and friends, etc.
- We try different approaches and treatments to achieve a better quality of life with the illness.
- The patient develops an experience of living with the illness and becomes her own caregiver.

## (S5.5) CHRONIC ILLNESS: A FULL-TIME JOB

- 8760 hours/year
- Average consultation time : 5 hours/year (0.06%) (Coulter, 2011)



## (S6) HEMOPHILIA: AN EXAMPLE OF HOW CARE HAS CHANGED (1/2)

### ■ Case:

- Hemophilia is a serious chronic illness that may result in death if left untreated. According to the Canadian Hemophilia Registry, there are almost 4,000 hemophiliacs in Canada. The treatment, which consists of an intravenous infusion, allows hemophiliacs to live almost “normally” by considerably increasing their life expectancy and improving their quality of life. However, the treatment requires at least one infusion per week. Some training is required to learn how to administer an intravenous infusion, and this training is usually given by a health professional (often a nurse).

### ■ Question:

- How do you think hematology care teams manage to provide appropriate training to the entire Canadian hemophiliac population?

## (S7) HEMOPHILIA: AN EXAMPLE OF HOW CARE HAS CHANGED (2/2)

### ■ Answer:

- Starting at a very young age, hemophiliac patients and their families are gradually equipped with the knowledge they require to become their own caregivers and full-fledged members of their care team:
  - Making self-diagnoses of internal bleeding
  - Managing and ordering of medications
  - Self-infusing
  - Coordinating care with the care team (nurse, physiotherapist, hematologist, etc.)
  - Managing the illness in partnership with health professionals for the duration of the patient partner's life.

## (S8) THE RISING LEVEL OF MEDICAL LITERACY

- The level of medical literacy in the general public has been rising due to:
  - The democratization of information (information and communication technologies);
  - The level of education in the general population, which continues to rise.
    - from 1998 to 2009, the percentage of university graduates rose from **21%** to **30%** in all of the 34 member countries of the Organisation for Economic Co-operation and Development (OECD), plus Brazil and Russia (OECD, 2011).

## (S9) LOOKING FOR HEALTH INFORMATION ONLINE

- The 2010 Bupa Health Pulse study was conducted in 12 countries: the UK, Australia, Germany, the USA, France, Spain, Italy, Russia, Brazil, China, Mexico and India.
  - In each country, at least **60%** of respondents said that they used the Internet to obtain health information.
- Of this group:
  - **68%** used the Internet to obtain information on medications
  - **46%** used the Internet to self-diagnose (McDaid & Park, 2010)
- Some health professionals see problems in this kind of online research (Thoër, 2013).

## (SI0) THE SOLUTION: MAKE THE MOST OF THIS MOMENTUM

- How should we respond to this new reality?
  - Solution: Make the most of patients' clear desire to become partners in their care and services, by developing partnering relationships with them.

## (S11) NONCOMPLIANCE WITH TREATMENT

- Problem: Levels of compliance with treatment are low.
- The rate of noncompliance with treatment in the developed countries is:

➤ **50%** (Jimmy & Jose, 2011)



## (S12) THE CONSEQUENCES OF NONCOMPLIANCE

- Consequences:
  - Health of patients may worsen
  - Overcrowding in the health system's primary care services
  - Higher health care costs.
    - In the U.S., 3% to 10% of annual spending on health is considered “wasted” due to noncompliance with treatment, representing \$100 billion to \$300 billion per year (Luga & McGuire, 2014).



## (S16) PATIENT PARTNERSHIP AND THE ISSUE OF COMPLIANCE

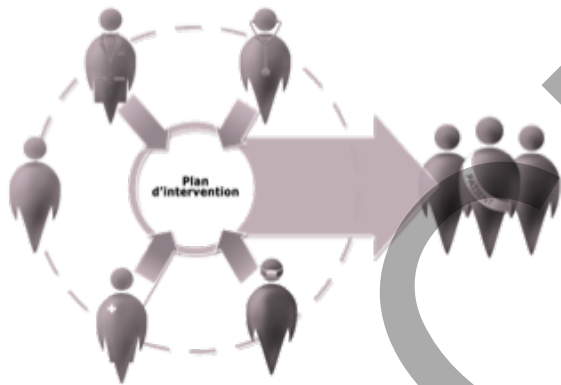
### 1. Saving time

- Professionals have too many patients.
- Partnering with patients takes more time.
- However, working in partnership will reduce the rate of noncompliance

### 2. The obese patient

- Usual approach: Meal plan based solely on Canada's Food Guide (the odds of compliance are poor)
- A plan developed in partnership: the patient's family situation and life plan are fully integrated (improves the odds of compliance)

# (S13) FROM BUILDING “FOR” TO BUILDING “WITH”



**PATERNALISM**

**PATIENT-CENTERED  
APPROACH**



**PATIENT PARTNERSHIP**



### 3. Some basic concepts



## (S15) PARTNERSHIP BASICS

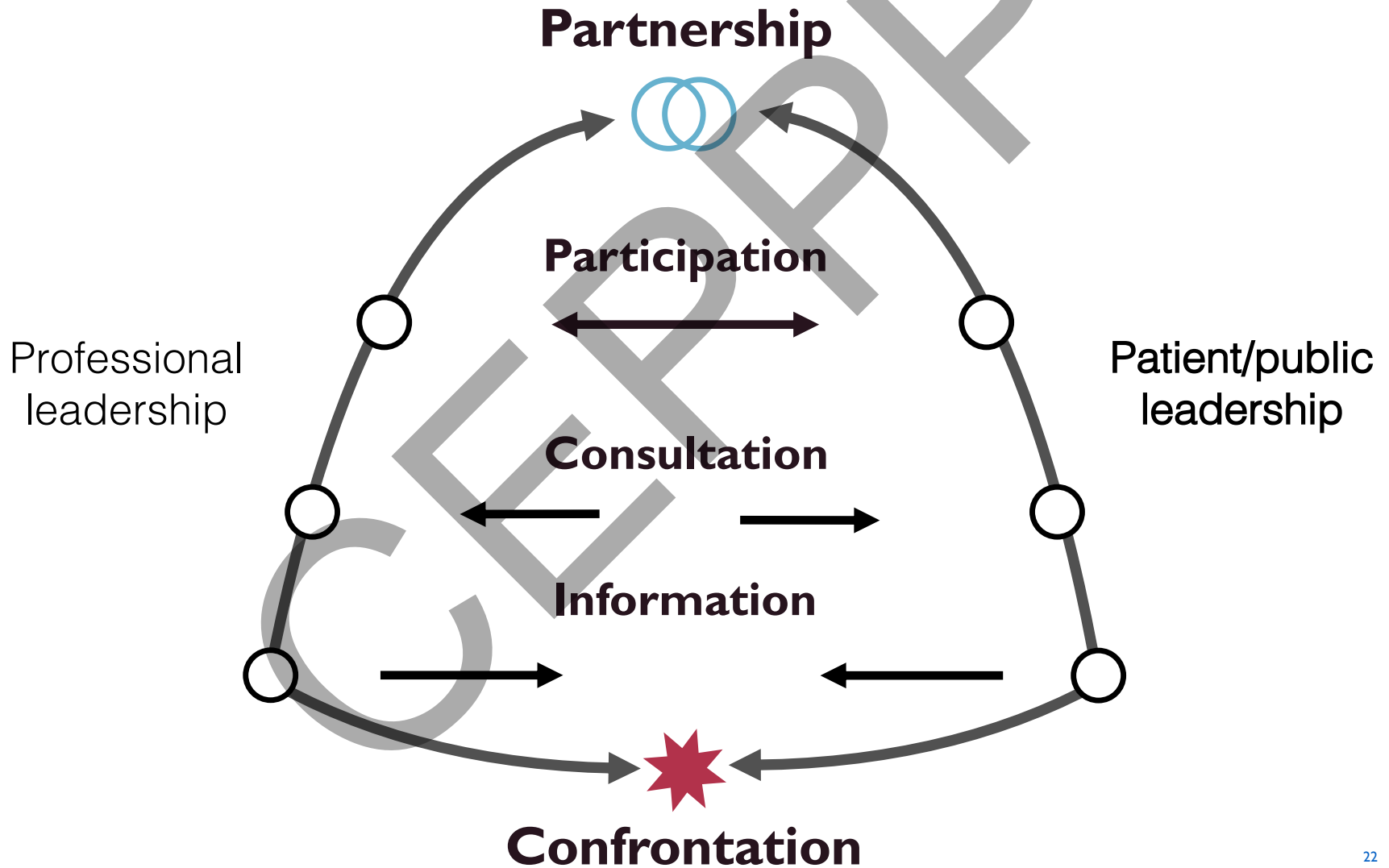
**PROFESSIONALS  
AND CAREGIVERS**  
Experts in illness



**PATIENTS**  
Experts in living  
with illness

- **Recognition of the complementarity of their expertise**
- **Recognition of their interdependence**

# (S17) THE CONTINUUM OF PATIENT ENGAGEMENT



## (S18) DEFINITION OF CO-BUILDING

A method of **collaboration** that encourages the emergence of a **shared basis of understanding** between patient partners, family members, researchers and health professionals.

Co-building is based on the **complementarity of experiential knowledge**, in order to develop and implement solutions that will be subject to a **consensus**, targeting **co-leadership** and **shared decision-making**.

## (S19) A COMPLEMENTARY CONTRIBUTION

|                      | <b>Co-building</b>  | <b>Representation and advocacy</b>  |
|----------------------|---|---|
| Source of knowledge  | <b>EXPERIENTIAL</b><br>Significant experience of health care and services | <b>TECHNICAL</b><br>Law, public policies and health services organization |
| Source of legitimacy | Knowledge derived from real, concrete experience                          | Represents patients' interests  |
| Contributions        | Co-creating and fostering shared decision-making                          | Positioning, defending, debating  |
| Objective            | To co-build improved health care and services                             | To have patients' rights recognized                                       |
| Strategy             | Build from within organizations   | Influence organizations from the outside                                  |

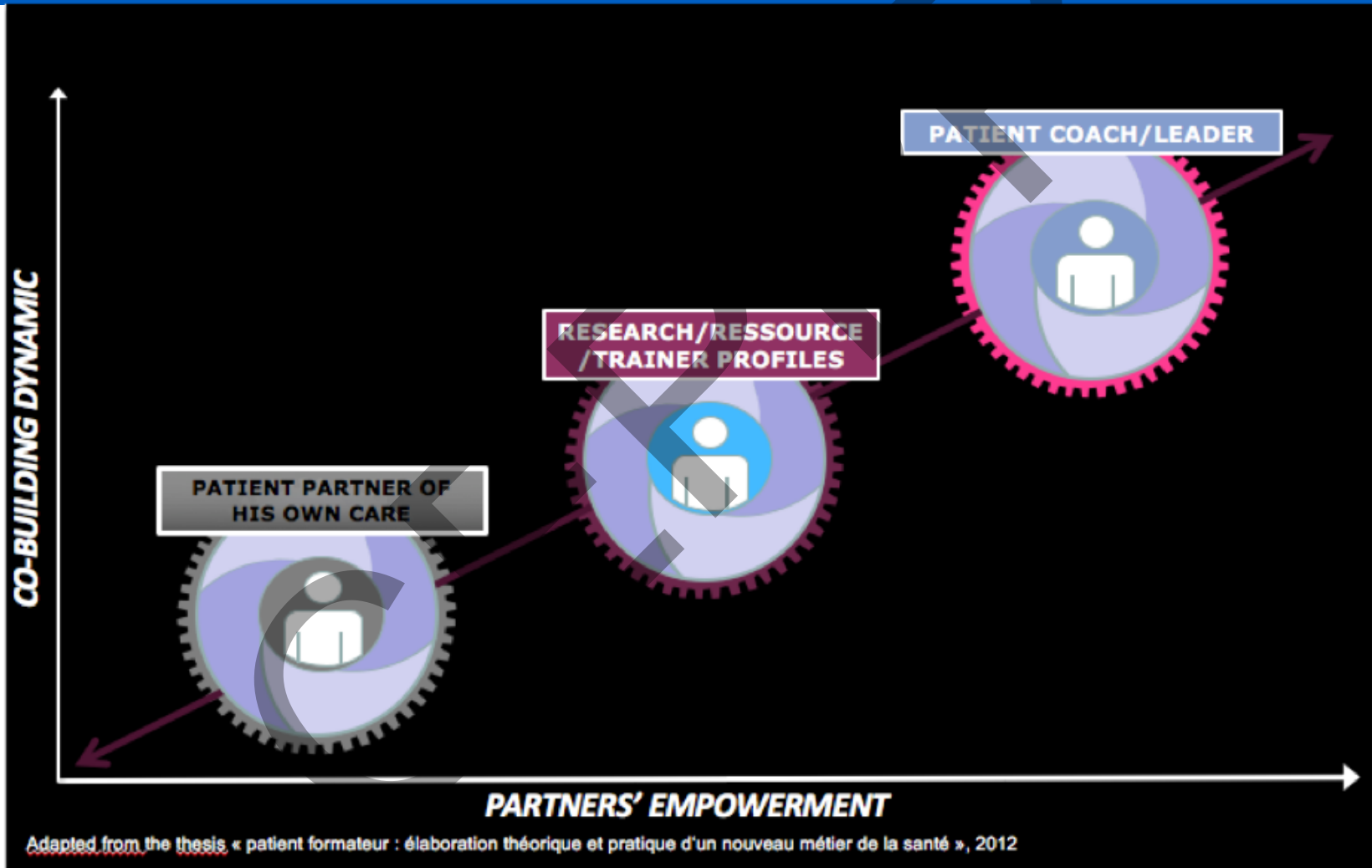


(SI.2)

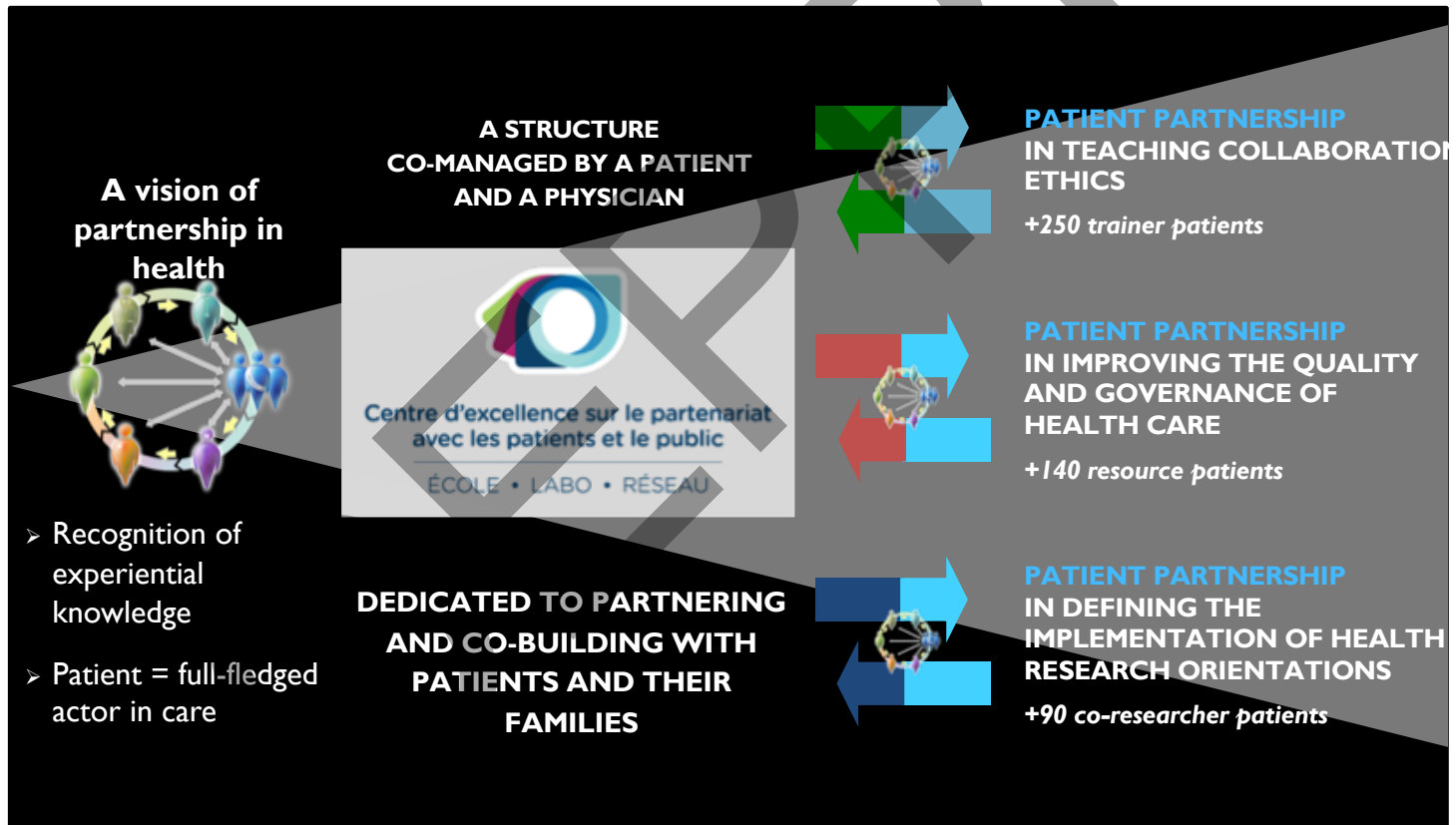
## 4. Our approach to social transformation



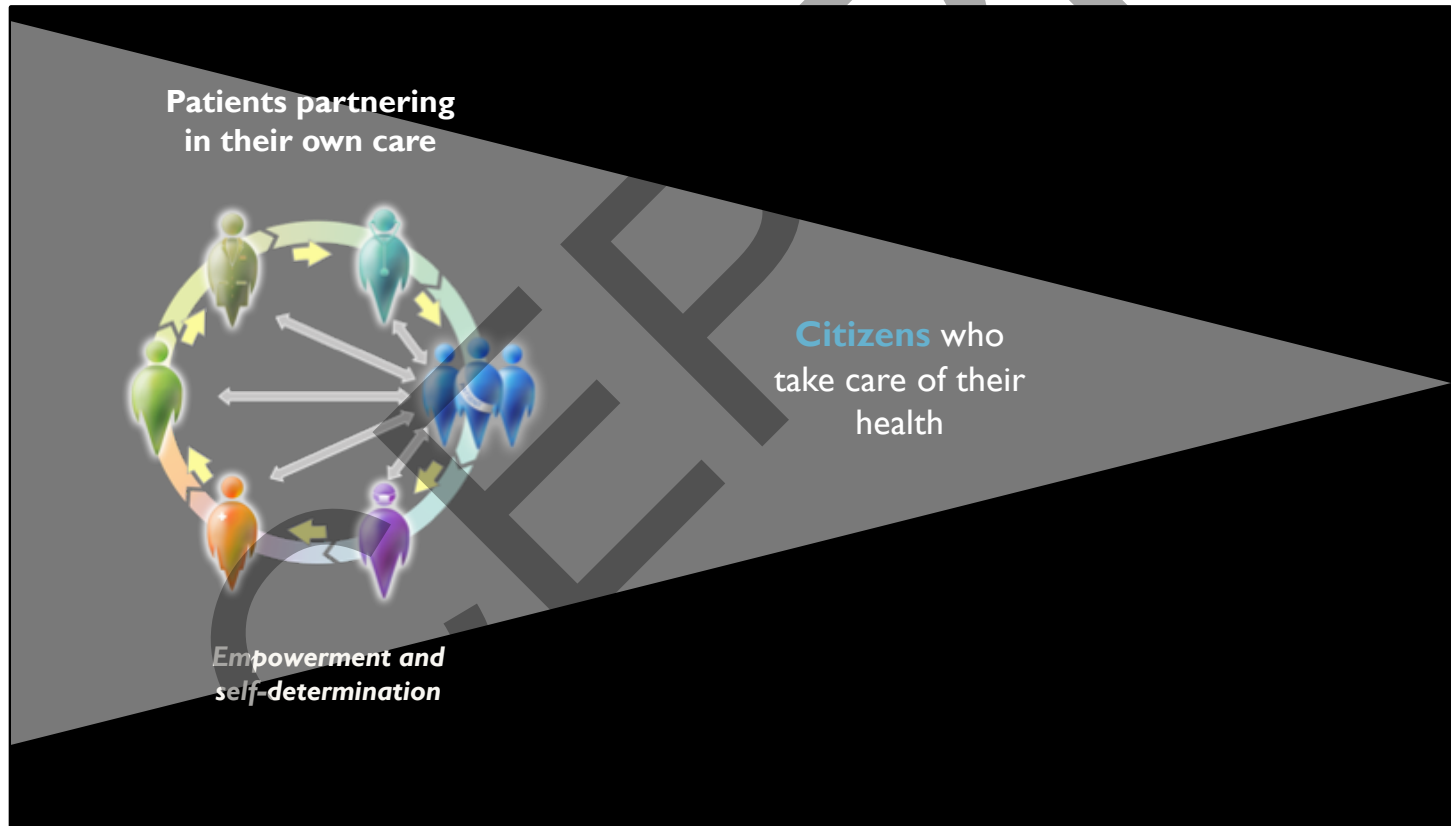
# (D20) THE TAXONOMY OF PATIENT COMPETENCIES



# (S21) WORKING IN PARTNERSHIP AT ALL LEVELS



## (S22) WHY PARTNER WITH PATIENTS?



# (S23) A SYSTEMIC APPROACH TO TRANSFORMATION

Université   
de Montréal

Initial and ongoing training  
of health professionals

Santé  
et Services sociaux  
Québec 

Public policies



Academic  
publications



Accreditation of health  
facilities

An ethics of care

  
IRSC CIHR  
Health research  
funds

# COURSE REVIEW - QUESTIONS

- 1. What do we mean by “partnership with patients and the public”?**
  - a. Definition of patient partnership: based on recognition of patients’ experiential knowledge and skills.
  
- 2. A new model of care for a new environment**
  - a. Increasingly chronic nature of illness
  - b. Rising level of medical literacy
  - c. Noncompliance with treatment
  - d. Changing models of care (paternalist – patient-centered approach – partnership)





## **1. Some basic concepts**

- a. Recognize the complementarity of knowledge and expertise
- b. The patient engagement continuum (information – consultation – participation – partnership)
- c. Differences between co-building and representation/advocacy

## **2. Our approach to social transformation**

- a. Taxonomy of patient competencies
- b. CEPPP activities and mission
- c. CEPPP's approach to systemic transformation



## KINTSUKUROI

Ancient Japanese art of fixing broken pottery with lacquer containing powdered gold in order to embrace the object's history and give it value, rather than trying to hide its "defects".



# INITIAL AND ONGOING TRAINING IN HEALTH PARTNERING



Partnership School



ceppp.ca

