Centre of Excellence on Partnership with Patients and the Public

SCHOOL • LAB • NETWORK

École du partenariat en santé

Foundations of patient partnership in health

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1. What is *patient partnership*?

WHAT IS PATIENT ENGAGEMENT?

- Definition of the Canadian Institutes of Health Research:
  - “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 (i.e., the process referred to as "knowledge translation").”
    (http://www.cihr-irsc.gc.ca/e/45851.html, consulted in May 2017)

PATIENT PARTNERSHIP: GOING ONE STEP FURTHER

- “The PP approach is rooted in such [patient-centered] 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)

PARTNERSHIP OR NOT?

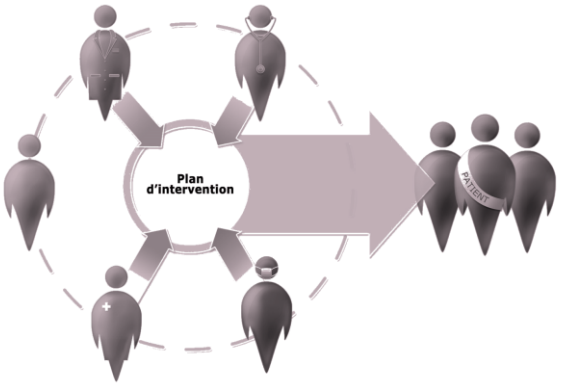
Case 1 : Isabelle	Case 2 : Martin
• Meets with each of her health professionals (HP) separately. • Builds her own intervention plan based on the recommendations of her HPs. • Her care team meet without her present, in order to discuss her case. • Her doctor decides of her treatment and she is expected to follow it responsibly.	• Meets with all of his HPs together. • Builds his intervention plan with his HPs. • When his care team meet, he (or a family member) is present. • He and his doctor decide of his treatment together.

2. A new model of care for a new context

WHY WE NEED A **NEW** MODEL OF CARE ?

- Change in population needs - from acute care to chronic care.
  - Who's the main and daily actor of care in those situations?
- A majority of patients don't properly respect their prescriptions.
  - Only bad patients?
- The majority of patients search online for health-related information.
  - A lever of collaboration?

FROM BUILDING « FOR » TO BUILDING « WITH »



PATERNALISM

PATIENT-CENTERED CARE

PARTNERSHIP OF CARE

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CASE STUDY: THE HEMOPHILIA CARE MODEL

- Case :
  - Hemophilia is a severe chronic disease which can be fatal when untreated. There are a little under 4000 hemophiliacs spread all over Canada. The treatment consists in a prophylactic (preventive) intravenous injection, given 3 times a week. This treatment greatly improves quality of life and life expectancy of patients. However, intravenous injections usually require trained hospital staff to be administered, and the day-to-day management of hemophilia requires very specific expertise from health professionals.

- Question :
  - How do hemophilia care teams deliver day-to-day management and preventive treatment to their patients, despite the obvious geographical and resource-related challenges?

HEMOPHILIA CARE : AN EXAMPLE OF PARTNERSHIP IN CARE

- Answer :
  - From a very young age, hemophilia patients and their families are trained to become caregivers and actors in their own healthcare team:
    - Self-diagnostic of bleeds and other complications
    - Ordering and management of coagulation products
    - Self-injection
    - Coordinating comprehensive care with the healthcare team (nurses, physiotherapists, hematologists, etc.)
    - Management of the disease in partnership with healthcare professionals all throughout the patient's life

3. Some core principles

CORE ASSUMPTIONS

HEALTH PROFESSIONALS

Disease experts

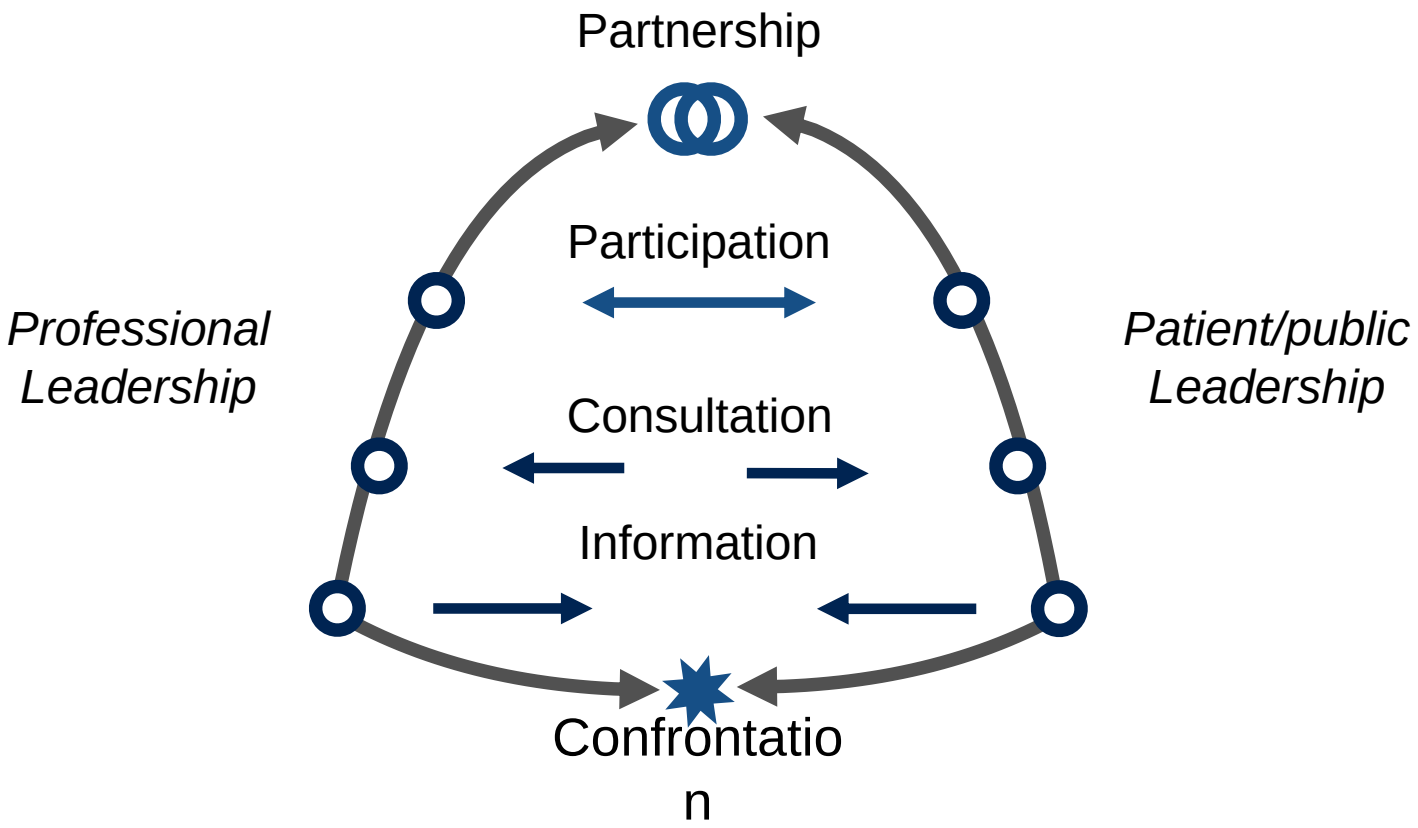
PATIENTS

Linving with an illness experts

Acknowledge complementarity

PATIENT PARTNERSHIP AT DIFFERENT DEGREES

Patient partnership is not relevant everywhere and every time.



HOW TO WORK TOGETHER - DEFINITION OF CO-BUILDING

A method of collaboration

that favours the emergence of a common base of understanding

between patients, family members, caregivers, researchers and health care providers.

It is founded on the sharing of complementary experiential-based knowledge

in order to elaborate and implement solutions based on consensus, with a view of shared decision-making and leadership.

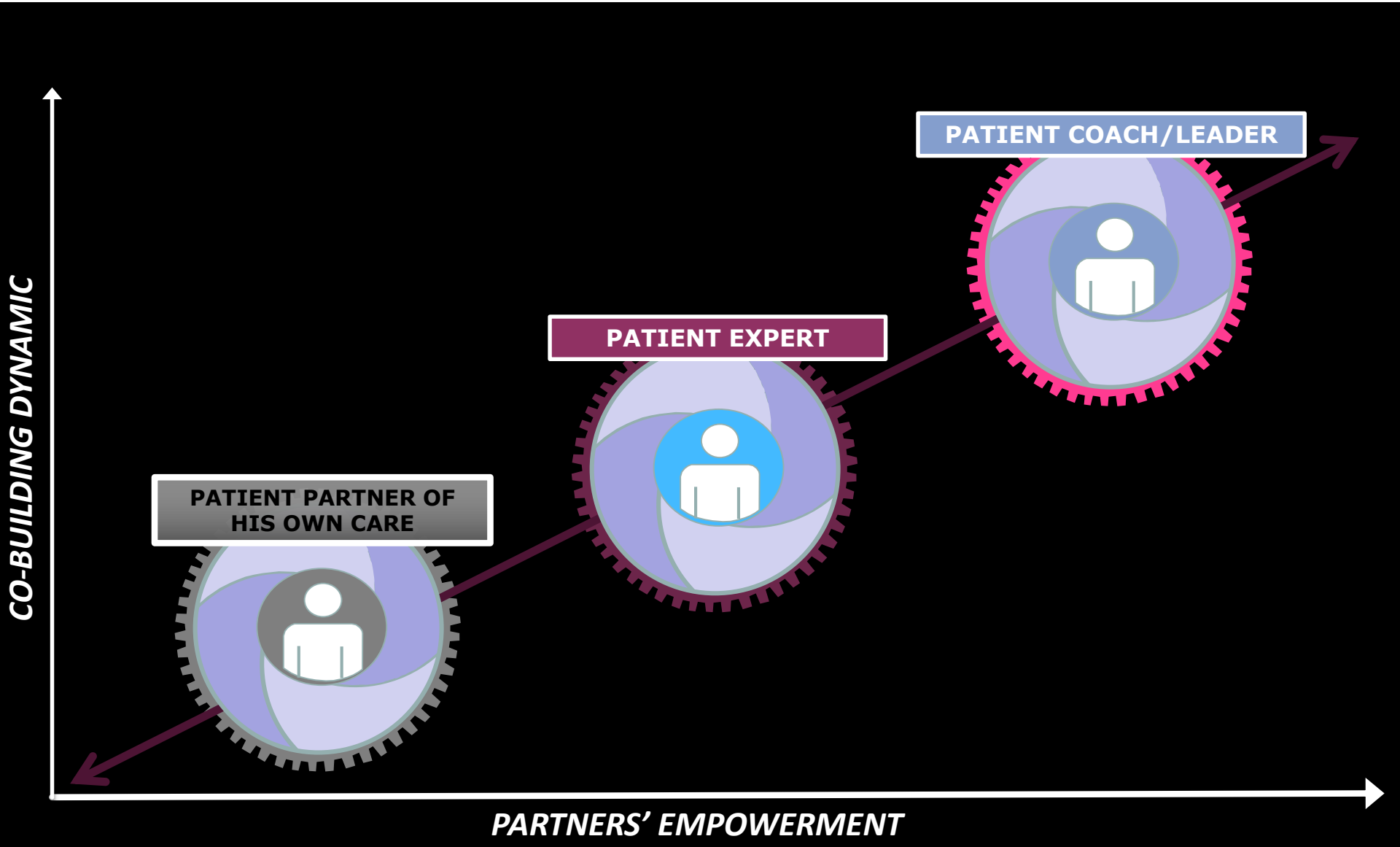
CO-BUILDING VS. ADVOCACY

	CO-BUILDING ENGAGEMENT	ADVOCACY REPRESENTATION
PRINCIPAL KNOWLEDGE	EXPERIENTIAL Significant experience of healthcare and services	SOCIO-POLITIC Organizational and policy knowledge
LEGITIMACY	EXPERIENCE-BASED KNOWLEDGE	REPRESENTATIVE OF A COLLECTIVE OPINION
ACTION	CO-DESIGNING, CO-CREATION	POSITIONNING, ADVOCATING, DEBATING
GOAL	IMPROVING HEALTHCARE AND SERVICES	RECOGNITION OF PATIENT RIGHTS
STRATEGY	BUILDING FROM INSIDE	INFLUENCING FROM OUTSIDE

4. Our approach for social change

EXPERTISE OF LIVING WITH ILLNESS

PATIENT COMPETENCY FRAMEWORK



Adapté de la thèse « patient formateur : élaboration théorique et pratique d'un nouveau métier de la santé », 2012

AN ECO-SYSTEMIC PERSPECTIVE

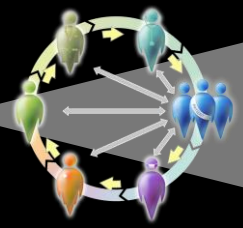
Health-care ecosystem - Decision-making spaces & knowledge creation spaces

Patient partnership in care

Populations that are partners in health

THE CENTRE FOR EXCELLENCE IN PARTNERSHIP WITH PATIENTS AND THE PUBLIC : OUR WORK SO FAR

OUR VISION OF PARTNERSHIP IN HEALTHCARE



- Recognition of experiential knowledge
- Patient = actor in his own healthcare

A STRUCTURE CO-MANAGED BY A PATIENT AND A DOCTOR

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ÉCOLE • LABO • RÉSEAU

DEDICATED TO PARTNERSHIP AND CO-CONSTRUCTION WITH PATIENTS AND THEIR FAMILIES

PATIENT PARTNERS
FOR TEACHING COLLABORATION AND ETHICS
+150 patient trainers

PATIENT PARTNERS
FOR THE AMELIORATION OF QUALITY AND GOVERNANCE IN HEALTHCARE
+140 patients resources

PATIENT PARTNERS
FOR THE DEFINITION AND APPLICATION OF HEALTH RESEARCH ORIENTATIONS
+90 patient co-researchers

5. Patient partnership in research

WHY PATIENT PARTNERSHIP IN RESEARCH ?

- To leave the echo-chamber (hyper-normalisation);
- To focus research orientations on population priorities and needs;
- To capitalize on the source of innovation constituted by the experience-based knowledge of patients;
- To facilitate knowledge mobilization (KM) and translation (KT);
- To strengthen CIHR's pillars of research 3 and 4 (Health services & Social, cultural, environmental and population health).

WHY PATIENT PARTNERSHIP IN RESEARCH?

- In a political and social perspective :
  - Patients have experiential knowledge of living with an illness;
  - Social responsibility (public funds);
  - Patients are increasingly empowered;
  - Patient engagement can lead to better research impact;

EXAMPLES OF ROLES AND RESPONSIBILITIES IN RESEARCH

- Setting research priorities;
- Determining which research projects should be funded;
- Conducting and developing research projects;
- Interpreting results of research;
- Participating in the communication, promotion and application of research findings to clinicians, the public and decision-makers;
- Identifying ethic issues in research projects;
- Evaluation of the research process and impact.

HOW TO BEGIN?

We need partners to:

- Possess relevant experience and competencies;
  - Patient recruitment and initial training.
- Master competencies required for constructive engagement
  - Patients-as-researchers continuous training.
  - Health researchers and clinicians initial and continuous training.
- Co-build a common goal.

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Thank you very much!

Please visit our website: CEPPP.CA

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