

BETWEEN CONSULTATION AND CO-CONSTRUCTION: INTEGRATION OF USER AND FAMILY CAREGIVER PERSPECTIVE

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INESSS ultra rapid overview

Mandate



Assess the **clinical advantages and costs** of technologies, medications and interventions used in health care and social services



Produce **recommendations and clinical practice guides** to ensure optimal use of technologies, medications and interventions used in health care and social services



Determine **service performance evaluation** criteria and, if applicable, service monitoring and **implementation mechanisms** within the recommendations and practice guides, in accordance with best practices in clinical governance



Keep the recommendations and practice guides **up to date**, **distribute** them to health and social service providers and publish them



Foster the **implementation** of the recommendations and practice guides, using various information, **knowledge transfer** and outreach tools

Source: Section 5 of the Act Respecting INESSS

Directorate of Evaluation and Support for Improvement of Intervention Methods — Social Services and Mental Health (DESA)

- General social services – front-line psychosocial care, crisis services
- Struggling youths and families
- Support for independent seniors
- Intellectual disabilities, physical disabilities and autism spectrum disorders
- Addiction and homelessness
- Mental health



TEAM COMPOSITION:

- Managers, coordinators, professional scientists, technical and support staff
- Diverse professional specializations: psychology, criminology, occupational therapy, psychoeducation, social work, epidemiology, sexology, cognitive ergonomics, ethics, etc.



WHO WE SERVE:

- Ministère de la Santé et des Services sociaux
- Institutions
- Clinicians
- Professional orders and associations
- Medical federations
- Associations of users and family caregivers



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PANEL OF USERS AND FAMILY CAREGIVERS

CONTEXT

- Vision: Implement a regular and permanent process of user engagement so that users become central actors in INESSS's production processes.
- Initial postulates:
 - The effectiveness of the intervention is linked to the user's experience
 - The user's point of view is essential in terms of acceptability and applicability of the recommendations made
 - The panel does not replace other consultative strategies with users and family caregivers
 - The panel must be relevant and satisfactory to its members and to the professional scientists and coordinators

Stakeholder Participation

Consultation	Collaboration	Co-construction	Deliberation
Health and social services professionals, patients, users, family caregivers or citizens, representatives	Health and social services professionals, researchers, managers, ethicists, patients, users or family caregivers, citizens	Patients, users, family caregivers, health and social services professionals	Researchers, professionals, managers, ethicists, citizens
Focus groups, interview, survey	Expert Advisory Committee, Working Group, Monitoring Committee	Patient or professional partnership within a team	Permanent Deliberative Committee
Collect information, perspectives and experiential knowledge; validate knowledge or interpretations	Obtain information or validate knowledge; obtain advice on directions to take or to take a stand on the relevance of topics	Work closely with the evaluation team to develop a mutual understanding of the subject being evaluated	Assess and weigh the arguments for and against the subject of the evaluation and provide guidance for recommendations

DIFFERENCE BETWEEN CONSULTATIONS AND THE PANEL



CONSULTATION with patients, users, family caregivers

OBJECTIVE: To consult with relevant stakeholders (patients, users, family caregivers) on a specific project in order to capture the diversity of perspectives (needs, experiential knowledge, priorities, interests, concerns)

Contributions :

- Personal experience with a health condition, care obtained and use of social services
- Current or past significant experience with the target situation (e.g., illness, condition, etc. depending on the focus of the evaluation)
- Current or past significant experience with the technology or health or social service intervention covered by the assessment project

⇒ The results of the consultation will feed into the final report by covering the stakeholder perspective that was not captured or included in the scientific literature, as scientific and experiential knowledge are complementary.



PANEL of users and family caregivers

MANDATE: To reflect with teams on the best ways to integrate the values, experiential knowledge and perspectives of users and their families regarding a particular project

Contributions :

- Bring the point of view of users and family caregivers to the knowledge of professional scientists
- Recommendations for consultations to be conducted, angles to be explored, perspectives to be considered to increase the scope of the evaluation
- Contribute constructively to the work of INESSS by positioning itself as a "proxi" for the general population

⇒ The panel's suggestions ensure that the human perspective is considered throughout the evaluation project



PREPARATION PHASE WITH THE USER-PARTNERS

A preparatory phase with user-partners was deemed necessary, especially to determine:

- The mandate of the panel of users by specifying the objectives
- The composition of the panel by establishing selection and diversification criteria
- The principles and operating procedures of the panel (Bylaws and regulations);
- The most favorable conditions for the operation and support of the panel

PANEL OVERVIEW

What is a “Panel”?

- A permanent advisory committee that draws on the experiential knowledge of people dealing with various issues

Mandates

1. Provide input on the teams’ work at different key stages of the scientific production process (project scoping, composition of working committees, consultations with users and family caregivers, formulation of findings and recommendations, etc.)
2. Discuss emerging concerns with professional scientists
3. Identify issues pertaining to the acceptability and applicability of recommendations
4. Support initiatives for involving *experiential experts* in the production process
5. Contribute to the development of knowledge transfer strategies involving users and family caregivers

RECRUITMENT OF USER PARTNERS

- Individual interview process by CEPPP
- Selection criteria:
 - Have received specialized social services in the Quebec public network, or have accompanied a loved one in a significant episode necessitating this type of service;
 - Have some perspective on their situation
 - Be able to reflect on elements that are broader than those related to a specific condition (organization and service offer, collaborative approaches or participation of user partners in care and services, use of experiential knowledge, etc.)
 - Have a critical and constructive analysis that supports the improvement of service delivery from the perspective of the person receiving the service.

PANEL OVERVIEW

Panel Members:

- 3 male and 3 female
- Between 25 to 65 years old
- Areas of expertise :
 - Physical disabilities
 - Seniors with reduced autonomy
 - Mental health
 - Intellectual Disabilities
 - Neurological impairment
 - Addiction and Homelessness
 - Troubled youths

PANEL OVERVIEW

Working Method:

- Four to five annual meetings
- Voluntary presentations by professional scientists
- Documents sent 14 days in advance
- 3 – 5 hours of virtual or in presence meetings (since Covid)
- Members are paid

PANEL OVERVIEW

Examples of topics covered:

- Families' perinatal and early childhood needs
- Reconciling living and care environments in long-term care facilities
- Empowerment for youth 6 to 21 years of age with intellectual disabilities
- Non-psychotherapeutic interventions for common mental disorders
- Children zero to seven years of age with neurodevelopmental disorders (NDDs)
- Diagnosis and treatment of seniors with signs of hearing impairments
- Children and youth experiencing or at risk for neglect and their families
- Revised protocol for cardiopulmonary resuscitation (CPR) in opioid overdose situations in the community (update)



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REVIEW

Marie-Pascale Pomey, Ph.D.

REVIEW GOALS

Primary goal:

- Assess the Panel of users and family caregivers' contribution to the work carried out by DESA at INESSS.

Secondary goals, to assess:

1. The Panel's implementation process
2. What Panel members have learned in the past and current year
3. What DESA scientists have learned about integrating that level of user insights into their work compared to usual focus groups
4. What INESSS has more broadly learned about integrating user insights into its work
5. Possible avenues for improving the Panel

METHODOLOGY

- Qualitative case study
- Semi-structured interviews
- Two interviewers
- Verbatim transcription
- Analysis of verbatim transcripts using NVivo (two coders)
- Results validated by Panel members and scientific coordinators

RESEARCH SUMMARY

- Data collected from March 2021 to January 2022
- 21 interviews (100%)
- 19 participants
 - 6 Panel members
 - 8 employees from DESA (professional scientists, coordinators, managers)
 - 5 employees from other directorates
- 49-minute average per interview
- 242 single-spaced pages of verbatim transcripts!

SOME VERBATIM

“I like making presentations to the User Panel more nowadays than I did when we first started... Maybe it’s because we’ve gotten better at expressing ourselves in lay terms or at pinpointing the parts of our work where their input really shines. It could also be because they’ve become better partner users.”

*“The professionals are often **surprised** by just how much they help us **better understand our issue in question**. I personally consider them to be (...) absolutely **essential to the process** (...), both before and during the project.”*

“I’ve started to realize that I’ve got something to say about a lot of things and I shouldn’t be afraid to share my opinions. And there’s always another person on the Panel who knows more than I do about certain topics, so I trust that the others will have something insightful to say.”

ADDED VALUE AT A BROADER PERSPECTIVE

Members are regular contributors to the production process:

- This strategy is permanent and transversal to all the projects and issues
- Through their regular exposure to the different stages of production and to the methodology of knowledge crossing, panel members are more likely to express their opinions and to contribute to the projects
- The Panel is complementary to the consultations and is of a collaborative level

ADDED VALUE AT A BROADER PERSPECTIVE

- A process that complements the scientific literature
- A means to consider user perspectives
- A Quebec-specific contextualization of an issue
- A better grasp of the challenges associated with the topics covered
- Suggestions for improving aspects of the topics covered (addressing blindspots)

FOOD FOR THOUGHT

“We’re human beings with hands-on experience with health care systems and social services. That’s why we’re comfortable and interested in being able to use our own experience in a more general way, to bring the process to a more general level, and share concerns we have, as users and close family and friends, that can benefit everyone.”

QUESTIONS?

THANK YOU!

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