

IT STARTS
WITH EACH
AND EVERYONE
OF US

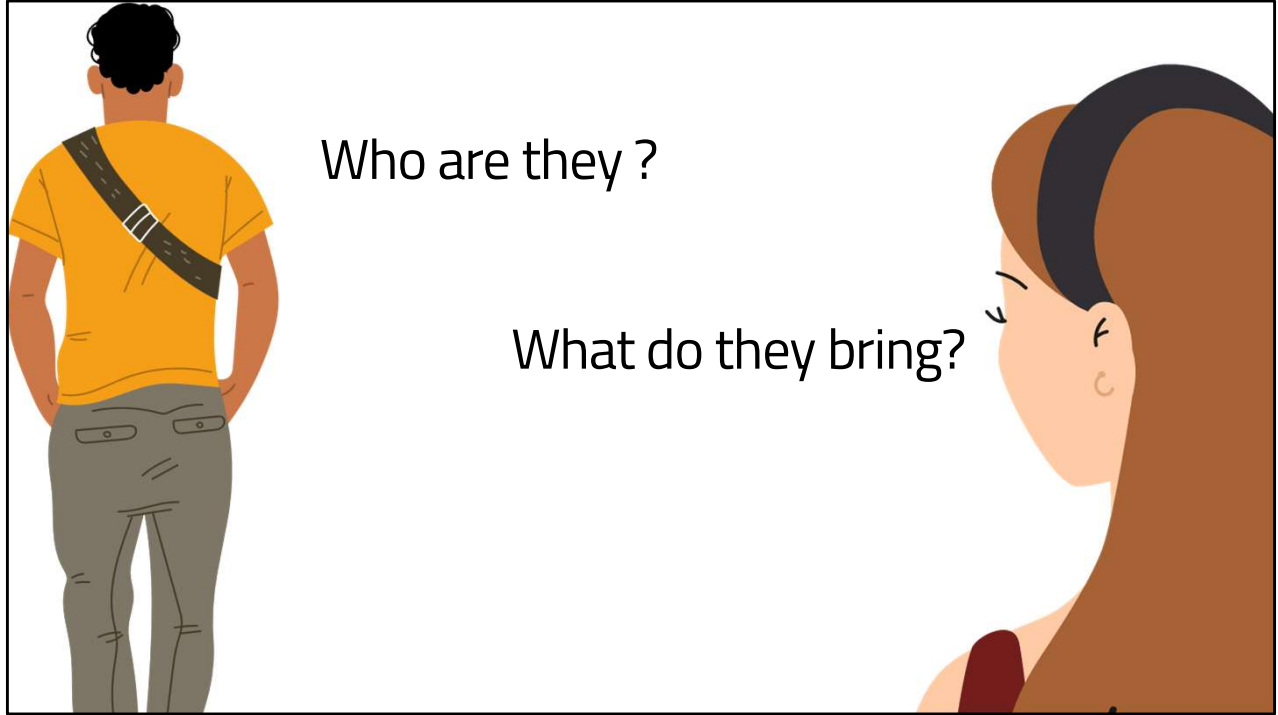


Being a partner in health starts with your own health. Your body is like a car — it's what you drive through life. If the mechanic warns you not to take curves at 120 because your suspension is weak, you can adapt... or not, and risk scrapping your car — and paying for it later. Health works the same way.

The difference is, no one really gets “driving lessons” for their body (well, except the professionals) — and if you scrap your *transportation device*, unlike a car, you don't get another one. That's why partnership begins with asking questions, paying attention, and taking care of yourself as best you can — or getting help when you can't.

You can also get involved in health by shaping how the system runs: what services are offered, how future professionals are trained, and what research should focus on. And you can help raise awareness, like car owners who share tips online.

Think of new EV owners forming forums and groups to support each other. In healthcare, it's the same: people who've learned a lot — either by taking great care of themselves or by living through serious “breaks” — have real potential to help others better understand how to engage in their own health.



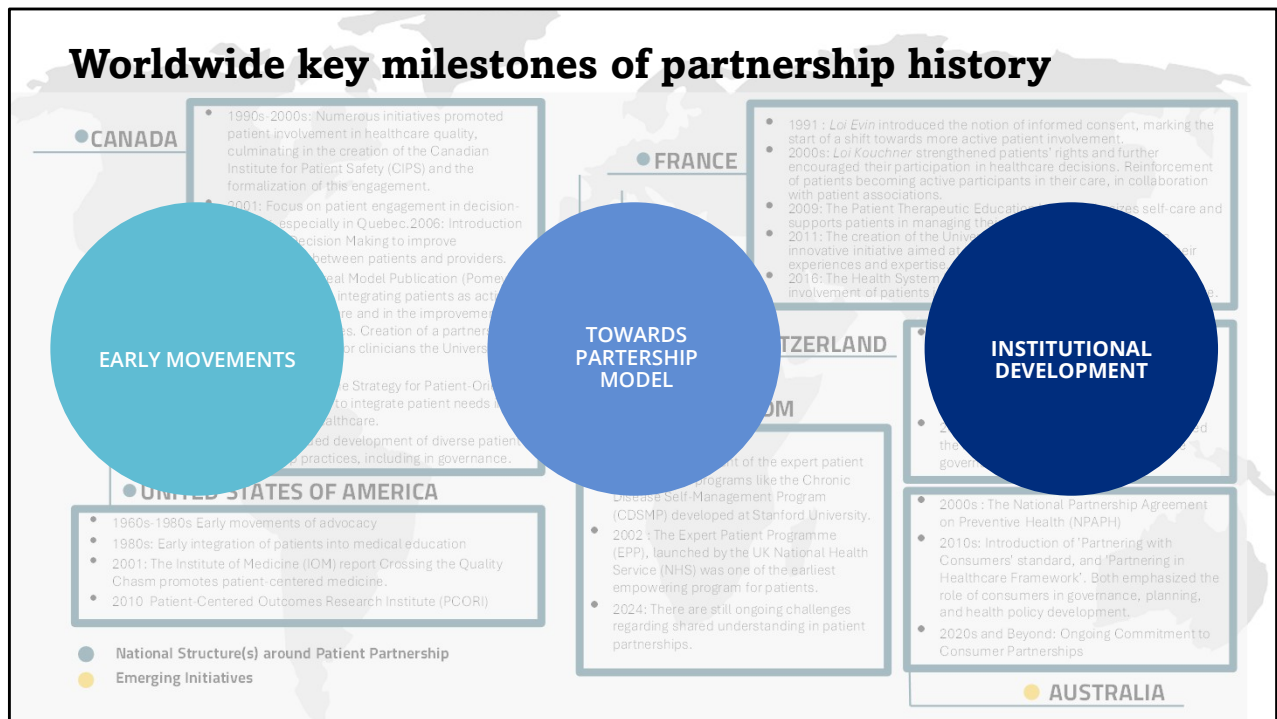
People with lived experience, who, personally or as a caregiver, have dealt with psychological, physical or social issues.

What they bring?

A valuable, complementary, and cross-disciplinary perspective. They help identify challenges and opportunities, and highlight blind spots in the system.

It's a meeting at the intersection of experiential, clinical, administrative, and scientific knowledge, which allows for deeper and more enriched discussions, better policy directions, and decisions that make more sense for everyone.

Where does it come from?



The history of patient partnership didn't happen overnight — it grew step by step. It started in the 60s with patient rights movements — that's when the motto *Nothing about us without us* imposed itself as the way to talk about partnering with patients.

In the 90s, we shifted from decisions *for* patients to decisions *with* patients, with models like the expert patient in the UK, the patient resource in France, and patient-centered care in the US.

By the 2010s, partnership was written into policies — in Canada, France, and even recognized by the WHO. Today, partnership is part of education, governance, research, care as well as prevention.

But is it applied in what you guys do on a daily basis?

Worldwide

Many participants in surveys but not very much partnership with patients and public



Patients as “Participants”

Patients as “Partners”

Filling in surveys

Cocreating the survey

Sitting on a focus group

Sitting on governance committees

Providing numbers for statistics

Deciding which outcomes matter

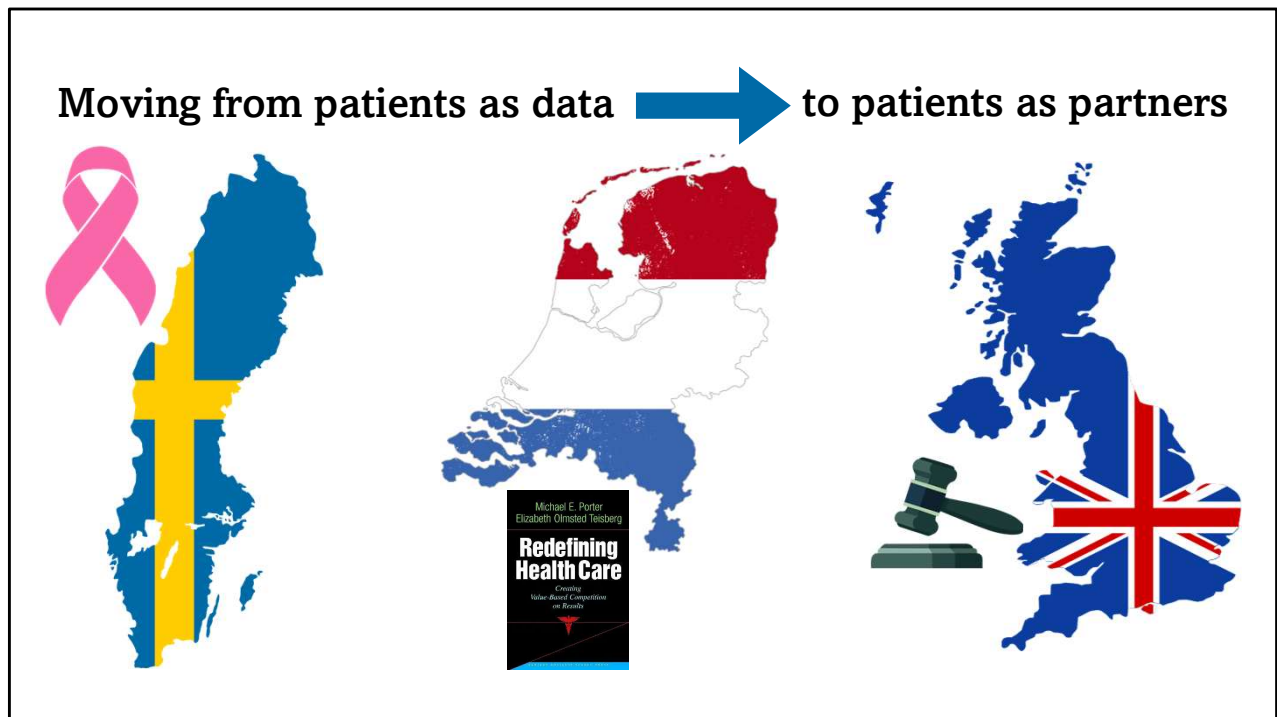
Adding Biomedical data

Adding quality-of-life & equity indicators

Stamp proofing value improvement plan

Co-designing value improvement

Not very much...When we look around the world, there are many examples where they talk about patient partnership but...it's not really partnership. Most of the time, patients are simply asked to fill in surveys or provide answers for statistics. In other words: they give their opinion but have no influence at all on how the questions were built, were they the right ones to address what counts for people? Were they understandable? And the answers...how do patients see the data analysis vs how professionals do? So.....a survey or a focus group is not patient partnership.



Even though there aren't many, some examples are worth mentioning.

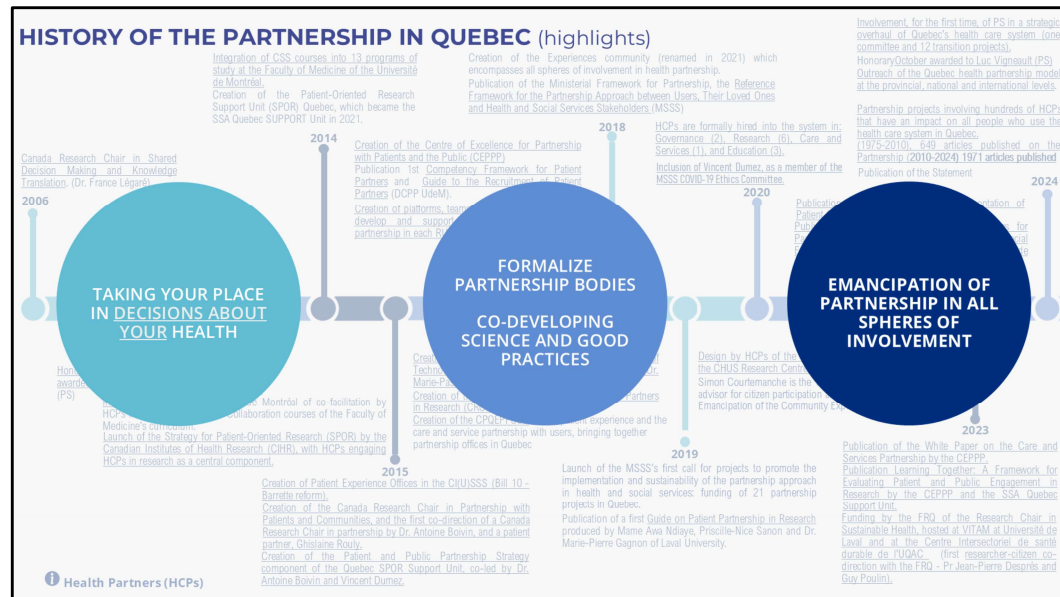
In Sweden, patients sit on the governance committees of the national breast cancer registry, where they helped introduce indicators on quality of life and rehabilitation — not just biomedical data.

In the Netherlands, some hospitals working on Value-Based Health Care brought patients into the teams deciding which outcomes to measure.

In England, in organizations like the National Institute for Health and Care Excellence, patients and caregivers are included in guideline committees and in the appraisal of new technologies. They don't just react after the fact: they help define which outcomes matter, what should be measured, and how evidence is interpreted.

These examples are still rare — yet they show what's possible when patients move from simply filling in statistics to actually shaping the conversation on what should be measured, and why.

Let's see how things evolved in Quebec.

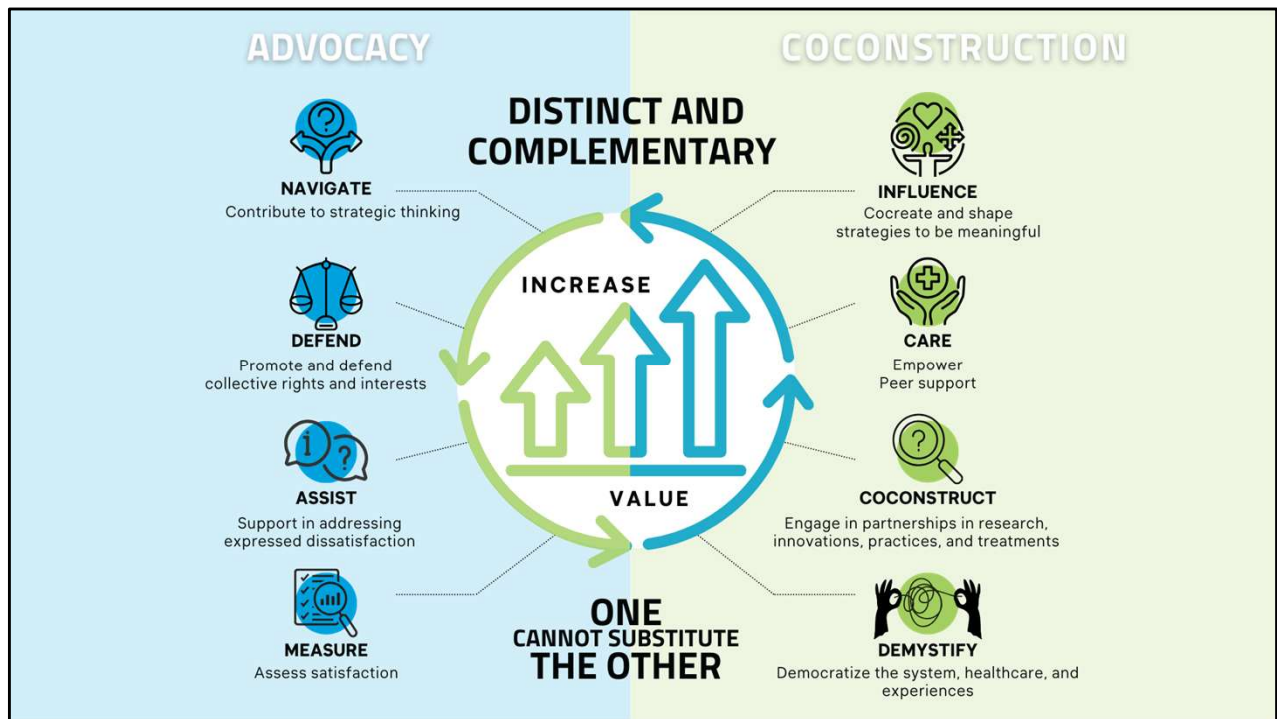


In Quebec, partnership took off with the Strategy for Patient-Oriented Research and the cr Montreal Model — now an international reference.

From there, partnership grew into a co-developed science, with best practices shaped tog In 2021, Quebec’s SPOR Support Unit gave a vote of confidence to its patient partners gro become the first provincial patient-partner community fully self-managed.

And today, we see more and more recognition of what partnership can bring. Patients are r teams, research chairs have been created in partnership with patients and communities, ; increasingly present on strategic health system committees.

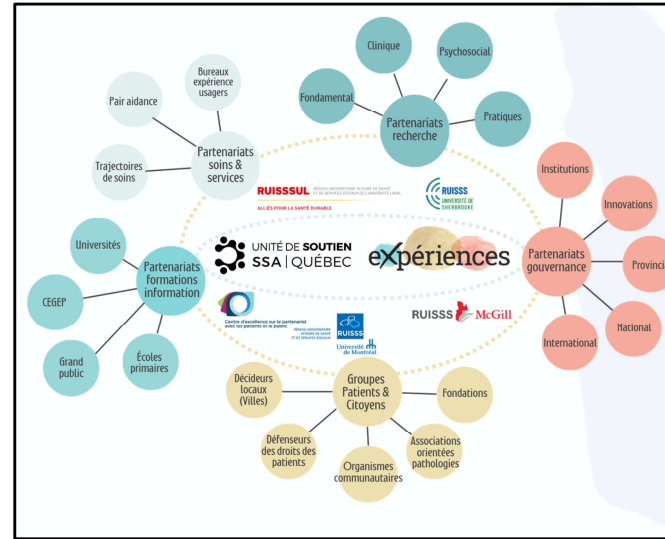
This all shows the progress Quebec has made — moving towards real inclusion of patients in health decisions, research, education, and clinical practice.



In many places, people don't distinguish between patient advocates and patient partners. But their roles are very different. Advocates defend and promote rights; partners act *within* organizations, co-constructing solutions that make sense in real life — with all imposed figures, limits, and obstacles.

For example, at a recent conference, a patient advocate insisted the government should guarantee any care or service to every patient. As a patient partner, my view is different: the government cannot promise that. It's public money — there are limits. What matters is being transparent, making hard choices, and setting priorities together.

And it's possible: during COVID, patient partners among the most vulnerables have drawn the line on ventilators. Contrary to what many expected, they did not ask to be prioritized — they disconnected themselves. These were hard but necessary conversations. Health cannot rest only on doctors' or policy makers' shoulders. It is a shared responsibility: your body, your car, your responsibility. So... how are patient partners involved in the health system?



They work with all stakeholders in the health ecosystem to ensure that decisions produce solutions that are as effective and aligned with patients' needs as possible.

In Quebec there is about 2500 health partners involved in the system



And they are engaged across the system — from governance to care where their presence is growing. An innovation worth expanding is peer support, there’s been research about it in clinical teams treating cancer and it works.

I discovered it by myself during my own cancer journey. At that terrifying moment before diagnosis, the only real help I got was from a woman in relapse. She simply normalized my experience and made it less dramatic. When I told her I was scared to death about chemo, she said: *“It’s not fun, but you’ll have good days. It’s not like in the movies.”* I thought, *she must know what she’s talking about.*

After my first chemo, I saw she was right. I even felt stronger than the week before — because fear and sleepless nights had drained me more than treatment itself. Wouldn’t outcomes be better if patients started day one in better shape? That’s what inspired the idea of a research project — and then Quebec's Breast Cancer Foundation adopted it and brought it to life.

Since 2021, seven trained cancer survivors now answer calls from women who are afraid, newly diagnosed, or already in treatment. They normalize what women are going through, guide them to reliable info, and help them navigate the system. And it works: anxiety drops by 46% after just one call.

But that’s easy...It direct care, hands-on, the impact is obvious and quite instant.

Let me give you a more abstract example, closer to some of your realities.

How do patient react to secondary use of health data in oncology?

How can we best inform them?

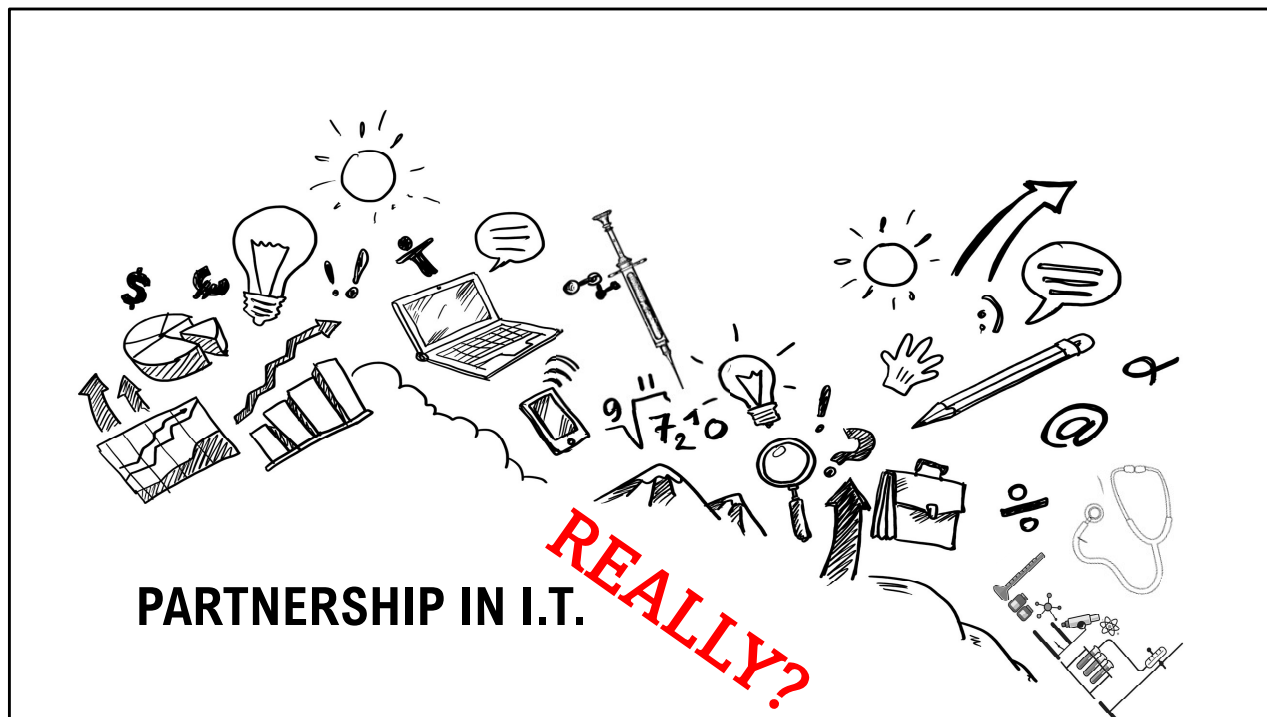


The question of building trust in data and AI was raised in a research project on secondary use of health data in cancer. Patient partners suggested adding a prospective study within the main one — to analyze how patients respond to information about it.

We all know AI and big data are powerful. But without patient trust, they won't deliver.

In this case, we talked about putting posters to inform patients about accessible information on the subject. There was a debate about the looks of the posters. Professionals wanted a very medical, corporate look. Patients wanted something punchy and fun. The results of the prospective study showed patients were far more attracted to the punchy version.

In this example, patient partners pushed the team to break out of the usual mold, and the result was a more effective, more human way to reach people.



Quebec IT systems are in constant evolution. In the past three years, new committees have finally brought the patient's voice directly into digital health design and decisions. A working group was set up to tackle all sort of issues such as instant access to lab results or letting patients add notes to their health record. With coaching, everyone learned to set boundaries, self-regulate, and make the collaboration as rich as possible. And even though at first, it felt as if people came from different planets, over time they've learned to work together — and today about twenty patient partners are actively involved.



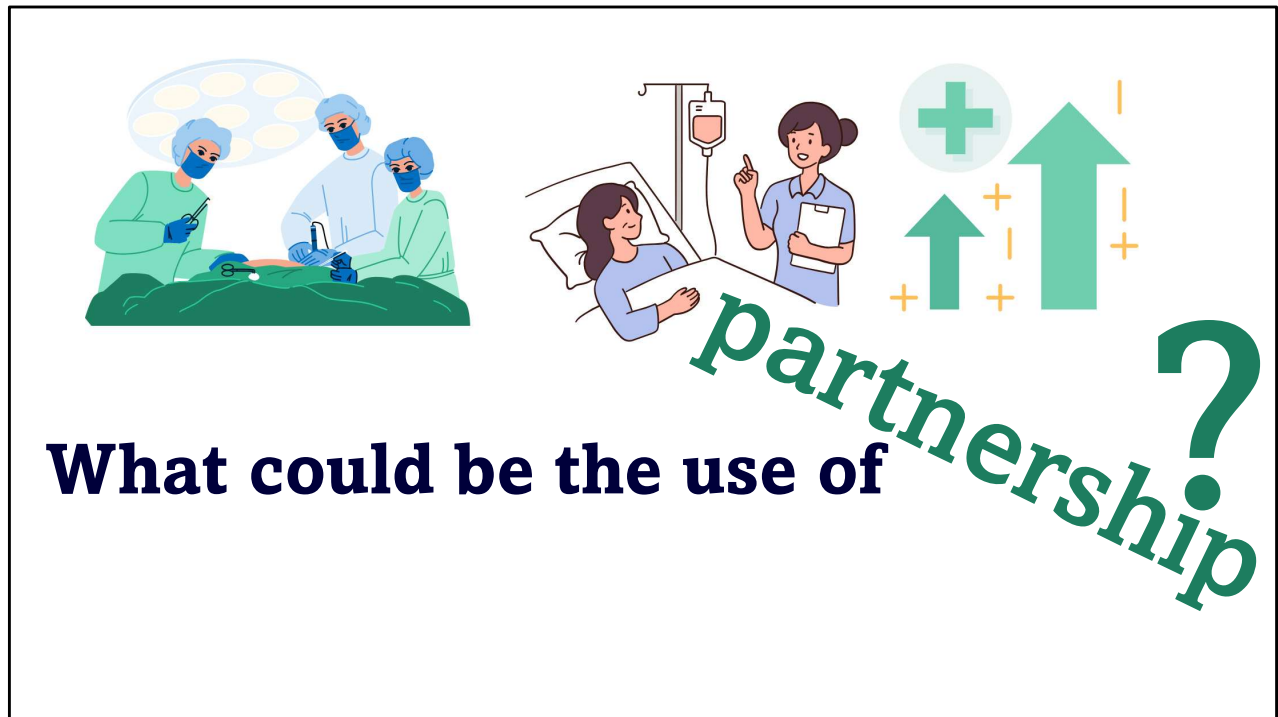
What could be the use of

partnership?

Now let's imagine what patient partnership in your teams might look like.

Imagine a team working on criterias to classify patients in maternity care. Patient partners could ensure categories don't overlook real issues — like self-capacities that will inform you about how women can or cannot apply recommendations and therefore might come back and end up costing more. Let's say your patient partner says, *"You know they're asking women to eat all these healthy foods while breastfeeding, but with \$70 a week to feed my family, if I do that I won't pay rent."*

Wether it's that or something else, they might bring informations that will help you better shape your criterias so they really inform predictability and decision making about what ressources to allocate to which group of patients.



Now think of a team building an AI system to monitor recovery after surgery. If you bring a patient partner on board, they could help you check whether the alerts are clear, whether the scores make sense, and whether the whole thing feels trustworthy.

They might even bring you elsewhere with questions like : ‘If this system is tracking my progress, why not share some of that information with me at my bedside?’

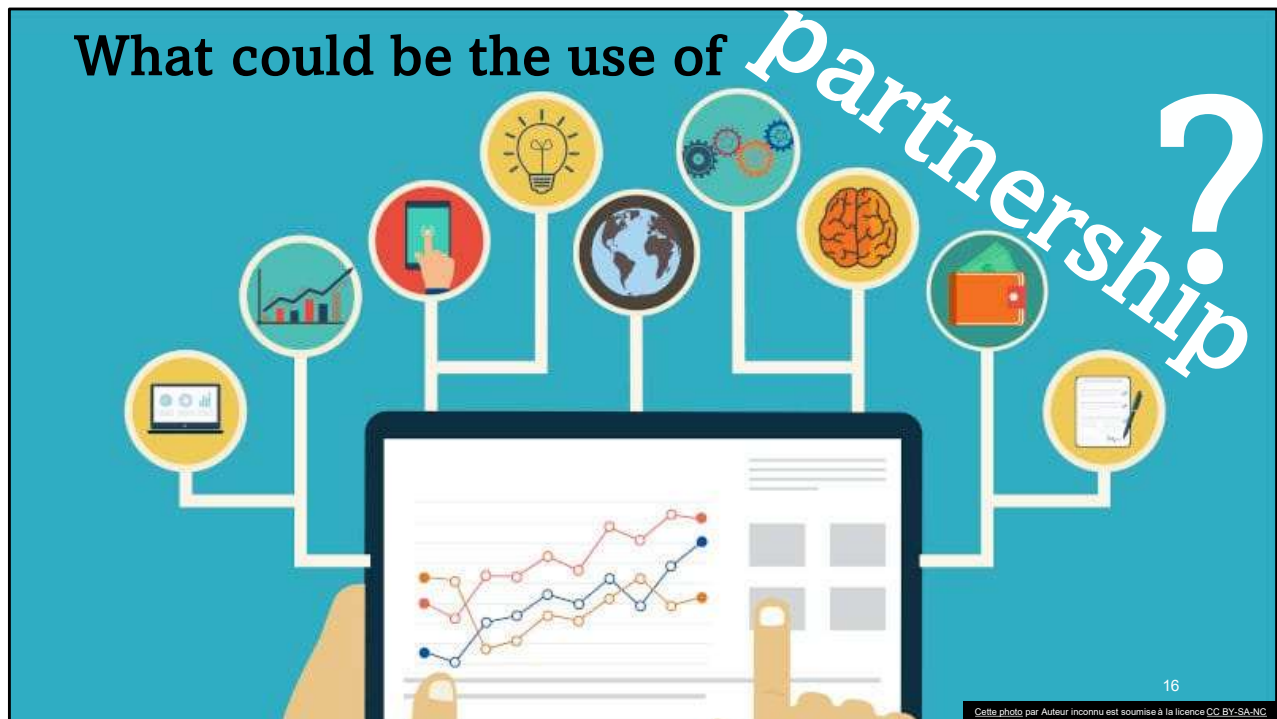
Insights like that can help make the tool not only technically strong, but also meaningful and useful for the people it’s supposed to serve.



Now think of resource allocation.

When deciding where money should go, bringing patients in from the start changes the conversation. They might ask, *“Wait — this procedure costs that much? Why spend here when it makes no real difference for us compared to another option?”*

In big health debates, everyone claims to speak “for patients” — yet patients are absent. Let’s stop speaking in their name and let them in the room. Because when patients are part of the equation, decisions become more transparent, collective, and meaningful for the whole community.



In value based healthcare now...Value-based healthcare links costs to outcomes — but who decides what counts? With patients in the room, the focus shifts. Let's say regarding length of stay. What if patient partners would say : *“Going back home matters very much to me and I’m ready to do whatever not to stay in the hospital too long.”* Suddenly, the system measures what truly creates value. And it’s not just theory — it’s been done here in Quebec. Erin Cook, presenting this week, has done it in her hospital.

Now, as we’ve seen, partnership can happen in specific projects, but also at a broader scale — up to the governance of the health system itself. And that’s what happened in Quebec

Full of Good Intentions...

10 reforms *in the interest
of the patient* since 1971

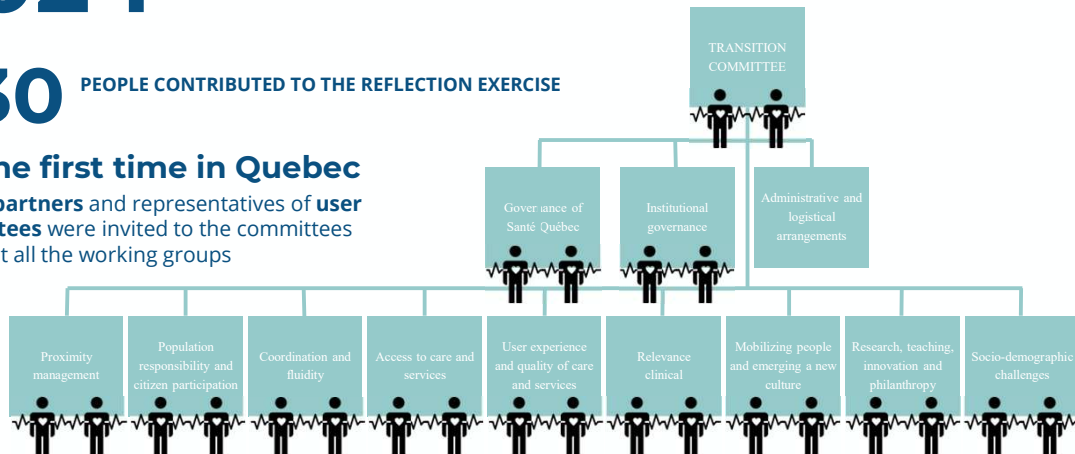


Since its foundation in 1971, Quebec's healthcare system has undergone 10 reforms almost one whenever government changed. They all have been carried with the best possible intentions towards the patients but it was only in the last one that leaders thought it was a good idea to bring patients around the decision table. In December 2023, the Government adopted a law that merged 33 regional systems into one large agency serving the entire population. For the first time, patient partnership was written into law. And it was just a beginning.

2024

830 PEOPLE CONTRIBUTED TO THE REFLECTION EXERCISE

For the first time in Quebec
Health partners and representatives of **user committees** were invited to the committees of almost all the working groups

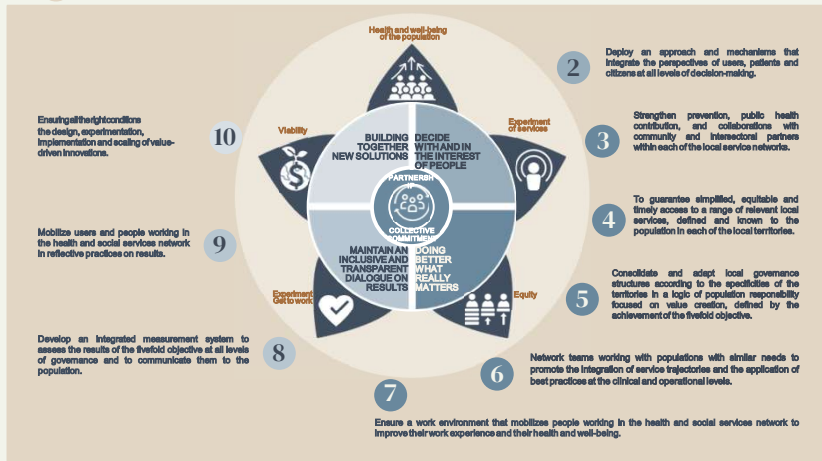


In January 2024, a group of 14 people from diverse expertises were assigned to The Transition Committee which had to think about a plan of transformation for the system. For the first time at such a highly strategic instance a patient partner was assigned....it was me...when I received the call from the Deputy Minister I thought I had done something terribly wrong...You can't imagine how my jaw dropped when I realized why he was calling me. Anyway...that's another story.

Under that committee 12 working groups had to think about specific issues and make recommendations. In the transition committee, I'm really happy to have insisted on the fact that patient partners had to sit at the table of those working groups too. It made a difference.

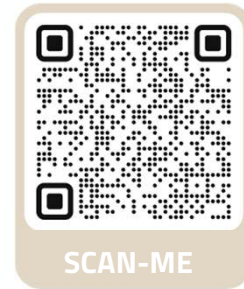
TOGETHER, FOR SUSTAINABLE TRANSFORMATION AND RESULTS THAT MATTER

- 1 Adopt and communicate the vision of population responsibility focused on value creation, defined by the achievement of the fivefold objective, to promote its appropriation by the network's teams and by citizens and support their commitment to the transformation.



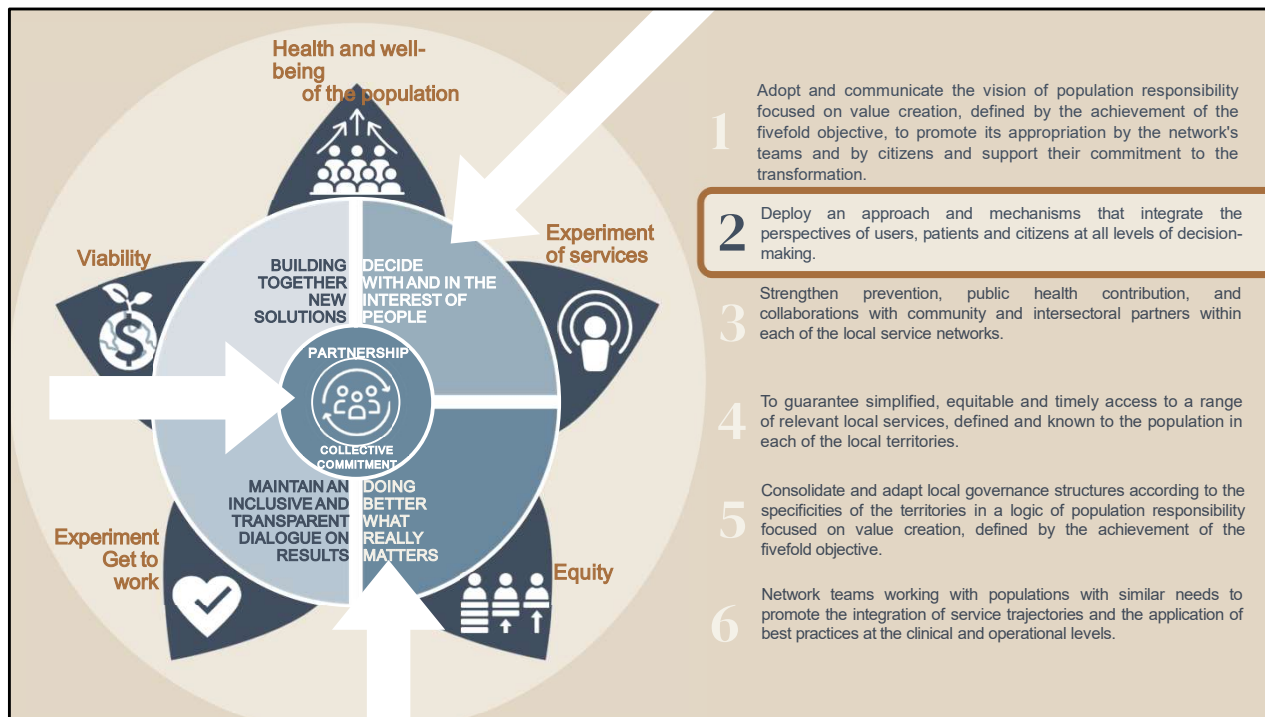
- 11 Implement a new culture of inclusive, agile, pragmatic, fair and accountable governance, focused on execution, to ensure the successful implementation of the Transformation Plan.

- 12 Systematically strengthen the management of major strategic initiatives, including the deployment of the transformation plan, by:
 - Adopting a rigorous but pragmatic preparation
 - Designating a dedicated and accountable person
 - Ensuring a dynamic and relevant choice of the necessary resources.
 - Promoting team engagement through organizing and collaborative communications

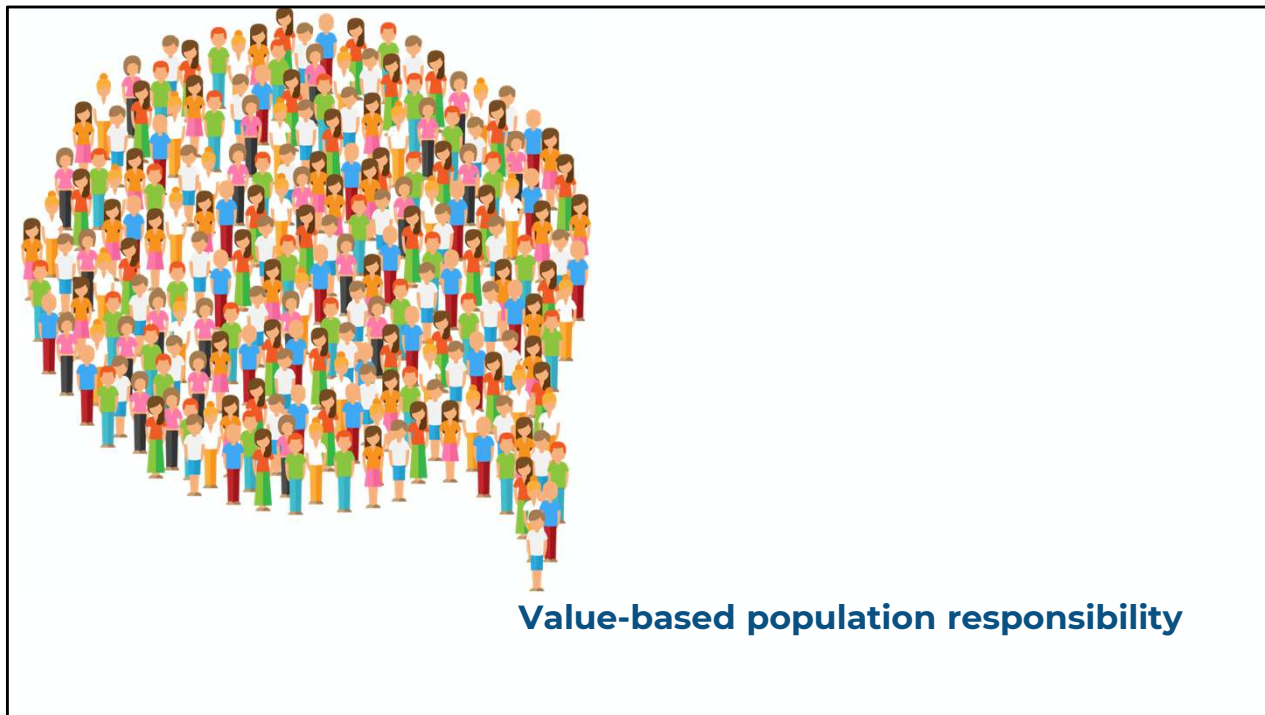


19

This is the final product of the year of work it took everyone to fulfill the job of consultation they had to do for their recommendations to be the reflect of what really counts. The transition committee ended up with twelve recommendations.



As you see partnership is at the center of everything – one the pillars is DECIDE with and in the interest of people and the second recommendation is about integrating patients and citizen at all levels of decision making. If it ended up that way, it's because of thos twelve patient partners out of all the 830 or so people who worked on all topics. Their involvement had such impact that each and every reports submitted underlined the importance of having the voice of patients around the table. I think this speaks quite loud about once you tried it, you don't want to go back.



Going deeper into the Transformation Plan

Population Responsibility and Value-Based Healthcare have now been merged. Traditionally, population responsibility meant maintaining or improving the health of people in a given territory. With rising costs, the question is: how do we get people on board without shifting the whole responsibility on them? Maybe by listening to what truly matters to them? and by sharing clear, transparent information about the system's limits? That's how the idea of **Value-Based Population Responsibility** took shape — linking responsibility for population health, with the voices and priorities of the people themselves.

Where once only policymakers sat at the table, the Transformation Plan made it clear: citizens whose lives are shaped by these decisions must also be there.

SANTÉ QUÉBEC

Plan 2025–2028 du réseau de la santé et des services sociaux
Coup d'œil sur la planification et les résultats attendus d'ici 3 ans

Prendre soin des gens. Aller de l'avant.

Mission
Offrir et coordonner des soins et services accessibles, de qualité et adaptés aux besoins de la population

Vision
Ensemble, pour la santé, le mieux-être et un réseau dont nous sommes fiers

Valeurs
Respect Collaboration Excellence
Engagement Bienveillance

Ce qui guide nos actions au quotidien

Prendre les devants
Avoir de l'impact

Agir au « nous »
Écouter et donner l'heure juste

4 orientations pour guider nos priorités

1 UNE SANTÉ PLUS ACCESSIBLE
Vers un réseau de santé et services sociaux accès dans la communauté

Envisager la santé de façon plus globale, intégrer la prévention et simplifier l'accès

Objectifs:

- Assurer un accès simplifié et équitable aux soins primaires et aux services de proximité
- Engager les citoyens pour qu'ils soient des acteurs de leur santé et mobiliser la communauté dans la prévention et les services
- Renforcer l'accès et la continuité de services sécurisants pour les communautés des Premières Nations et Inuit.

2 UN PARCOURS PLUS FLUIDE
Vers des services de qualité qui comptent pour les citoyens.

Prioriser l'efficacité et la pertinence des soins

Objectifs:

- Coordonner la prise en charge des grands utilisateurs et des populations vulnérables (personnes en difficulté, aînées en perte d'autonomie, santé mentale)
- Optimiser l'efficacité et la fluidité des trajectoires de soins et de services sociaux (urgence, chirurgies, hospitalisation)
- Prioriser l'offre de soins et services selon la pertinence, la qualité et la valeur créée pour la population.

3 UNE ORGANISATION PLUS HUMAINE
Vers l'engagement et la fierté

Rebâtir la confiance des personnes ouvrant dans le réseau de la santé et des services sociaux

Objectifs:

- Valoriser, fidéliser et développer les talents et le leadership
- Assurer l'engagement favorisant la stabilité des équipes de travail et la continuité des services
- Développer un milieu de travail sain, sécuritaire et durable, propice au mieux-être

4 DES FAÇONS DE FAIRE PLUS PERFORMANTES
Vers un système efficient et productif


Créer de la valeur et répondre aux besoins grandissants en adéquation avec les ressources disponibles

Objectifs:

- Optimiser, anticiper et ajuster les opérations en continu pour assurer un pilotage efficace du réseau en temps réel
- Planifier en fonction des besoins anticipés, des résultats de santé et de l'utilisation optimale des ressources
- Alléger le fardeau administratif et accorder plus de temps à la prestation de services aux usagers
- Améliorer les synergies des fonctions administratives en soutien aux opérations cliniques

Catalyseurs
Éléments essentiels à la transformation

- Communication simple, claire et accessible
- Gouvernance et imputabilité
- Données soutenant la prise de décision
- Transformation numérique et interopérabilité
- Innovation et avancées scientifiques



SCAN ME

TO CONSULT SANTÉ QUÉBEC'S STRATEGIC PLAN OR ITS SUMMARY

8 indicateurs phares								
pourcentage de personnes ayant un professionnel ou une équipe de soins de première ligne attiré après avoir fait la demande	91,7 %	1 632 008	34,5 M	0 %	63,3 %	6 316	13,9 %	printemps 2025
Mesure de départ:								
Cible 2027-2028:	> 98 %	1 340 000	43,1 M	90 %	75 %	1 000	8 %	+ 5/100 par rapport à la mesure de départ

The Transition Committee's work directly inspired Santé Québec who also worked with patient partners on their Strategic plan, and traces of the Transformation plan I just talked about can be seen here too. Its mission states: *to offer and coordinate quality care and services that are accessible and adapted to the population's needs.* Among the guiding principles: *Work together, listen, and be transparent.* And across all four priorities, you can connect the dots. Again...The patient's voice has been heard.

TABLEAU SYNOPTIQUE

STRATÉGIE NATIONALE DE PRÉVENTION EN SANTÉ 2025-2035

LA VISION
Un Québec où la santé et le bien-être de la population sont au cœur des choix collectifs et individuels, à chaque étape de la vie.

LA FINALITÉ
Réaliser des gains additionnels en santé par une intensification des efforts structurés, une meilleure intégration des actions et une mobilisation de tous les acteurs de la société civile.
Deux résultats sont visés d'ici 2035 afin de contribuer à améliorer la santé et le bien-être de la population et à alléger la pression sur le système de santé et de services sociaux:

- Réduction de 10 % du fardeau des maladies évitables.
- Réduction de 10 % de l'écart de mortalité prématurée lié aux inégalités socioéconomiques.

LES ORIENTATIONS ET LES AMBITIONS COLLECTIVES
Quatre grandes orientations visent à rassembler et à responsabiliser tous les acteurs de la société pour travailler davantage en prévention. Elles se traduisent en 19 ambitions collectives qui viennent catalyser les efforts vers des buts communs à atteindre.

LES PRINCIPES DIRECTEURS

Création de valeur: Faire de la prévention un moteur de prospérité et de vitalité pour l'ensemble du Québec. La prévention crée de la valeur pour la société entière, bien au-delà des gains individuels et du seul secteur de la santé et des services sociaux.

Équité et justice intergénérationnelle: Atteindre les inégalités sociales de santé dès aujourd'hui et pour les générations à venir.

Collaboration intersectorielle: Agir sur l'ensemble des déterminants de la santé exige l'engagement de toutes et tous, tous secteurs confondus, selon leur champ d'action et leurs ressources.

Innovation: Fonder les actions sur les savoirs scientifiques et expérientiels, ainsi que les nouvelles approches, méthodes ou technologies pertinentes, afin d'évoluer constamment et en adéquation avec les différents besoins et réalités.

Transparence: Assurer une communication claire des résultats pour garantir la mobilisation de la population et des partenaires.

Partenariat avec les citoyennes et citoyens: Renforcer le partenariat avec les citoyennes et citoyens pour identifier les enjeux, coconstruire des solutions, ainsi que mettre en oeuvre et évaluer les actions de prévention.

LA PRÉVENTION, C'EST LA SANTÉ

ORIENTATION 1 RÉDUIRE LE FARDEAU DES MALADIES ÉVITABLES
Ambitions collectives:

- Les choix alimentaires sains, abordables et durables sont à la portée de toutes et tous.
- Toutes et tous peuvent adopter des modes de vie plus sains et actifs dans leur quotidien.
- Toutes et tous adoptent un mode de vie sans tabac.
- La consommation d'alcool ainsi que les méfaits sont en régression.
- Les interventions cliniques préventives sont accessibles à toutes et tous en temps opportun.

ORIENTATION 2 S'ENGAGER POUR DES GÉNÉRATIONS EN SANTÉ, AUJOURD'HUI ET DEMAIN
Ambitions collectives:

- Tous les parents ont les ressources et compétences requises pour appuyer le développement de leurs enfants.
- Les enfants et les jeunes évoluent dans un contexte favorable à leur développement optimal.
- Le niveau de bien-être est élevé pour toutes et tous.
- Les personnes vivant en contexte de vulnérabilité disposent des moyens et des compétences pour répondre à leurs besoins de base.

ORIENTATION 3 PRÉSERVER ET BÂTIR DES MILIEUX DE VIE SAINS ET DURABLES
Ambitions collectives:

- Toutes et tous ont accès à la nature et peuvent pratiquer des activités de plein air.
- Les environnements naturels et bâtis favorisent un mode de vie actif, sain et sécuritaire.
- L'aménagement des espaces dans la communauté favorise le vivre-ensemble.
- Toutes les personnes qui travaillent bénéficient de conditions qui assurent leur santé et leur sécurité.
- Les communautés déploient des actions qui protègent la santé et réduisent les effets des changements climatiques.

Un modèle d'action intégré

GUIDING PRINCIPLES
Partnership with Citizens:
Strengthening collaboration with citizens to identify issues, co-create solutions, and implement and evaluate prevention actions.

Also, in the recent National Health Prevention Plan, patient partners were involved — and one of its guiding principles is to *partner with citizens*. Patients have been heard.

Now... where does a government start when it decides to involve patients? That's exactly where the Position Paper created by the Experience Community can help set the wheel in motion.

POSITION PAPER

ON PARTNERSHIP

From public policy to population health:
Partnership, **a wise choice to create value for the benefit of the community**

NOVEMBER 2024

expériences
UNITE DE SOUTIEN
SSAI QUÉBEC

SCAN ME

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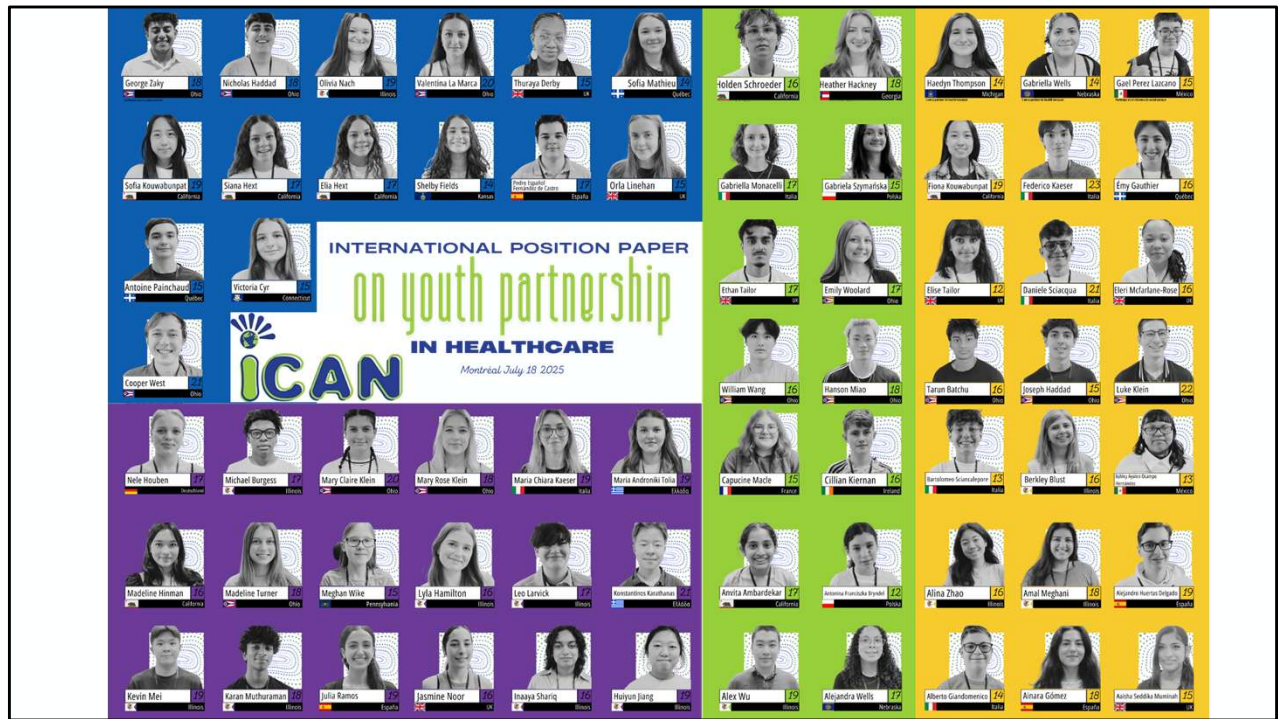
We took a step back to assess the state of health partnership across the ecosystem, to reflect on what has been learned, but also identify the gaps and blind spots, to finally put forward recommendations. For the first time in a paper like this, the roles were reversed: it was led entirely by patient partners and health professionals were helping the patients. Here's what came out of it.



The five areas of engagement were identified — and we noticed issues. It became clear that we needed a shared understanding of what partnership is, and what it is not. We needed to align our practices so they don't contradict each other. We must dedicate the right resources, give partnership proper recognition, and involve the population in their own health. These recommendations include concrete courses of action, grounded in the experiential knowledge of about fifty people who have been deeply engaged in partnership for many years.



We've talked a lot about partnership — and I bet no one thought about kids. But yes, kids too.
Last summer, some of them from here took part in writing an international paper on partnership with youth



All 76 wanted to bring it back to their 11 different countries, the fruit of their reflexion. And in that paper, IT'S ALL THEIR IDEAS.
So, What do they want?

About this Position Paper

This position paper was co-developed by 76 young people aged 12 to 23 from 11 countries, during the 2025 ICAN (International Children's Advisory Network) Summit held in Montreal from July 14 to 18.

Through a co-construction process with peers and adult allies, youth identified four key priorities to strengthen the development of meaningful partnerships in health with young people. Their voices reflect diverse realities, but a shared goal: to be recognized as active contributors to the health systems.

The following recommendations are a call to action for leaders, professionals, and institutions to build sustainable partnerships with youth on health-related matters.

Accessibility

Accessibility in health partnership for youth means ensuring that all young people — regardless of age, background, literacy level, or support network — can understand, engage with, and benefit from opportunities to be partners in their care and in the healthcare system. This requires access to clear information and a proactive approach to promoting partnership.

- **Use Youth-Friendly Communication Styles & Tools**
Use clear, positive, and accessible language across various communication tools (social media, portals, videos, printed materials). Focus on personal experience and avoid technical jargon. Ensure that information is easy to find.
- **Actively Explain the Benefits of Engagement**
Promote partnership through social media campaigns, hospital portals, and peer support. Demonstrate the importance and value of youth involvement in a concrete and appealing way; first for youth and their siblings, then for their parents.
- **Create Support Structures Co-Led by Youth**
Develop an organization or centralized platform, co-led by young people, that compiles information on opportunities, trustworthy and regularly updated resources. In order to give young people the space and freedom to engage at their own pace, allow trusted adults, such as parents, to be present for support.

Dialogue

The dialogue continuum calls for constant communication reciprocity between young people, patients, and medical professionals. It prioritizes human connection, emotional safety, and transparency over mechanical or repetitive feedback tools in order to guarantee that young people's voices are truly heard and respected.

- **Go Beyond Impersonal and Repetitive Surveys**
Replace repetitive, impersonal questionnaires with more dynamic and open formats that allow young people to express themselves freely. Use conversations, interviews, or storytelling approaches tailored to each individual.
- **Co-Create Feedback Tools with Youth**
Engage young people in designing surveys and questions so that they reflect their language, lived experience, and emotional needs — avoiding cold or ambiguous terms, and allowing responses in their own words.
- **Encourage Real Connections and Ongoing Dialogue**
Ensure professionals actively listen to youth, without discounting, making assumptions or passing judgment. Relationships ought to be intimate rather than business-related. It should promote continuity, trust, and peer support, particularly for young people who receive ongoing or repeated care. Young people should also realize that healthcare personnel are people with their own limitations and difficulties. Realizing this promotes respect for one another and reasonable mutual expectations.

Youth Must Have a Voice in Health Decisions

Young people should be fully involved in the development of policies, social development, services, care and research that impact their health in addition to being listened to when it comes to decision-making in the fields of health, education, and social communities. Real decisions involving hospitals, schools, communities, and the healthcare system at large must be influenced by their opinions.

• Include Young People in Decision-Making Groups

Create youth advisory committees not only in hospitals, but also in schools, public health organizations, research facilities, communities and legislative bodies. Ensure regular meetings, public visibility (e.g. via social media and public spaces), and give them real influence over decisions (e.g., voting role).

• Consider Youth Views in Public Policy Development

Engage youth directly in the creation of laws or regulations pertaining to social communities, the educational system, and health. Their viewpoint needs to be methodically collected, taken into account, and presented to decision-makers on an equal basis with any other contextual factor that influences the choices made by those in positions of power.

• Bring Decision-Makers to Young People

Leaders in the fields of health care, education, and social services should meet young people where they are, in youth groups or schools, to help them understand their potential role in those areas. Younger generations can engage with decision-makers, ask questions, provide feedback, and exchange ideas through clubs, podcasts, and open forums.

Education & Training

Young people must have access to an understandable healthcare system and be aware of their own health conditions in order to fully participate. The goal of education and training should be to give young people the skills, information, and self-assurance they need to take charge of their own health, the health of their peers, and ultimately their role as collaborators in the larger healthcare system.

• Integrate Health Literacy in the Curriculum of Schools

Include topics such as shared decision-making, health literacy, and youth rights in health. To enhance learning at all levels, use age-appropriate resources like interactive exercises, infographics, and videos. Educational content should be tailored specifically to young people, but also developed distinctly for their siblings, families, teachers, coaches, and other important individuals in their environment. Providing education and support to these individuals is essential to ensure a shared understanding and meaningful involvement in youth health.

• Provide Youth Training and Certification Programs

To create a sustainable learning environment, youth must be heard and respected by healthcare professionals. Their expertise and contributions need to be acknowledged completely. Whether it concerns themselves, their loved ones' health, or the healthcare system, official training programs must be created in order to accomplish this. These courses ought to lead to certification, be standardized, and be easily accessible. They need to be co-developed with trained partnership specialists and seasoned youth partners.

• Promote Participation that is Empowering and Safe

Professionals need to learn how to interact with youth in a safe, inclusive, respectful, and genuine way. Additionally, young people need to learn how to communicate their needs to professionals. Youth can be encouraged to talk freely about health issues through surveys, professional dialogue spaces, or youth-focused organizations, whether they are located online or in schools.

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They want partnership that feels real — accessible, desirable, supported.

They want to be involved, not just questioned.

They want dialogue that continues, not one-off consultations.

They want a seat at the table — even at policy level.

And they want decision makers to step into their world, to see their reality.

Three things struck me most:

They want to learn about health early.

They want partnership recognized — even certified.

And they want it to be safe, empowering.

So really, that's not so different from what their adult colleagues want. It's the next generation saying: This system will be ours tomorrow. Bring us in before it's too late to get us on board!"

THANK YOU!
Danke
Merci
謝謝
amuchas Gracias
धन्यवाद
Salamat
Shukriya
Mahalo
Xiexie
arigato
kiiitos



CATHERINE.WILHELMY@USHERBROOKE.CA

Links to all documents discussed

Plan de transformation
Ensemble, pour une transformation durable et des résultats qui comptent
Comité de transition - Janvier 2023

**POSITION PAPER
ON PARTNERSHIP**
From public policy to population health:
Partnership, a wise choice to
create value for the benefit
of the community

**LA PRÉVENTION,
C'EST LA SANTÉ**
STRATÉGIE NATIONALE
DE PRÉVENTION EN SANTÉ 2020-2025

**SANTÉ QUÉBEC
PLANIFICATION
STRATÉGIQUE
2025-2028**
Prendre soin des gens
Aller de l'avant.

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UK's Patient representatives role description: [patient-representative-role-profile-may-2025.pdf](#)

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[The guidelines manual - Appendix L: The guideline development process - an overview for stakeholders, the public and the NHS](#)

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