

FOSTERING COLLABORATION WITH PATIENTS, USERS, CAREGIVERS AND CITIZENS AT INESSS

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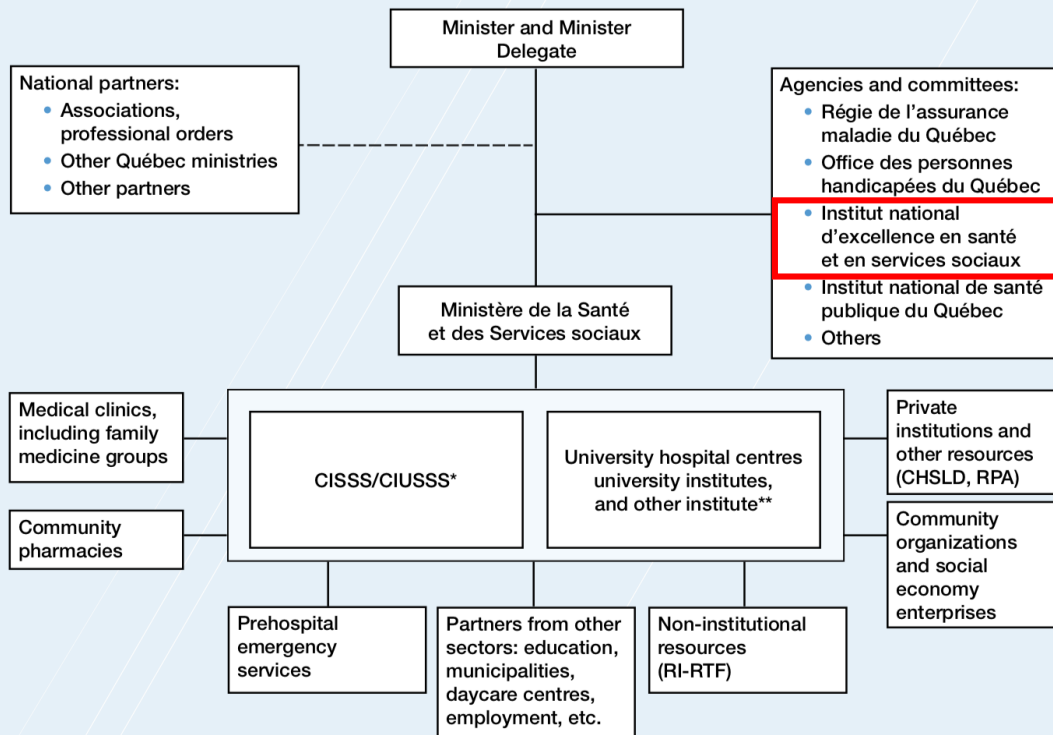
European Social Network
Co-production Forum 14-15 nov. Lisbon
Overcoming Challenges in Co-production

*Institut national
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Québec 

QUÉBEC HEALTH SYSTEM

Structure of the Health and Social Services System



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INSTITUT NATIONAL D'EXCELLENCE EN SANTÉ ET EN SERVICES SOCIAUX (INESSS)

INESSS is committed to:

- Global assessment of value of technologies, drugs and interventions used in health care and social services
- Consideration of clinical, populational, economic, organizational and socio-political aspects
- Implementation of responsible and sustainable innovation

INESSS's products:

- Knowledge products with recommendations (practice guides, clinical guidelines, quality standard)
- Knowledge products without recommendations (state of practice, state of knowledge)
- Knowledge transfer tools and activities

PATIENT AND PUBLIC INVOLVEMENT IN INESSS GOVERNANCE

Act respecting the Institut national d'excellence en santé et en services sociaux (I-13.03)

- “carrying out the consultations it deems appropriate prior to drawing up recommendations and developing practice guides so that **the opinions of interested groups and the general public** are taken into consideration” (Art. 5, par. 7)
- “sets up standing committees to study scientific questions. The committees must be made up of scientists, clinicians, ethicists, managers and **members of the general public.**” (Art.10)

Strategic Plan 2016-2020:

- “To better structure **the contribution of patients, users and lay caregivers**”

Three-year Business Plan 2019-2022:

- “the Institute intends to intensify collaboration between its scientific directorates and **increase the participation of users and stakeholders.**”

IN 2018 AND 2019...

41% of INESSS's products with recommendations have integrated the perspective of patients, users, caregivers or citizens (9 of 22 products with recommendations)

64 patients, users, caregivers or citizens were involved in interviews or focus groups (many more in surveys)

Satisfaction rate of 89% of patients, users and caregivers with their contribution to the work of INESSS

EXAMPLE – CLINICAL PRACTICE GUIDELINES REGARDING INTELLECTUAL DISABILITIES

“Effective interventions that improve the independence of youths aged 6 to 21 with intellectual disabilities”

- Take into account the point of view of users and parents in order to understand their expectations, their needs and the challenges they face.
- Participation:
 - Adding a parent to the advisory committee
 - Focus group with young people with intellectual disabilities (11 participants)
 - focus group with parents who have a child with an intellectual disabilities

EXAMPLE – USER PANEL

“ Implementing a regular, permanent process to involve users to ensure that they become central actors in the knowledge-production processes of the INESSS social services branch. ”

The objectives of the User Panel are:

- to feed the reflection of the project teams at certain key stages of scientific production (project framing, composition of working committees, consultations with users and relatives, development of recommendations, etc.);
- to inform project teams on emerging concerns;
- to alert on issues related to the acceptability and applicability of recommendations.

DIFFERENT LEVELS OF ENGAGEMENT



Consultation

Taking advice

Collecting data on stakeholder practices, needs, values, preferences and/or attitudes

Collecting experiential and contextual data (e.g. interviews, user focus groups)



Collaboration

Working together

Recognizing, understanding and confronting each other's perspectives in order to influence decision-making and recommendations

Data collection and validation; shared development of recommendations (e.g. committees with user members)



Partnership

Building together

Co-creating and co-building projects, approaches and innovative solutions with stakeholders

Decision-making by stakeholders; cross-sectional support for projects (e.g. user-partner)

Professional Leadership

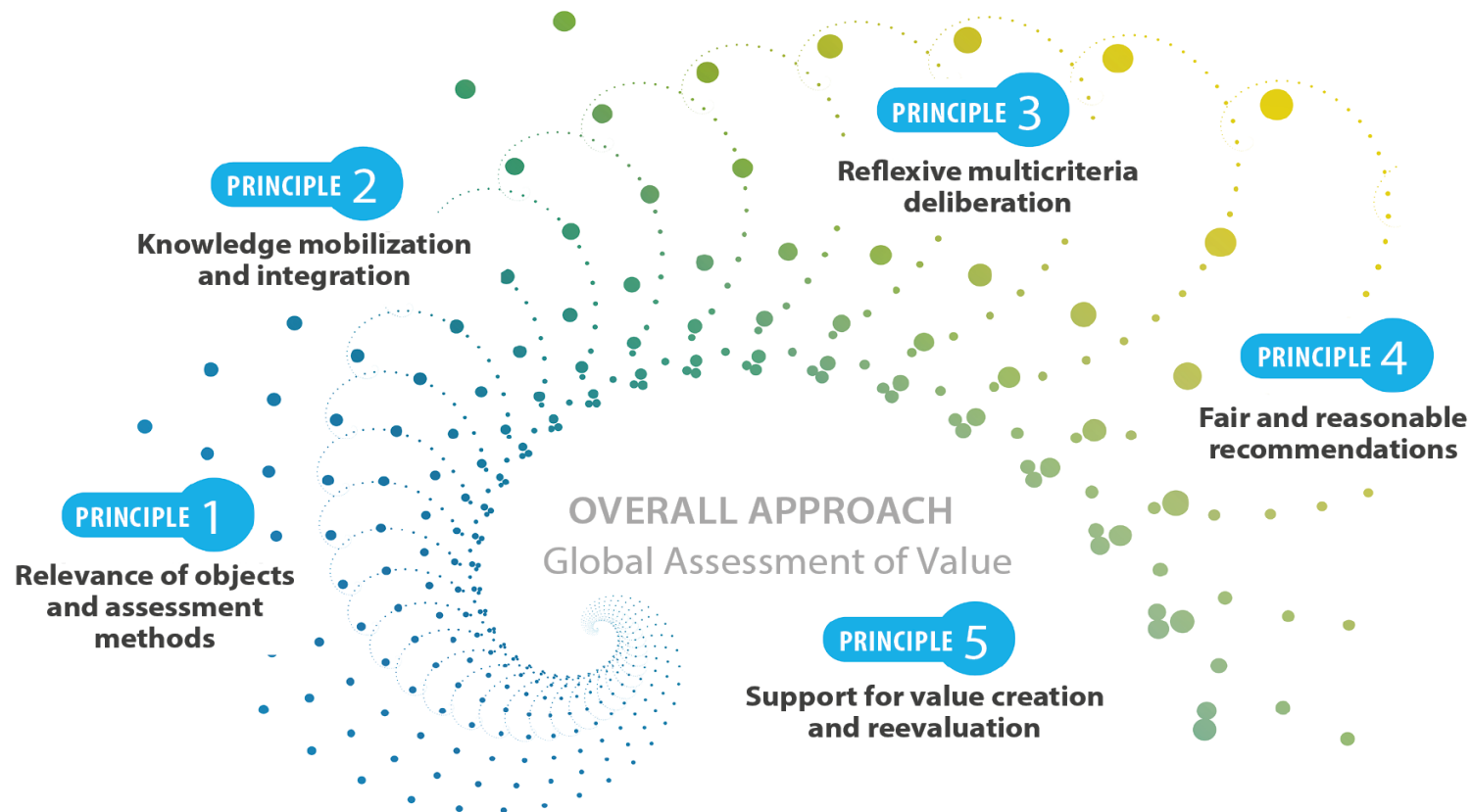
Collaborative Leadership

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INESSS INSTITUTIONAL FRAMEWORK



DIFFERENT TYPES OF CONTRIBUTION

	Patients / Users	Caregivers	Patient/User Representatives	Citizens
Contribution	<p>Experiential knowledge generated as a result of undergoing an illness or condition and using (health or social) services</p> <p>Advisory role</p>	<p>Experiential knowledge generated by the hardship of illness or condition caused to the significant other and his use of (health or social) services.</p>	<p>Perspectives on a given community's experiential knowledge, interests and right</p> <p>Advocacy role</p>	<p>Collective perspectives stemming from a population's plurality (common good, population health, societal values)</p> <p>Accountability, legitimacy</p>

Thank you!

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