CLINICAL TELEHEALTH IN QUÉBEC:
an ethical perspective

Summary and recommendations

COMMISSION DE L'ÉTHIQUE
EN SCIENCE ET EN TECHNOLOGIE

Québec
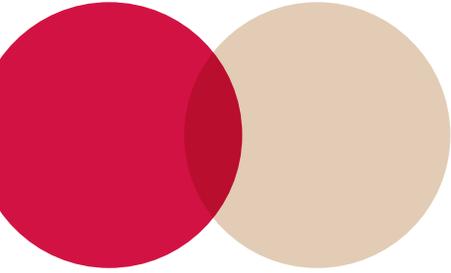
To facilitate the reading of the text, the masculine
is used without any discriminatory intent.

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LIST OF INITIALISMS AND ACRONYMS

AETMIS   Agence d'évaluation des technologies et des modes d'intervention en santé
[Agency for the evaluation of technologies and methods of intervention in health; now INESSS]

AHSSS   Act respecting health services and social services

ASSS   Agence de santé et de services sociaux [Health and social services agency]

CAI   Commission d'accès à l'information [Commission for access to information]

CEST   Commission de l'éthique en science et en technologie
[Commission for ethics in science and technology]

CHI   Canada Health Infoway

CHU   Centre hospitalier universitaire [University hospital centre]

CMPA   Canadian Medical Protective Agency

CMQ   Collège des médecins du Québec [Québec college of physicians]

CNA   Canadian Nurses Association

CSSS   Centre de santé et de services sociaux [Health and social services centre]

CST   Canadian Society of Telehealth (now the Canadian Telehealth Forum)

ECG   Electrocardiography

EEG   Electroencephalography

EHR   Electronic health record

EMG   Electromyography

ICT   Information and communications technologies

INESSS   Institut national d'excellence en santé et en services sociaux
[National institute for excellence in health and social services]

MRI   Magnetic resonance imaging

MSSS   Ministère de la Santé et des Services sociaux [Ministry of health and social services]

PACS   Picture archiving and communication system

PET   Positron emission tomography

RAMQ   Régie de l'assurance maladie du Québec [Québec health insurance board]

RSSS   Réseau de la santé et des services sociaux [Health and social services network]

RUIS   Réseau universitaire intégré de santé [Integrated university health network]

SMS   Short Message Service

WHO   World Health Organization

EXECUTIVE SUMMARY
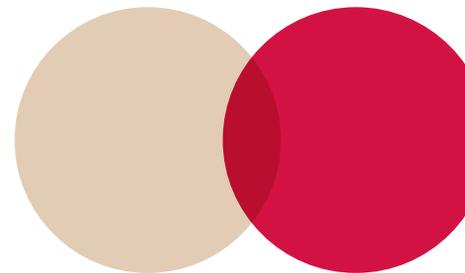
Clinical telehealth refers to the delivery of remote health care using information and communications technologies (ICT). It allows consultations, monitoring and clinical follow-up to be provided at a distance. It is much more than a set of technologies: it supports the implementation of integrated service networks by facilitating communication between multiple stakeholders. The network approach meets the objectives of Québec's health care system which is facing staff shortages, population aging and the transformation of health care delivery.

To fulfil its promise, telehealth must be part of a global vision shared by all stakeholders. This vision places health needs and respect for professionals and users at the centre of any deployment of telehealth in the network. Otherwise, more harm than good would be done.

To be acceptable from an ethical standpoint, telehealth must respect four principles that are central to our health care system: access to appropriate quality care, a fair and equitable distribution of resources, the sharing of responsibility between stakeholders, and the free and informed consent of individuals.

As a priority, the relevant people and organizations identified in the recommendations made by the Commission de l'éthique en science et en technologie (CEST) must:

- Establish more appropriate monitoring, evaluation, liaison and knowledge transfer mechanisms to make quality data on the effectiveness of telehealth applications available;
- Support users, informal caregivers and professionals in the transformation of the health care setting brought about by this innovation;
- Support professional practice, in particular through guidelines and training, in order to maintain and improve the quality of the clinical relationship, offset the limitations of the technology used and prevent situations of vulnerability;
- Respect individual autonomy when remote care is provided in the user's home (home telecare);
- Ensure the security of health information when it circulates or is stored outside the health network.
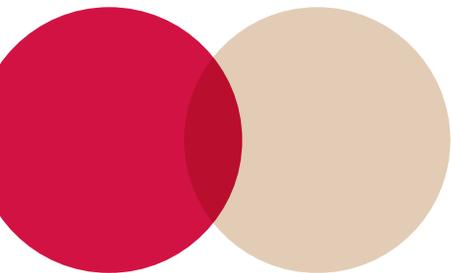
GUIDE TO ETHICAL REFLECTION FOR TELEHEALTH STAKEHOLDERS

This guide is intended to support stakeholders (health professionals, managers, technicians, etc.) in their process of reflection when they are required to make a decision regarding the use of telehealth.

It provides a list of questions to ask in order to make a responsible and ethical decision. For each question, references to the relevant sections or tables are also included.

1. Understanding of the situation

In this situation, what are the relevant characteristics of the telehealth application?

See the five characteristics of telehealth on p. 2 as well as Table 4.

What are the expected benefits?

What are the risks?
What are the possible harmful consequences for users and their relatives?
What are the consequences for care providers, managers and support staff?
What are the consequences for the health care system and society in general?

Refer to the situations described on pp. 5-13.

2. Existing framework

Can legal or professional ethics standards guide the decision?

3. Reflection on ethical principles and values

Are the principles considered central to the health care system respected?

See Table 2 and the section "Principles to respect" on pp. 5-7.

In this context, how are core values expressed?

See Table 3.

Are any other values involved? Do they give rise to value conflicts?

4. Reflection on the solutions to adopt

What are the possible solutions to the dilemma?

What are the consequences of these solutions for people and organizations?

How do these solutions relate to the values mentioned?
Do some respect more values or put emphasis on those considered the most important?
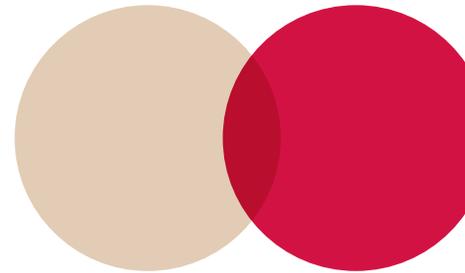
5. Validation of the solution adopted

Is the solution adopted acceptable to the other parties concerned?

Can it be generalized to other similar situations?

Would you feel comfortable justifying this solution publicly?

THE POSITION STATEMENT IN SHORT

Québec was one of the first places where telehealth projects were carried out, especially as of the 1990s. They were masterminded by a few health professionals who were enthusiastic about the potential of ICT in health. This method of remote health care delivery was recognized and overseen by the Ministère de la Santé et des Services sociaux (MSSS) in 2005 as part of the integration of services.

In the coming years, telehealth will have a growing impact on clinical practice and health care in Québec. Yet the ethical issues it raises have not been the subject of comprehensive reflection. Today, this reflection is imperative.

The purpose of this position statement is to address the lack of ethical reflection, increase public awareness of the issues raised by telehealth and support decision making by the people and organizations concerned.

More specifically, in the position statement, the Commission sets out the conditions for the optimal development of telehealth from an ethical standpoint. Telehealth applications are so wide-ranging[1] that a single position statement on the matter cannot, if it is to be accessible and useful, cover all the details of the specific policies to be implemented. The Commission takes an important first step that can be completed by future studies.

What you will find in the position statement	What you will not find in the position statement
✔ An overview of the objectives of telehealth	✘ A detailed and technical presentation of telehealth applications
✔ Characteristics relevant to its ethical evaluation	✘ A clear position for or against telehealth
✔ An analysis of the risks it involves and the issues it raises	✘ A list of what to do and what not to do
✔ A clarification of the values that must be taken into account	✘ Answers to all questions
✔ Tools to guide decision making	
✔ Recommendations for decision makers and stakeholders	

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1   See Table 4.

Table 1. A guiding principle

Health is of core importance to human well-being. The development of new technologies and new practices must be encouraged if they allow the delivery of better health services to the population at the best possible cost.

A vision to share	A phenomenon to understand	An ethical framework to support decision making	Issues that must be addressed as a priority

• **Put telehealth at people's service:** Its development must be based on demand and appropriateness rather than on supply and advances in technology.
 	
• **Act in an integrated, coherent and transparent manner, while respecting three principles:**
  • Assessment of needs and mobilization of professionals
  • Clinical utility and security of applications
  • Cost-effectiveness
	• **Five characteristics relevant to an evaluation:**
	  • Hybrid character: both tool and service
	  • Distance
	  • Multiple stakeholders involved
	  • Variety and quantity of the data collected
	  • Interoperability
	
	• **Four challenges in decision making:**
	  • Innovation
	  • Evaluation
	  • Organization
	  • Funding
		• **Four principles to respect:**
		  • Access to appropriate quality care
		  • Fair and equitable distribution of resources
		  • Sharing of responsibility by the different stakeholders
		  • Free and informed consent of individuals
		
		• **Four values to promote:**
		  • Trust
		  • Autonomy
		  • Solidarity
		  • Beneficence/ non-maleficence
			• **Innovation and the transformation of the health care setting**
			
			• **The quality of the clinical relationship and the protection of people in vulnerable situations**
			
			• **The medicalization of the living environment and individual autonomy**
			
			• **The confidentiality of health information and respect for people's privacy**

SUMMARY AND RECOMMENDATIONS
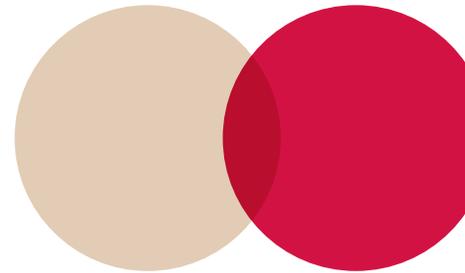
A vision to share

Telehealth is part of the project to create integrated health and social services networks in order to improve the health care system. It has four main objectives

- Increase access to services;
- Provide timely, continuous care;
- Promote user participation;
- Improve quality of care.

However, achieving these objectives requires a strong political will to ensure that all stakeholders share the same vision and act in a coordinated manner.

It also means refocusing telehealth development on a "demand-pull" approach, centred on health needs, to address certain problems in the health care system. At present, other approaches are also contributing to the development of telehealth: a "technology-push" approach, where technology is the main driver of change in the health care system, and an individualistic version of the demand approach, focused on individual preferences.

The Commission recognizes that health is of core importance to human well-being and therefore states the following guiding principle: the adoption of new technologies and new practices must be encouraged if they allow the delivery of better health services to the population at the best possible cost.

The Commission stresses the importance of:

Basing the organization of telehealth in Québec on a global approach that supports integrated health care networks in order to maximize its benefits and ensure the coordination of the multiple stakeholders involved;

Ensuring its use is based primarily on demand and appropriateness rather than on supply and advances in technology and respects three minimum conditions of acceptability:

- Assessment of patient needs and mobilization of professionals upstream, which means the diversity of clinical settings and users must be taken into account;
- Demonstration of the clinical utility (ability to improve health) and security of each application;
- Maintenance of cost-effectiveness.

Characteristics relevant to an ethical evaluation

Despite their differences, telehealth applications share five main characteristics that involve both benefits and risks.

1) A hybrid concept:

Telehealth comprises two complementary dimensions: on the one hand, technological applications (tools) and, on the other hand, the new methods of health care delivery (services) they support. For example, videoconferencing technologies allow medical consultations to be conducted at a distance (teleconsultations).

The ethical issues raised by telehealth stem from both the technological and the service dimensions due to the transformation of the health care setting they bring about.

2) The distance factor:

Telehealth allows communication and the delivery of care at a distance, great or small, for example between a large centre and a remote region, between two neighbouring institutions or between an institution and the home of the professional (telework) or user (telecare). Most importantly, not all distance barriers can be measured in kilometres. Think of communication difficulties, the dispersion of people with a given disease or the risks associated with transporting people who are in an unstable physical condition.

However, communication and the delivery of remote care raise the issue of the quality of the relationship between the user and his professional care provider as well as between professionals who must trust each other without actually meeting.

3) The multiple stakeholders involved:

Clinicians, designers and technicians, public bodies and private companies must all collaborate, despite sometimes divergent interests, from the design of applications to their implementation and service delivery.

On an ethical level, this raises the issue of responsibility sharing between stakeholders and that of guarantees as to the confidentiality of the health information they have access to.

4) The variety and quantity of data collected and transmitted:

The data used in telehealth is varied (multimedia), digitized and high volume due to the increased storage capacity.

The main issue is ensuring the confidentiality and security of the data.

5) Interoperability:

Telehealth applications acquire added value when they are networked, are mutually compatible and communicate information effectively between one another.

The easier, even automatic circulation of information means that different ways must be found to ensure confidentiality and that the consent process must be adapted.

Challenges for decision makers and stakeholders

In the current context, four major challenges stand in the way of the deployment of telehealth in the network. Noteworthy is the cross-cutting issue of collecting and disseminating information relevant to decision making.

1) Innovation and the rapid evolution of technology and knowledge:

New ways of keeping decision makers' and stakeholders' knowledge and skills up to date are needed given the rapid pace of innovation in the field of telehealth.

For example, decision makers do not always have time to wait for the results of evaluations. Moreover, these results can rapidly become obsolete. In organizations, the use of hard-to-monitor technologies such as personal devices (smartphones) complicates the regulation of practices. In general, stakeholders need to constantly develop new knowledge and new skills.

2) The evaluation of telehealth technologies and practices:

Whenever possible, more evaluations must be carried out and they must be adapted to improve both the *availability* and the *quality* of data used in decision making.

Indeed, several of Québec's telehealth projects do not include any evaluation process. Furthermore, meta-analyses conclude that existing evaluations rarely allow generalizable conclusions to be drawn on the benefits of telehealth. Cohorts are often very small and there are many variables that must me considered, such as human, clinical, and organizational factors. Lastly, the evaluation processes that currently provide the information needed for decision making are suited to existing technologies, on which a lot of data can be collected, and not to emerging technologies.

3) Organizational issues:

Telehealth requires change management and improved dissemination of information between stakeholders.

Multiple stakeholders are involved and they each have their particular expertise and concerns. Their ways of communicating and interacting are also transformed due to distance and the network approach. During a project, coordination and information sharing are necessary, in particular to ensure ethical requirements at all levels of action are met.

4) Funding telehealth and the allocation of resources:

Some telehealth applications will have to be given priority over others based on user needs, expected benefits and available resources.

Telehealth requires major investments to design, implement and upgrade applications and infrastructures. The resources available are, however, limited and health care spending is already rising sharply and steadily. In telehealth as elsewhere, choices will have to be made.

Tools for taking action

Telehealth must contribute to the improvement of the health care system. This requires a vision to structure government intervention in telehealth, the coordination of networked stakeholders and the sharing of quality information, essential for informed decision making.

The Commission is therefore making an initial series of recommendations so that, collectively, we can equip ourselves with the right tools to take action in telehealth. While not specifically derived from the field of ethics, these four recommendations are intended to ensure the minimum conditions are met for the ethical deployment of telehealth and to produce the knowledge required for decision making.

The Commission recommends:

(R-1)   That professional orders in the health sector introduce a monitoring mechanism:

    1) for emerging telehealth practices, in particular health professionals' use of personal mobile devices such as smartphones as they evolve and are implemented;

    2) using an interprofessional and intersectoral approach;

    In order to be able to track the use of these technologies and ensure adequate quality control;

(R-2)   1) That all telehealth initiatives in Québec be accompanied by an independent and external evaluation, as far as possible, and based on rigorous scientific methods;

    2) That the Réseaux universitaires intégrés de santé (RUIS) oversee these evaluation processes given their research and evaluation mission as well as their responsibility with respect to telehealth development in their territory;

(R-3)   1) That the Institut national d'excellence en santé et en services sociaux (INESSS) be mandated to evaluate telehealth applications that are already in use, or those most likely to be widely adopted, and which have major implications for the health care system (for example in terms of target population, health problem concerned, cost, acceptability, etc.);

    2) That these evaluations integrate, as far as possible, ethical aspects and take into account the economic, clinical, organizational, professional and social dimensions of telehealth and its integration into health care systems, clinical practices and, in some cases, people's everyday life and living environment;

(R-4)   That the national coordination table of the Réseaux universitaires intégrés de santé (RUIS) institute a mechanism for the liaison and transfer of knowledge and best practices in telehealth in order to improve the dissemination of evidence across the network.

Principles to respect

Telehealth is being deployed in a context where the health care system is in transition. To guide its deployment, the Commission has defined four ethical principles that are central to our health care system and that must be respected when introducing any new technology or new method of health care delivery.

Table 2. Four principles that are central to our health care system			
Access to appropriate quality care	Fair and equitable distribution of resources	Sharing of responsibility between stakeholders	Free and informed consent of individuals

• Principle related to the values of solidarity and beneficence/non-maleficence
• Pay special attention to technological, geographical and economic constraints to access
• Strengthen the following mechanisms:
  • quality control
  • evaluate of the appropriateness of interventions
  • patient home support
	• Principle related to the value of solidarity
	• Provide the most useful and most effective services with the means available to us
	• Make choices that take users' preferences and values into account without ever sacrificing the pursuit of the common good
		• Principle related to the values of trust and beneficence/non-maleficence
		• Remain vigilant against the risk of dilution of responsibility due to the large number of stakeholders
		• Clearly define each person's responsibilities and establish coordination mechanisms between stakeholders while avoiding legal overprotection
			• Principle related to the value of autonomy
			• Take note of the changes introduced by telehealth in order to adapt the consent process

1) Access to appropriate quality care:

People are entitled to have access to the best possible health care for their clinical needs, irrespective of their ability to pay, social status, cultural or ethnic identity, place of residence, etc.

With respect to access, four instances were studied and the following observations made:

- The technology infrastructure must be comparable across institutions and regions;
- The choice of regions where implementation is a priority should not be influenced by factors that are not clinically relevant;
- The consequences of telehealth on the distribution of human resources between institutions and regions must be given particular consideration;
- The shift in care from health institutions to the user's home through telecare must not give rise to tariff barriers to access.

The Commission recommends:

(R-5)   That the Ministère de la Santé et des Services sociaux (MSSS) ensure that disparities in computerization between institutions in the health care network do not prevent users from receiving the care they need or adversely affect the quality of care;

(R-6)   That the Government of Québec support, for example through the Connecting Rural Communities program, installation of a broadband Internet connection when it is necessary for a telehealth project that is clinically appropriate and promotes access to quality care in a remote region;

(R-7)   That the Government of Québec ensure that the funding methods used in telehealth do not adversely affect access to quality care, particularly in the case of home telecare. A person's ability to pay should not limit his access to the health care he needs.

With respect to quality, the lack of harmonized practice standards and measures to ensure the reliability of the data collected by the user himself at home is problematic.

The Commission recommends:

(R-8)   1) That professional orders define practice standards for telehealth;

2) That councils of physicians, dentists and pharmacists of health institutions apply these standards by using harmonized clinical protocols;
So that each user can have access to equivalent protection measures in the different institutions participating in a telehealth activity;

(R-9)   That professionals be available to assist users who have to use medical instruments and collect data at home in order to ensure the information collected is reliable.

Access to appropriate quality care also depends on the resources available. Constraints to access may be necessary due to limited resources. Under what conditions are constraints acceptable? The Commission believes they are acceptable only if they respect a principle of fairness and equity.

2) A fair and equitable distribution of resources:

Health care system resources (financial, material or human) must be used responsibly and allocated in accordance with transparent criteria that respect population needs and the common good.

To determine priorities in telehealth, the Commission proposes procedural considerations, that is, that relate to how decisions are made. It would be hasty to take a position on the substantive issues.

Indeed, in addition to health gains, telehealth can have very varied benefits that are not promoted in the same way by the different stakeholders; think of gains in user friendliness, cost (for the user, the health institution, the health care system as a whole or an insurance company), time (by reducing travel time for users or professionals), etc.

However, factual data about these benefits still needs to be interpreted in relation to values to identify the desired outcomes and thus the criteria on the basis of which rationing is ethically acceptable.

This exercise requires the participation of various stakeholders, in the first instance that of users. It has a democratic dimension and is therefore a matter of public debate.

The Commission recommends to all the stakeholders involved:

(R-10) 1) That all decisions regarding prioritization in telehealth be made in a spirit of transparency and inclusion;

2) Consequently, that different types of expertise be recognized and professionals, managers, users and civil society mobilized.

3) The sharing of responsibility between the different stakeholders:

Coordination and collaboration between designers, engineers, clinicians, technicians and managers are necessary, for they all make decisions at various times in the process that have an impact on the nature and quality of services. However, due to the large number of stakeholders involved and interoperability, there is a risk of responsibility being fragmented between stakeholders, or even between the human and the machine, and thus diluted.

Each person must therefore understand the objectives and the consequences of the actions taken and the decision-making chain must be fragmented as little as possible. When providing clinical follow-up for a person, each professional's responsibilities must be clear so that the user is not left to fend for himself.

4) The free and informed consent of individuals:

Both an ethical and a legal requirement, a person's consent must be obtained prior to any health intervention. The person must give his consent freely, that is, without any undue influence or coercion, after being sufficiently informed of the risks and benefits of the different options available to him.

Users must be able to consent to the method of care delivery and be informed of the benefits and risks of using telehealth compared with traditional care delivery   that is, face to face , or no care.

The health care professionals responsible to seek and obtain the user's consent might have to provide further information and explanations, such as:

- That a teleconsultation may require that multiple professionals discuss the user's health situation and history through telecommunication technologies;
- That a teleconsultation may require the presence of non-medical personnel to operate the technical equipment at both the requesting site and the provider site;
- That the teleconsultation may be recorded (if it is the case);
- That telehealth systems, although they are secure, are not infallible. They could fail to work properly and unauthorized third-parties could, in rare circumstances, gain access to the data transmitted;
- In the case where professional(s) and user(s) are located in different jurisdictions, the relevant information about the professionals' licenses, the procedures to ensure a proper medical follow-up and the complaint mechanisms.

Users should also be informed of their privacy rights and the measures taken by the health care provider to protect them.

Local practice standards and guidelines could impose further obligations on health care professionals concerning free and informed consent.

Table 3. Four core values to guide reflection and decision making

Trust	Autonomy	Solidarity	Beneficence/non-maleficence
• Represents an ideal where relationships are characterized by mutual respect and consideration so that responsibilities can be entrusted to another person with the certainty that he will not act contrary to our own interest or a common interest. • Fundamental role in the clinical relationship and between stakeholders in the network who must work together in a new method of care organization and delivery. • Democratic context: institutions must act in a way that maintains citizens' trust.	• Refers to a person's ability to decide for himself or participate actively and in a meaningful way in decisions concerning him, to act in accordance with his values. • Central concept with respect to the patient's place in the caregiving relationship. • Equally important for informal caregivers and professionals.	• Based on the ties between all the members of a single community. • Presupposes an awareness of the effects of our current actions and choices on others with a view to engagement and interdependence. • In practical terms, solidarity motivates people to take other people's needs and vulnerabilities into account and not to sacrifice other people's and the community's interest for their individual interest alone.	• Results from the fiduciary nature of the relationship between health professionals and patients. • Motivates professionals to ensure that the services provided to patients are always in their best interest, that situations of vulnerability are rigorously taken into account and that patients are thereby protected from potential harm.

Issues that must be addressed as a priority

Telehealth raises issues in a wide range of particular situations. The Commission focused its attention on four main issues that should be addressed as a priority.

1) Innovation and the transformation of the health care setting

Telehealth is redefining the social roles of users, informal caregivers and professionals. It is upsetting the balance of the tasks each is responsible for.

On the one hand, users play a more active role in the clinical relationship. They also assume more responsibility. Very little is known about the consequences for users of these new expectations of them. The available studies show that increased user responsibility means that they must develop sometimes complex knowledge and skills. These expectations may be excessive for some people.

On the other hand, informal caregivers must be given recognition and support for the important role they continue to play in telehealth. While users gain autonomy, there is a risk of marginalizing the informal caregiver's role, precisely when his tasks are becoming more complex owing to technology.

The Commission stresses the importance of:

Taking informal caregivers' needs into account when assessing the acceptability of telehealth projects;

Allowing informal caregivers to have a say in decisions concerning them and in the public debate on telehealth.

The Commission recommends:

(R-11) That professionals provide informal caregivers with all the relevant information and support so that they are truly integrated as partners in the caregiving relationship;

(R-12) That institutions in the health and social services network and any other entities involved in providing services ensure:

1) that the technology deployed also supports informal caregivers;

2) that it does not place an undue burden on them;

3) that measures are taken to minimize risks, where applicable.

Lastly, the new communication and collaboration networks that are being established between professionals in telehealth rely on relationships of trust that must be built. Managers must bear this in mind when carrying out projects in order to respect professionals' needs in this regard.

2) The quality of the clinical relationship and the protection of people in vulnerable situations

Primarily due to the distance factor, telehealth involves a new type of presence that is no longer direct or physical. Rather it depends on the use of technology that has not only benefits, but limitations too.

The changes telehealth brings to the clinical relationship can create or aggravate situations where people are more vulnerable. These particular situations must be taken into account when designing, evaluating and using telehealth applications.

Above all, new expectations with respect to users' role in the clinical relationship, including those related to their increased responsibility, must be qualified. Measures must be taken to avoid making people more vulnerable.

The Commission recommends:

(R-13)   That professionals ensure that each person's limitations are respected concerning their participation in their management via telehealth when they simply have neither the resources – financial, psychological or physical – nor the know-how to take on more responsibility;

(R-14)   That institutions ensure, as far as possible and in accordance with the person's wishes, these limitations are addressed.

We know now that the practical consequences of telehealth on maintaining a quality clinical relationship depend on many variables. Further research to better identify these variables and how to influence them will allow preventive or compensatory measures to be defined that can be used to offset the limitations of telehealth.

The Commission recommends that the relevant research and regulatory bodies:

(R-15)   Continue research on the effects of telehealth on the clinical relationship and disseminate the findings;

(R-16)   1) Systematically integrate key human and social dimensions into this research to inform ethical analysis and judgement, for example:
- the consequences on the relationship of trust, communication and emotional support;
- the influence of cultural and socioeconomic factors, literacy and available resources;

2) Seek the viewpoints of both care providers and users;

(R-17)   Identify situations where the distance factor may be a problem so that it can be addressed, where applicable;

(R-18)   Develop guidelines and technology standards, when required, for the different clinical settings.

However, guidelines are not enough. Indeed, technology, practices and knowledge are evolving too rapidly. Furthermore, situations are so varied that general statements cannot guide professionals in all particular cases. In these cases, the people involved must exercise their professional judgement to ensure a quality clinical relationship.

The Commission recommends:

(R-19) That professional associations and orders continue to promote the responsible practice of telehealth and ensure their members receive adequate support and training.

Moreover, telehealth must not be a burden for professionals, who are already under considerable pressure, and thus leave less time for quality contact with users.

The Commission recommends:

(R-20) That the competent authorities support professionals by providing human and technical resources to accompany the change brought about by the adoption of telehealth.

Lastly, there is great potential for telehealth to meet Aboriginal communities' considerable health needs. Systemic and cultural barriers to health care access still exist in these communities. The acceptability of telehealth among Aboriginals depends on how closely it is aligned with their own health objectives. It also depends on adopting an approach that takes cultural differences into account so that practice can be adapted if necessary.

The Commission stresses the importance of:

Telehealth improving access to care for Aboriginals.

The Commission recommends:

(R-21) That representatives of Aboriginal communities, irrespective of where they are located on Québec's territory, be directly included in defining objectives and means before a new method of care delivery, and more specifically telehealth, is introduced;

(R-22) That professionals, in their approach to their remote practice in Aboriginal communities, take interactions between cultures and their effects on the therapeutic relationship into account;

(R-23) That the competent authorities provide professionals working in these communities with the necessary support and training resources.

3) The medicalization of the living environment and individual autonomy

Some telehealth interventions can be done directly from the user's home. Yet the home holds special significance, for it is a living environment, a private place. Introducing a medical approach into this environment can be an extremely sensitive undertaking and jeopardize the person's autonomy.

Québec's Home Support Policy stipulates that the person's autonomy at home must be respected as much as possible. Achieving a balance between measures to ensure the person's safety, the protection of his privacy and his well-being must be guided by respect for each person's values.

Respect for the person's values must also guide any adjustments required in his home so that he can receive home support through telehealth. Similarly, user needs that exceed the technology's capabilities, such as emotional needs, must not be overlooked.

The Commission reiterates:

That telehealth cannot fully replace the care and support provided to people.

The Commission recommends:

(R-24) That institutions in the health and social services network, organizations or the people responsible for designing, purchasing or installing telehealth equipment ensure that they invade the person's physical home environment as little as possible and that an effort be made so that adjustments to his home respect the person's wishes.

4) The confidentiality of health information and respect for privacy

Telehealth leads to increased sharing of health information. Furthermore, the information collected is varied and the volume of data is much higher. Data can also be stored and kept accessible for a longer period of time.

With respect to the protection of privacy, the Commission considers that the current legal and professional ethics framework is sufficient. Indeed, the latter defines the scope of health information sharing and ensures that it is used for purposes for which the person has given their consent.

The Commission reiterates the importance of:

Ensuring that the only confidential information collected in a telehealth project or activity is that required by professionals to exercise their professional judgement and provide health care;

Ensuring that this information can be used for clinical purposes only, in the user's interest;

Ensuring that, in a telehealth project or activity, the person's explicit consent is obtained and recorded if confidential information is collected or used for other purposes, such as research, evaluation and quality control.

With respect to the confidentiality of health information, the issue is to strike the right balance between protecting confidentiality and sharing information in order to provide the user with safe, quality care. Maintaining this balance requires trust between a user and the health professionals he deals with.

The Commission recommends:

(R-25) That professionals show greater transparency with users by informing them about the health information sharing practices that may be used by health care team members as well as the measures taken to protect their personal information.

With respect to the security of health information, the most serious risks result from sharing information using technologies that are not directly monitored by the health and social services network. Such technologies are much more likely to compromise the confidentiality or integrity of information due to their mobility, their use for personal purposes, the risk of losing the device (for example, a cell phone), etc.

Caution

There is a risk of a breach of confidentiality and security of health data when it is shared using tools that are not monitored or are more at risk, such as personal devices and non-secure or cloud-based Internet connections.

Most importantly, clinics, health institutions and the Régie de l'assurance maladie du Québec (RAMQ) remain the trustees of users' health information. As such, they must ensure they prevent the risks of piracy or theft; retrieve data that is stored on the servers of a third party, for example, if the latter declares bankruptcy; or have adequate remedies if data is stored in another jurisdiction.

The Commission recommends:

(R-26) That the Government of Québec, through the Commission d'accès à l'information (CAI) or otherwise, safeguard the security and confidentiality of health information that may circulate outside the strict limits of the health network.

Future directions

The purpose of the Commission's recommendations is to provide a system-wide ethical framework for telehealth. It is an important step, but nonetheless only a first step. More specific issues will arise in each clinical setting. To address these, research and evaluation must continue.

Legal issues, such as access to complaint mechanisms, should be addressed by the competent authorities. The recent creation of a committee by the Collège des médecins du Québec (CMQ) to review its 2000 background paper on telemedicine may provide an opportunity to do so.

Lastly, time should be taken to learn from telehealth experiences in Québec and other countries to ensure the success of the reforms undertaken in the health care system to provide quality services for citizens. In this light, this may even be an ethical duty for the government.

Table 4. Telehealth technologies by group and context of use

Group of technologies	Teleconsultation (real-time synchronous telehealth)	Teleimaging (store-and-forward system or asynchronous telehealth, in differed time)	Telecare, telemonitoring and interactive telehealth (combination of synchronous and asynchronous elements)
Context of use	Clinical practice support across the territory Remote or isolated regions	Clinical practice support across the territory Remote or isolated regions	Home care Real-time follow-up Applications in the living environment Applications on or in the body User follow-up as he goes about his activities (mobile applications)
Level of technological complexity	Simple to complex CMPA level III	Simple to complex CMPA level II	Simple to very complex CMPA levels I, III and IV
Stage of development	Advanced In use 1st and 2nd generations (CST)	Advanced In use 2nd generation (CST)	Some applications at the advanced stage Pilot projects Some applications still at the research stage 1st and 2nd generations (CST)
Type of data used	Voice and image data (real-time video feeds) Physiological monitoring data	Still images Video feeds Digitized monitoring data EEG, ECG, EMG, PET, MRI, etc.)	Physiological or environmental monitoring data Still images Video feeds Voice and text data, in particular for clinical instructions
"Service" aspect: main characteristics	Reduced travel Remote consultation, but in real time More stakeholders involved New relationships between stakeholders	Few organizational consequences Increased rapidity Increased flexibility Facilitates delocalization of the clinical procedure	Relationship based on standardized measures Transformation of care and work organization (continuum of care) Care integrated into a life routine Increased user responsibility for health Increased participation
"Tool" aspect: examples of technologies	Videoconference (monitors, cameras, microphones, etc.) Digital medical peripherals (ultrasound imaging system, electrocardiogram, digital stethoscope, etc.)	Picture archiving and communication systems (PACS)	Telephone, email or text messaging (SMS) reminder systems Interactive Internet health portals Electronic follow-up systems (computer terminals, interactive electronic protocols supported by a visual interface such as a questionnaire, etc.) Applications for smartphones and tablets Digital medical peripherals Motion sensors and algorithms to detect situations considered abnormal Biosensors (invasive or non-invasive) Microchip-based drug delivery (device implanted in the body)

N. B.: - All the technologies shown generally require transmission networks (intranet, VPN, Internet, cloud-based, etc.) as well as servers to store information and, for the health professional, to allow access to it from another device (smartphone, personal computer, etc.).

- The levels of telehealth interventions defined by the Canadian Medical Protective Agency (CMPA) and the generations of telehealth applications identified by the Canadian Society of Telehealth (CST) are shown in tables 5 and 6 respectively.

Table 5. The four levels of telehealth interventions

Level	Description
Level I	Involves activities such as the transfer of medical records, faxes and e-mail over analogue telephone lines
Level II	Refers to the transmission of X-rays and other images and the use of telemetry and still video (e.g., teleradiology and telepathology)
Level III	Involves interactive video, satellite and microwave transmission and images (e.g., teleconsultation)
Level IV	Includes experimental applications such as smart gloves that would allow palpation in surgery guided by a specialist and performed with the help of robotics

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Table 6. The generations of telehealth technologies

| Technologies de télésanté	Description
1st generation: • Codec-based videoconferencing *Thinking about the EHR*	• Non-integrated telehealth hardware-based solutions with no capture or creation of data Criteria: Workflow analysis for EHR integration as a deliverable
2nd generation: • Home telehealth • Store and forward • Teletriage *Integrating with the EHR either directly or indirectly*	• Potentially integrated telehealth solutions that create and capture data Criteria: Application must support minimum messaging standards in order to access EHR directly or through a clinical information system
3rd generation *Fully integrated with the EHR*	• Fully converged solutions, i.e., part of larger clinical systems Criteria: Complete compliance with EHR standards

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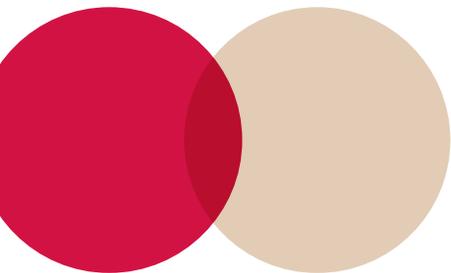
COMMISSION'S CONSULTATION ACTIVITIES AND WORK PERFORMED ON A CONTRACTUAL BASIS

The following people participated in the round table held on february 8, 2013 to inform the steering committee about the organization and delivery of care using telehealth

Jean Boulanger
Director of Information Technologies,
Centre hospitalier universitaire (CHU) de Québec

Carine Daurat
Director of Telehealth,
Centre hospitalier de l'Université de Montréal (CHUM)

Johanne Desrochers
Nurse, Telehealth Co-Chair, McGill University Réseau universitaire intégré de santé (RUIS) and Associate Director of Telehealth, McGill University Health Centre (MUHC)

Dr. Jean-Paul Fortin
Full Professor, Department of Social and Preventive Medicine, Université Laval and Researcher, Centre de recherche sur les soins et les services de première ligne du CSSS de la Vieille-Capitale [Primary health care and services research centre, Vieille-Capitale health and social services centre]

Christian-Marc Lanouette
Telhealth Project Manager,
Ministère de la Santé et des Services sociaux (MSSS)

Renald Lemieux
Assistant Director,
Direction de la qualité, planification, évaluation et performance [Directorate of quality, planning, evaluation and performance] and Director of Telehealth Activities, Université de Sherbrooke Réseau universitaire intégré de santé (RUIS)

Dr. François Lespérance
Professor of Psychiatry,
Université de Montréal, Assistant Executive Director of Medical and Academic Affairs, Centre hospitalier de l'Université de Montréal (CHUM) and Co-Chair of the Telehealth Table of the Université de Montréal Réseau universitaire intégré de santé (RUIS)

The following people participated in the round table held on march 11, 2013 to inform the steering committee about the evaluation of telehealth technologies

Pascale Lehoux
Full Professor,
Department of Health Administration,
Université de Montréal

Guy Paré
Full Professor, HEC Montréal and Holder of the Canada Research Chair in Information Technology Management in the Health Sector

Claude Sicotte
Full Professor,
Department of Health Administration,
Université de Montréal

The following people and organizations participated in a consultation day on april 9, 2013

Professional orders

Collège des médecins du Québec (CMQ)
Dr Yves Robert, secrétaire

Ordre des infirmières et infirmiers du Québec (OIIQ)
[Québec order of nurses]
Caroline Roy, Consulting Director,
Department of External Affairs

Ordre des pharmaciens du Québec (OPQ)
[Québec order of pharmacists]
Diane Lamarre, President;
Guylaine Bertrand, Coordinator of Professional Practice

Ordre professionnel des technologistes médicaux du Québec (OPTMQ)
[Québec order of medical technologists]
Nathalie Rodrigue, President

Industry representatives

TELUS Health
Éric Bourbeau, Vice-President,
Business Development in Québec;
Louis-Marie Boivin, Sales Director

Mr. Bourbeau and Mr. Boivin also acted as representatives of the **Canadian Association of Medical Technology Companies (MEDEC)**

The following people participated in the round table held on may 3, 2013 to inform the steering committee about the ethical issues

Johanne Desrochers
Nurse, Telehealth Co-Chair,
McGill University Réseau universitaire intégré de santé (RUIS) and Associate Director of Telehealth, McGill University Health Centre (MUHC)

Dr. Jean-Paul Fortin
Full Professor, Department of Social and Preventive Medicine, Université Laval and Researcher, Centre de recherche sur les soins et les services de première ligne du CSSS de la Vieille-Capitale [Primary health care and services research centre, Vieille-Capitale health and social services centre]

Dr. Isabelle Mondou
Assistant Clinical Professor, Department of Social and Preventive Medicine, Université de Montréal and Coordinator of the Research Ethics Board, Agence de la santé et des services sociaux (ASSS) de Montréal

Marie-Claude Prémont
Lawyer, Full Professor,
École nationale d'administration publique

The following people agreed to do a critical review of the first version of the position statement

Pierre Blain
Executive Director,
Regroupement provincial des comités des usagers
[Provincial association of users' committees]

Marie-Pierre Gagnon
Associate Professor, Faculty of Nursing, Université Laval
and Holder of the Canada Research Chair in Technologies
and Practices in Health

Dr. Mona Gupta
Assistant Clinical Professor,
Department of Psychiatry and Associate Professor,
Bioethics Programs, Université de Montréal

The commission awarded a short-term contract to the following person

Julia Sotousek
Doctoral student in law, Université Laval

The Commission would like to thank all those who collaborated in its reflection and contributed to the content of its position statement on clinical telehealth. The comments and opinions expressed therein are those of the Commission alone.

MEMBERS OF THE STEERING COMMITTEE
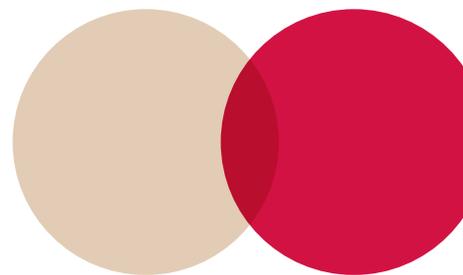
Committee chair*

Dr. Pavel Hamet
Professor
Université de Montréal

Committee members*

Denis Beaumont
Executive Director
TransBIOTech

Claude Jean
(until December 12, 2013)
Executive Vice-President and
General Manager
Teledyne DALSA
Member of the Board of Directors
NanoQuébec

Marc Lalande
(until November 23, 2012)
President/Treasurer
Quebec Aboriginal Science and Engineering Association
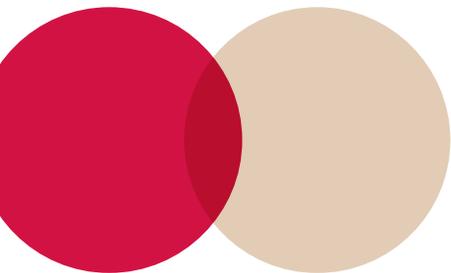
Ex-officio members

Nicole Beaudry
Notary
Secretary General of the Commission de l'éthique en science et en technologie (CEST)

Édith Deleury
Professor Emeritus, Faculty of Law
Université Laval
President of the Commission de l'éthique en science et en technologie (CEST)

Secretariat of the Commission

Dominic Cliche
Ethics Advisor
Meeting Secretary

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* The chair and members of the steering committee are also members of the Commission de l'éthique en science et en technologie (CEST).

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Professor Emeritus, Faculty of Law
Université Laval

Members

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Valérie Borde
Scientific Journalist

Pauline D'Amboise
Vice-President of Cooperative Support and
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Desjardins Group

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Dany Rondeau
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Observer

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Assistant Deputy Minister, Direction générale de la planification, de la performance et de la qualité [General directorate of planning, performance and quality]
Ministère de la Santé et des Services sociaux (MSSS)

Secretary General

Nicole Beaudry

www.ethique.gouv.qc.ca

Clinical telehealth refers to the delivery of remote health care using information and communications technologies (ICT). It allows consultations, monitoring and clinical follow-up to be provided at a distance.

Integrated into a global vision shared by all stakeholders, it can be beneficial. In particular, it supports integrated service networks, in response to a number of problems facing Québec's health care system.

From an ethical standpoint, telehealth must respect the principles of accessibility, quality, equity, responsibility and autonomy that are central to our health care system. It also raises issues with respect to the transformation of the health care setting, the quality of the clinical relationship, the protection of vulnerable people, the medicalization of the living environment and the confidentiality of health information.

In the position statement *Clinical telehealth in Québec: an ethical perspective*, the Commission de l'éthique en science et en technologie reports on the vision that emerged from the consultations it held and which is intended to ensure that the development of telehealth will be of benefit to all.

To support ethical reflection and responsible decision making, the Commission defines the characteristics relevant to an ethical evaluation of telehealth applications and the values involved.

Taking note of the major challenges facing decision makers and stakeholders, it makes a series of recommendations that mainly concern the production and transfer of knowledge; quality control; funding; support for users, informal caregivers and professionals; the prevention of situations of vulnerability; individual autonomy; and the protection of health information.

The full position statement (in French) as well as this English summary and the Commission's other publications are available at the following address: www.ethique.gouv.qc.ca.

The mission of the Commission de l'éthique en science et en technologie is, on the one hand, to inform, raise awareness, receive opinions, stimulate reflection and organize debates on the ethical issues surrounding developments in science and technology and, on the other hand, to propose guidelines to assist stakeholders in their decision making.