

A stylized map of the province of Quebec, composed of many small, colorful human figures in various poses, representing a diverse population.

**INCLUSIVE PRACTICES**

**IN PARTICIPATORY**

**OR PARTNERSHIP-BASED**

**RESEARCH WITH SOCIALLY**

**EXCLUDED PERSONS**

A large, pink puzzle piece graphic that fits into the overall design, containing the text 'With the ENGAGE Committee'.

With the  
**ENGAGE**  
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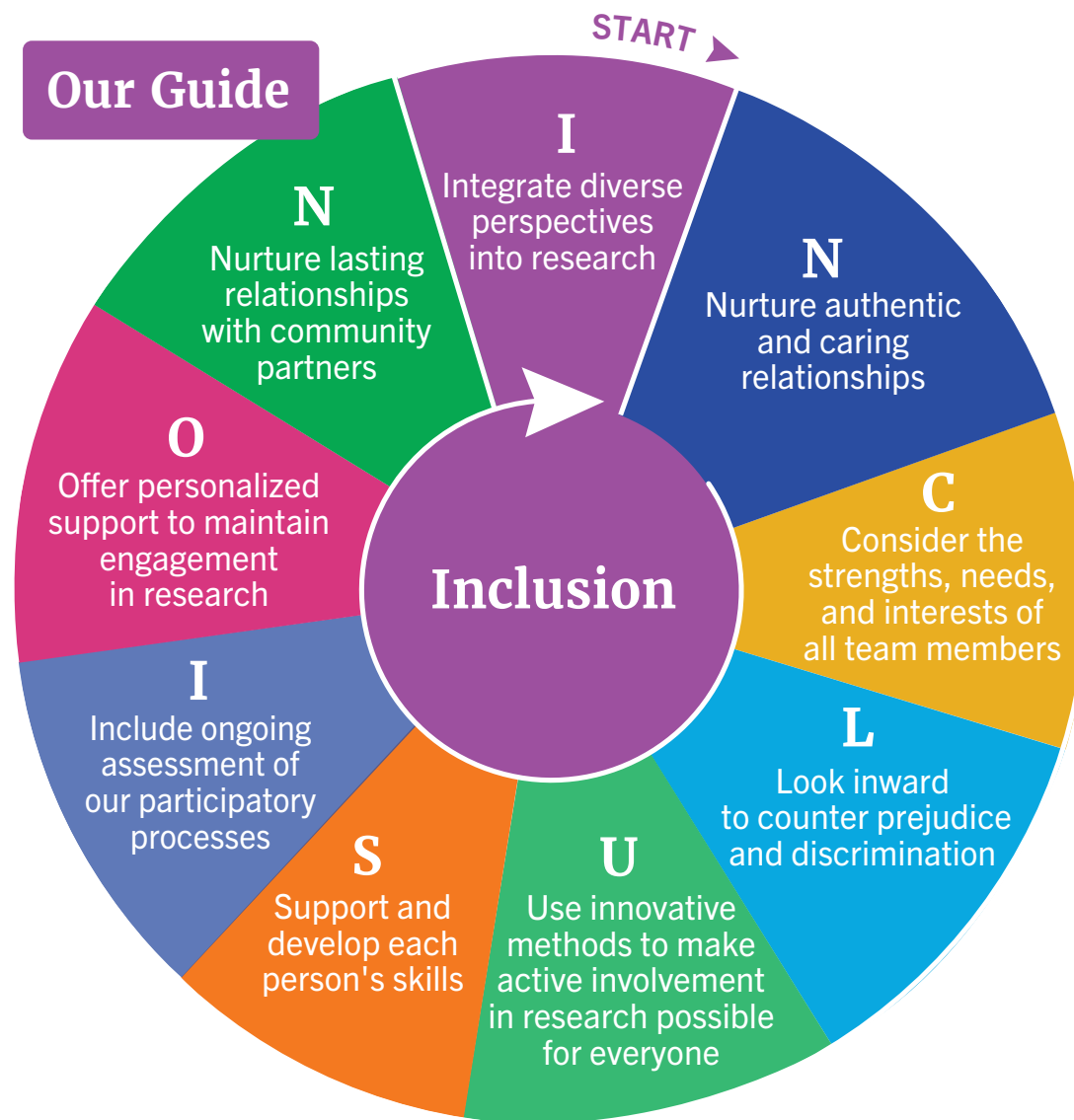
*\*The work was not undertaken under the auspices of PHAC as part of their professional responsibilities. The work was undertaken within the context of the co-authors' affiliation with an external institution, where warranted and applicable. The views expressed are their personal views and not those of PHAC.*

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## SUMMARY



### I Integrate diverse perspectives into research

By integrating into our teams a representative variety of people concerned by our research — including socially excluded persons — we can gain a more complete picture of a situation through the pooling of diverse experiences, skills, and ways of thinking.

### N Nurture authentic and caring relationships

Building a team requires, among other things, developing authentic relationships with people who are socially excluded. Caring is an important catalyst for this, as is creating spaces where each individual knows they will be respected, listened to, and supported, regardless of their opinions, ideas, or skills.

### C Consider the strengths, needs, and interests of all team members

Considering and valuing the strengths and interests of people who are socially excluded, while taking their needs into account, helps foster their long-term involvement. Openness, flexibility, and recognition of their knowledge as accepted on the same level as other types of knowledge are therefore essential.

### L Look inward to counter prejudice and discrimination

Recognizing and becoming aware of one's own stereotypes (thoughts) and prejudices (feelings) stemming from beliefs and social norms instilled from an early age is an important step in avoiding discrimination (actions) that can sometimes be unconscious and can perpetuate deep inequities.

### U Use innovative methods to make active involvement in research possible for everyone

Adapting research to the people who engage in it — rather than expecting them to adapt to the needs of the research — requires finding new ways of working to include people who might not otherwise be able to participate in research.

### S Support and develop each person's skills

Promoting the emancipation of socially excluded individuals by giving them the means to gain more power over their own lives and become key players in improving their health conditions and transforming health systems.

### I Include ongoing assessment of our participatory processes

Regularly assessing our practices, as well as the needs and well-being of individuals — which may change over the course of the project — will foster effective collaboration with our community partners.

### O Offer personalized support to maintain engagement in research

Providing educational, material, emotional and cultural support keeps people engaged in research. It's important to tailor the support to the perspectives of the people involved, as they are in the best position to know their specific needs.

### N Nurture lasting relationships with community partners

Nurturing meaningful and lasting relationships helps to sustain the positive impacts of community partners' participation in research while fostering the emergence of new participatory projects.

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## INTRODUCTION

This guide is intended as an orientation tool for research teams whose objective is to strengthen the health system and improve population health through partnerships with users, patients, lived experience experts, or community-based members or organizations, known as **community partners**. These partnerships are part of a learning health system that relies not only on scientific evidence, but also on the inclusion of all stakeholders — including community partners — to improve its practices. More specifically, this guide discusses how teams can work in partnership with persons who are socially excluded. These individuals have credible and legitimate knowledge. Their participation in research can help generate solutions and outcomes that are relevant and conducive to health equity, which is based not only on access to care and services in the health care system, but also on other social factors, such as access to housing, healthy nutrition, and education, as well as income redistribution to improve population health overall.

« **Users, patients, lived experience experts, or community-based members or organizations, known as community partners** »



IPPR: Inclusive participatory or partnership-based research

### WHY THIS GUIDE TO INCLUSIVE PARTICIPATORY OR PARTNERSHIP-BASED RESEARCH (IPPR)?

Health systems and their recent reforms are known to have produced inequities in the use of care, which contributes to health inequities (Browne et al., 2018; Loignon, Dupéré, et al., 2022; Mercer & Watt, 2007). People with fewer resources (e.g., low income, barriers to mobility, low literacy) and those marginalized by social policies have less access to health care and services and experience stigma in the health system (Dixon-Woods et al.,

2006; Loignon et al., 2018). This compromises health system equity, but IPPR with people experiencing social exclusion is a solution that has demonstrated benefits for health system improvement and population health (Wallerstein et al., 2018). These individuals are not a homogeneous group; they represent a diversity of exclusion experiences. They may be excluded because of their class, race, sociocultural, or gender identities, or





because of the prevailing social biases against them. They include, among others, neurodivergent individuals, people receiving social assistance, or members of sex- and gender-diverse communities.

These socially excluded persons have been little, or insufficiently, brought into participatory and partnership-based research aimed at improving the learning health system. Indeed, most such

## WHAT IS IPPR ?

IPPR in health is collaborative research created with the active participation of people who have lived experience within the health system, including those who are socially excluded. It values the contribution and uniqueness of their experiential knowledge and takes into account their expertise

## WITH WHOM IS IPPR CONDUCTED ?

IPPR promotes greater equity in health by giving all people equal opportunity to participate in research that concerns them, regardless of their skills or social status. It takes into consideration perspectives that are still under-valued in research and promotes the empowerment of socially excluded persons, who can then play a key role not only in improving their health conditions, but also in trans-

research has involved people with access to care and services or those living in favourable social conditions (e.g., high education level, high income) (McCoy et al., 2018). This low involvement of socially excluded persons in participatory or partnership-based health research undermines efforts to achieve social justice and equity values and compromises the social responsibility mission of the health system.

concerning their health needs and the obstacles they have encountered in their care and service trajectories (Loignon, Leblanc et al., 2022). Finally, IPPR is research conducted WITH socially excluded persons, not ON them.

forming care, services, and other components of the health system. To achieve true equity in our health and social services system, the inclusion of socially excluded persons must be a key priority. Those who work or are involved with people who are socially excluded are considered allies and can also be involved in IPPR.

## WHO DEVELOPED THIS GUIDE?

This guide was co-developed by the members of the ENGAGE committee, which includes three researchers with expertise in inclusive participatory research, two liaison officers who support the quality of collaboration among the members, and seven community partners with diverse expertise in participatory or partnership-based research, social exclusion, care trajectories, and health inequities. The ENGAGE committee has been active since 2018 and is part of the Office of Social Accountability (OSA) at the Faculty of Medicine and Health Sciences of Université de Sherbrooke (UdeS).

## WHAT WILL YOU FIND IN THIS GUIDE?

In this guide you will find ideas, tools, and suggestions for overcoming barriers and enabling the authentic participation of community partners concerned with issues of social exclusion in participatory or partnership-based research projects. Accordingly, this guide addresses the preparation required before undertaking an IPPR process, the creation of a research team concerned with greater inclusion, and the implementation of an inclusive and safe research process based on developing

relationships of trust with socially excluded persons and community partners. Finally, the importance of sustaining the research commitment of these people is discussed. This guide is intended to support researchers, community partners, and all interested parties by encouraging reflection on inclusive practices and by providing concrete tools for conducting IPPR WITH people who are socially excluded.

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**Episode: Engaging in Inclusive Research**



## RESEARCHER PREPARATION

Preparation on the part of researchers is a key step in implementing inclusive practices in participatory or partnership-based research. Without such preparation, both community partners and researchers may have negative experiences that could lead them to disengage. According to ATD Fourth World, which has developed international expertise in the merging of knowledge with people living in poverty, the key to good preparation lies in the consideration of the other, and “knowledge is developed in a relationship” (ATD Fourth World, 2016).

### TAKING INTO ACCOUNT THE REALITY, CONCERNS, AND NEEDS OF SOCIALLY EXCLUDED PERSONS

Before starting a concrete IPPR process, researchers are advised to take the time required to understand the reality, concerns, and needs of people who are socially excluded and their motivations for engaging in such a project, and to express their openness to these matters. This will make it possible to conduct research focused on the real needs and interests of people experiencing social exclusion, while helping to empower them, that is, giving them the means to change things. This understanding is further enhanced when researchers meet with these persons before a project even begins.

*« We need to get researchers to see things differently, to be more human and less Cartesian, and to get more on board with the idea of a relationship. It takes researchers who are more open, more sensitive, who are able to make room for these people and take on all that that entails. »*

*(ENGAGE committee member)*

*“ You can come in with general questions, but you have to leave lots of room for these people to contribute with their questions, their interests, their needs that then shape the project. ”*

*(Isabel Heck)*

The research team will then be able to target the most appropriate type of IPPR based on the needs and interests of both the socially excluded participants and the team members, on the research objectives, and on the resources available to carry

### INTROSPECTION AND POSTURE

To effectively engage socially excluded persons with all their potential, it’s advisable to do some introspection on our own identity, with our cultural and social references. This means becoming aware of our own professional and personal motivations for engaging in IPPR and of their potential impacts on the project. It’s also important to be conscious of our own stereotypes (thoughts) and prejudices (feelings) in relation to socially excluded persons, which stem from beliefs and social norms inculcated in us from a very young age, so as to avoid discrimination (actions), sometimes unconscious, and the perpetuation of deep-seated inequities. Finally, this introspective work should also be done on the privileges we have been granted because of our social class, education, ethnic background, or any other element of our identity. This examination will help us understand how the unfair granting of privilege to some people contributes to the phenomenon of health inequities (Leblanc et al., in review; Nixon, 2019). This awareness is an important step in order to avoid potential discrimination stemming from our stereotypes and biases, to develop egalitarian social relationships with persons

out the project effectively (possible financial compensation for the partners, ability to provide training or skill-building, available time and funding, etc.).

experiencing social exclusion, and to use research as a tool for social justice.

*“ Research is only a lever for producing and mobilizing knowledge that is useful for action, thus making it possible to transform concrete situations, or at the very least to exert influences on these situations. ”*

*(Isabel Heck)*

In adopting this approach, the researchers and the various team members are preparing to value the knowledge of socially excluded persons and to give it a legitimate place, even if this knowledge challenges and calls into question current academic knowledge and research practices (ATD Fourth World, 2016, 2021).

To do this, it's helpful to adopt a learner's posture in order to acknowledge and value the knowledge and skills of people who are socially excluded. Adopting a learner's posture means setting aside professional or clinical assumptions or reflexes when interacting with them and welcoming their stories and contributions. It's also important to show cultural humility, that is, to acknowledge past mistakes in research, and to understand that the relationship between researchers and socially excluded persons requires that we be attentive to the social distance or cultural gap that may arise in the presence of class or cultural differences. Humility also means recognizing the limits of our own knowledge and asking ourselves how this knowledge can be complementary to other knowledge.

“  
*There's the whole emotional side that's required for knowledge building and that comes through experiential knowledge. When people report on their experiences with services received, this provides concrete support for decision-making regarding the provision of treatment. The perspectives of these persons can also generate knowledge about the perceived improvement of their health status, a highly relevant aspect of treatment in a recovery context.*  
 ”  
 (Michel Perreault)

Finally, it's advisable to plan not only for the time, but also the energy and the human and material resources required to provide personalized support to the partners. Likewise, flexibility and creativity are needed to minimize any exclusion or instrumentalization related to research participation and to continuously adapt to the changes needed for effective collaboration. This will ensure a more inclusive and authentic IPPR process while promoting greater participation by those included in the project.

“  
*When we work collaboratively in a participatory way, I'm just one person, the same as everyone else. I bring my knowledge and I'm very aware that these people ... have experiential knowledge, [and] I don't have that. So we're complementary.*  
 ”  
 (Jacinthe Rivard)

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**Episode: Social Prejudice and Inclusive Research**



## SETTING UP AN IPPR

To conduct a successful IPPR, several steps can be taken: putting together a diverse research team, designing an inclusive and safe participatory process, and building trust with socially excluded persons and community partners.

### CREATING A DIVERSE AND INCLUSIVE RESEARCH TEAM

A diverse team is one that includes a wide range of attributes, qualities, profiles, experiences, and ways of thinking (UdeS, 2022a). These are what make it rich, particularly in terms of promoting innovation in research, better social relations, a more open work climate, and stronger performance (UdeS, 2022a). To achieve this, it's important to have a representative diversity of people who are affected by the research and to include socially excluded persons in the teams, regardless of their skills and social status. This often requires more of our time, as well as innovation in how we conduct research, from recruitment to management practices.

However, a diverse team in terms of representation does not necessarily make for an inclusive team. One of the keys to building an IPPR team

is to develop authentic and trusting relationships with socially excluded persons. This makes it possible, over time, to build participatory projects that influence each other and that support the continuous improvement of expertise (Feige & Choubak, 2019; Macaulay, 2016), as well as to set up inclusive diversity management practices.

To facilitate recruitment and foster a diverse and inclusive research team, several strategies are suggested below as examples. It's important to consider what is best in the research context, while taking into account the strengths and weaknesses within the research team.



## STRATEGIES TO FOSTER DIVERSITY AND INCLUSION IN A RESEARCH TEAM

- Know the characteristics and profiles of the people and communities concerned by our research, to ensure they are well represented on the team and to put in place support adapted to their needs.
- Go directly into the living environments of the people and communities concerned by our research (Cruz & Higginbottom, 2013; Fetterman, 2020).
- Use intermediaries — individuals or organizations — who are involved with the people and communities concerned by our research (Health Quality Ontario, 2017).
- Engage individuals who share elements of identity with these people and communities to decrease social distance and barriers to accessing experiential knowledge (Muhammad et al., 2015).
- Encourage a diversity of academic and professional expertise within the research team.
- Invite community partners with experience in IPPR to join the team.
- Have transparent and respectful discussions about who we are (e.g., skills and challenges), our motivations and expectations, and our preferences and ways of doing things (e.g., inclusive management practices).
- Explain clearly why involving community partners is critical to our approach and present a variety of roles and levels of engagement (INVOLVE & National Institute for Health and Care Research [NIHR], 2012).
- Develop written, visual, and audio recruitment materials tailored to the individuals or communities concerned by our research (e.g., persons with low literacy).
- Use plain language that is accessible to all.

« *My experience as a stigmatized homeless person and substance user in several research projects has enriched my status as a facilitator and liaison officer within the ENGAGE committee. My sensitivity to others and to judgments has created a bond and a new dynamic, and above all an egalitarian relationship that is helpful for communication and sharing confidences.* »

(ENGAGE committee member)

“ *These people are far removed from the networks, and one possible strategy is to reach out to the community setting or to spend time in the spaces where these people are. We did a search, we went to the barber shop, the laundromat, everywhere that we could see people.* ”

(Isabel Heck)

“ *To work as a team, no matter with whom, the key is to understand each other's issues, needs, and positions, to agree on what we're going to build, and to believe in what each of us is doing.* ”

(Michel Perreault)

## A PITFALL TO AVOID

We must be careful not to fall into the trap of doing what's “easy” and always recruiting from the same circle, network, or environment. To avoid this, it's advisable to routinely review the diversity and representativeness of the people included in our projects.

« *Reflect on why it's always the same people who get involved, and don't keep doing things the way they were done in the past. We need to do things differently.* »

(ENGAGE committee member)

In line with this inclusive approach, the selection of community partners who will join the project is based on their motivation to engage in the research project and on the bonds that the team members develop together. Those bonds are rooted in compatible expectations regarding this research experience and in a shared potential goal that is mutually satisfactory. Having some idea of each person's general profile also helps ensure they are representative of the chosen communities and allows the researcher to prepare for the collaboration by making sure the necessary resources are available to support each of these individuals appropriately.



## DESIGNING AN INCLUSIVE AND SAFE RESEARCH PROCESS

### Setting up a structure and activities adapted to the needs

In an IPPR, it's important to adapt the research project, and not to expect socially excluded persons or community partners to adapt themselves to the needs of the research.

First, to get grounded in such an approach, it's useful to reflect and discuss with everyone the different types of engagement possible. These can be deployed simultaneously, depending on the motivation and capacities of the people involved, or at different stages of the research process. As well, the types of engagement and the support provided should be consistent. For example, if a skill-building approach is chosen, it may be worthwhile to provide coaching, training, and progressive engagement to develop people's skills in line with their own pace, abilities, and interests, so that they will have a positive experience. Openness and flexibility are also required over time to adapt the commitment of those involved, so as not to add pressure, such as the feeling that they always have to participate fully.

« We can't force partners to work in a structure (academic) that isn't theirs. Rather, we need to adapt the working structure to the partners' abilities. »

(ENGAGE committee member)

Then, to ensure the meetings are accessible to all, it's important to recognize that each individual is in the best position to know their particular needs, and as such, it's important to get them to express those needs in order to facilitate their involvement (INVOLVE & NIHR, 2022). To this end, clear and concrete operating principles can be co-constructed with the team members to discuss the frequency, schedule, and location of meetings that are convenient for everyone, compensation preferences, and methods of communication.

### ELEMENTS TO ENSURE FAIR COMPENSATION

- Compensation should take into account not only technical tasks performed, but also program and service improvements that result from the experiential knowledge of individuals and the emotional burden associated with their participation.
- Appropriate compensation will reduce the stigmatization of people who are socially excluded by adopting an approach based on their strengths (Feige & Choubak, 2019).
- It may be beneficial to provide different types of compensation to the people involved in line with their needs (e.g., letter of achievement, festive thank-you activities).

It's also advisable to provide human and material support upfront (e.g., IPPR training, access to a computer) to ensure that people are properly equipped to begin their involvement. As well, it's better to cover any costs associated with individuals' participation, through an advance or prompt reimbursement, so that they aren't under any financial pressure (INVOLVE & NIHR, 2022). It's important also to keep in mind that community partners may have expenses that differ from those of the researchers (Feige & Choubak, 2019; Strategy for Patient-Oriented Research [SPOR], 2014). For example, they may have costs related to adapted transport, child care, or employment of a caregiver during the primary caregiver's absence.

“ People don't realize how hard it is to always be working around the difficulties you experience on a daily basis, to share memories of difficult experiences, and to live with the frustration of not seeing things change. With the co-researchers, we made Wellness baskets with soaps, candles, and cookies so that everyone can look after themselves.

(Jayne Malenfant)

Finally, to encourage the engagement of socially excluded persons, it's important to discuss each person's expectations for the project and to identify a shared goal for the IPPR. To do this, it can be beneficial to share, in all humility, the limitations of the research project, the different time constraints that are to be expected in a research process (e.g., ethical requirements), the available budget, the tenuous nature of long-term funding, and the potential barriers to social and political impacts. In this context, having short- and medium-term goals and valuing the research process as much as the achievement of results can foster commitment from those involved.

## Sharing roles and tasks

It's important to identify and define, ideally as a team, the roles and tasks to be carried out during the research project. Once this exercise has been carried out, it will be easier to share roles and tasks equitably, in accordance with each person's motivation, strengths, and abilities, and to plan the various activities related to the project over time (Patient-Centered Outcomes Research Institute [PCORI], 2021).

However, people's expectations, motivations, and abilities may change over time, so it's important to repeat this process at different times during the project and to adapt the assigned roles and tasks on a regular basis.

*« The relevance of the partners' participation in the different stages of the research project is defined in line with their motivation: where they have no interest, we shouldn't engage them, and wherever they're motivated to get involved, we should! »*

*(ENGAGE committee member)*

### TIPS FOR EQUITABLE TASK SHARING BASED ON STRENGTHS AND SKILLS DEVELOPMENT

- As a team, define the tasks required to carry out the project successfully and to support people's participation.
- Determine together the skills needed to complete each task and identify as a team which individuals have these skills or wish to develop them (Muhammad et al., 2015; The UK Public Involvement Standards Development Partnership, 2019).
- When assigning tasks, take into account the social and/or cultural identity of team members, in order to be able, for example, to find the best people to make contact with people who are socially excluded (Muhammad et al., 2015).
- Tailor people's tasks to their motivations and availability (The UK Public Involvement Standards Development Partnership, 2019).

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**Episode: Valuing Knowledge and Reciprocity**



## BUILDING RELATIONSHIPS OF TRUST WITH SOCIALLY EXCLUDED PERSONS AND COMMUNITY PARTNERS

As mentioned above, the heart of an IPPR lies in developing an authentic, sustained, and reciprocal relationship of trust with people who are socially excluded and with community partners. Several factors are helpful for establishing such a relationship: caring, adapting our ways of doing things to the specific needs of socially excluded persons, and creating a safe interactional space.

### Caring

The culture of caring is increasingly important. Caring means showing empathy, listening, acknowledging others, and seeking to understand their feelings and experiences.

*« The depth of the partners' feedback on their experiential knowledge depends on the trust among team members.*

*We need human warmth. »*

*(ENGAGE committee member)*

### TO CREATE A TRUE CULTURE OF CARING, IT'S RECOMMENDED, AMONG OTHER THINGS, TO:

- Be open-minded and curious to learn from others' experiences.
- Take the time to find ways to allow people who are less likely to speak to do so, while being careful not to rush them and also respecting their choice not to speak.
- Make sure to allow people to express their thoughts fully, without interruption, and to wait for your turn to speak (ATD Fourth World, 2021; PCORI, 2021).
- Accept people without judgment, and value their comments and confidences (PCORI, 2021).
- Encourage people to not just defend their own point of view, but also to consider those of others and to make connections between their personal experiences and those of others (ATD Fourth World, 2021).
- Encourage active listening by reducing distractions, maintaining eye contact with the speaker, asking open-ended questions, rephrasing to verify your understanding, and putting words to what's not being said (UdeS, 2022b).
- Demonstrate caring and sensitivity when certain questions come up (for instance, plan to address certain issues one-on-one or when the person is more open to receiving them).
- Recognize and acknowledge the importance of mutual expression of emotions.

“  
 Yes, you have to offer something in return. Sometimes, it's having tear-filled eyes when a participant tells you something and that person senses that you've been touched, in a way, you've offered them your vulnerability. The give-and-take is very much about being transparent and open... No matter what question a participant asks, you have to open up, you have to be transparent, and you have to talk about it.  
 ”

(Jacinthe Rivard)

### Adapting how we do things based on the needs of people who are socially excluded

It's also recommended that we pay close attention to the unique characteristics of people who are socially excluded and adapt our ways of doing things accordingly. To do this, it's important to keep in mind the individual, social, and structural barriers that socially excluded people face on a daily basis, and to try to break them down, one by one, in order to establish a relationship of authentic trust and to foster their engagement in research.

### EXAMPLES OF INDIVIDUAL, SOCIAL, AND STRUCTURAL BARRIERS TO KEEP IN MIND

- Low income or financial insecurity/poverty
- Issues related to literacy and access to education
- Prejudice and discrimination based on gender, ethnicity, racial or Indigenous status, sexual orientation, etc.
- Prejudice, stigma and discrimination against people with social problems (poverty, judicial experiences, substance use, homelessness, etc.)
- Traumas and negative past experiences in the health care system

### A PITFALL TO AVOID

Be careful not to fall into the trap of paternalism and infantilization — for example, by controlling the discussion under the pretext of protecting the person or because they don't have the capacity to understand the concepts being discussed — which only generates even more exclusion and marginalization.

Maintaining egalitarian relationships requires being aware of one's own attitudes, whether conscious or unconscious, and taking the time to rebalance power by ensuring that everyone understands, is on the same page, and feels comfortable expressing themselves.

« Listen and take in all confidences or comments without judging their relevance... Don't try to control the discussion, but rather let the conversations flow. »

(ENGAGE committee member)

For example, we need to be aware of the traumas generated by social and health inequalities as well as by the structures in place, structures that could be reproduced in research. It's thus essential that we strive actively to ensure we don't cause people or community partners to experience or relive trauma (Roche et al., 2020). We can do this by opening a dialogue with them about exclusion, trauma, and their feelings in general. In doing this, we can be attentive to the stress, anxiety, and frustration that engagement in research can create when, among other things, people feel excluded or exposed to a risk of disclosure of their life experiences and identity, or feel under pressure to perform (Ibáñez-Carrasco et al., 2019). It's important, therefore, to remain alert to each person's emotional well-being from the earliest stages of IPPR.

To learn more about working with socially excluded persons and to open up a dialogue about emotional well-being, group training or workshop sessions can be set up. Such activities focus, for example, on equity, diversity, and inclusion (EDI) or on historical and structural issues. They are intended to deepen our understanding of the social exclusion that may be experienced by members of a research team and to foster the development of reciprocal relationships among all involved.

### Creating a safe interactional space

Finally, it's important to create a safe interactional space, a space in which each person knows they will be respected, listened to, and supported, whatever their opinions, comments, or skills. This safe space thus helps reduce the power hierarchies within the research team so that all team members can express themselves freely and share their knowledge fully (Muhammad et al., 2015).

“  
 There's a long period when people need to create that safe space and trust, and talking about themselves is what builds that. At first, what they tell us is what they feel able to say, what they've been used to saying. Sometimes they tell us what they think we expect to hear, but then, gradually, trust is built.  
 ”

(Jacinthe Rivard)

« The accumulation of tasks and deadlines can generate stress and anxiety. It's important for the researcher to check in regularly to see how the partner is feeling about their tasks, and to see if they need help. »

(ENGAGE committee member)



## STRATEGIES TO SUPPORT THE DEVELOPMENT OF A SAFE INTERACTIONAL SPACE

- Emphasize people’s psychological, emotional, and physical safety, e.g., by being welcoming, consistent, giving the right information, being alert to non-verbal cues, and regularly reminding people of the need for confidentiality and mutual respect (Alunni-Menichini, 2020; ATD Fourth World, 2021).
- Be transparent: openly communicate the progress of the research, including mistakes, successes, and changes made, and clarify why certain things are done one way rather than another (Liabo et al., 2020; PCORI, 2021).
- Communicate inclusively, for example, by encouraging people to speak up and reminding them that their opinions will be heard and considered.
- Use inclusive language, particularly by using language that is accessible to everyone, agreeing on the terms to be used, avoiding expressions that label people (e.g., avoid “suffer from” when referring to people with disabilities or health conditions), and using epicene language (SPOR Evidence Alliance, 2021).
- Reverse power dynamics by encouraging each team member to adopt both a learner and teacher posture; use methods that smooth out the hierarchization of knowledge, such as the photovoice method, the walking interview, the problem tree, scenario-building to explore issues; and give leadership to community partners (ATD Fourth World, 2021; ENGAGE, 2022; Feige & Choubak, 2019; Loignon et al., 2018; NIHR, 2021; Strategy for Patient-Oriented Research [SPOR], 2015).
- Advocate for consensus decision-making: “Move from a culture of voting to a culture where the decision is the outcome of a process... where finally the decision falls like a ripe fruit.” (ATD Fourth World, 2021, authors’ translation).
- Organize informal social activities to develop relationships of trust between team members and, in so doing, help them discover their similarities as well as differences, deconstruct preconceived ideas, and develop a sense of complementarity (ATD Fourth World, 2016).

## REMEMBER!

- The people involved in our projects, including the researchers, may still be experiencing social exclusion or have loved ones who are experiencing social exclusion.
- They may, as a result, have difficulty disengaging from their emotions in the research process and setting certain limits on their participation, which may make them feel more isolated or uncomfortable.
- A support network must be put in place, as a team, from the beginning of the collaboration and must be accessible to all as needed.

*The important thing is to have mechanisms for providing support among team members, as well as the support of a professional who is available when needed. It’s very important to meet regularly to debrief, to be able to divide up the work, while looking after each team member.*

*(Nadia O’Brien)*

One way to ensure a safe space from the beginning of the project is to co-construct and adopt principles of collaboration. These will set out the values and behaviours to be adopted throughout the project by all members of the research team.

## EXAMPLES OF IMPORTANT PRINCIPLES OF COLLABORATION ACCORDING TO THE ENGAGE COMMITTEE

- Be inclusive: respect and value differences among team members (PCORI, 2021).
- Be caring: listen to others and communicate in an inclusive manner.
- Be authentic.
- Be forgiving: recognize people’s right to make mistakes and be willing to let it go if we’re offended by certain statements.
- Promote flexibility and compromise: facilitate decision making and conflict resolution.
- Demonstrate humility: openly acknowledge the limits of our own knowledge and the value of the knowledge of others.
- Make mutual respect a priority.
- Value all forms of engagement and contribution (Loignon et al., 2018).
- Recognize that there are power inequalities within the team and commit to reducing them as much as possible by exploring and developing ways of working together as a team (The UK Public Involvement Standards Development Partnership, 2019).



It's recommended that mechanisms be put in place to express disagreements in a respectful manner and that space and time be provided on a regular basis to openly address any tensions felt in the group (Godrie et al., 2021, Introduction). Also, it's essential that everyone be aware that tensions and conflicts can arise at any time and that they need to prepare for them from the beginning of the project.

*« An open and honest conversation can bring awareness to some of the micro-aggressions experienced and can lead to change... Researchers should also name any discomforts and misunderstanding... It's a learning process on everyone's part. »*

*(ENGAGE committee member)*

### TIPS FOR INTERVENING IN A TENSE OR CONFLICTUAL SITUATION (INVOLVE & NIHR, 2022)

- Refer to the procedure developed at the beginning of the research project.
- Acknowledge that there is a problem, identify it (people involved, source of conflict, consequences), and take action. Each situation is unique, and a different response may be required each time.
- Ensure that everyone involved is heard, whether one-on-one or in a small or large group.
- Provide time and various tools to everyone involved to support reflection and expression (writing, confiding, etc.).
- Maintain, when requested, the confidentiality of what they say.
- Take on the role of mediator to rebuild relationships between people in conflict, and find a compromise, or in the case of a major conflict, consider using an external facilitator.
- Establish, with the individuals involved, a timeline for making the required changes.
- Follow up with those involved to ensure that the situation is resolved.
- Reflect collectively on what we have learned from the conflict and how we can modify our approach for the rest of the project.

*« We shouldn't be afraid to talk about the problematic situation again, so that it doesn't become a taboo and we risk losing the safe space permanently. »*

*(ENGAGE committee member)*

**ENGAGE: The Podcast Series on Inclusive Research**  
**Episode: Fostering a Dialogue around Inclusive Research**



## THE IPPR PROCESS

Conducting an IPPR generally requires more time than other types of research, since it is a co-construction process, and it's recommended that each stage of the project be tailored to the needs and capacities of those involved. Here we will look at some practices to help an IPPR run smoothly.

First, **maintaining trust and a safe space** is valuable, as it encourages people to name, without fear, their needs and the challenges they face, both within the project and in their personal lives. It's important to have access to this information and to make adjustments as needed, as this can influence their motivation and ability to engage in the research.

*« Having difficulty keeping up with discussions [in terms of pacing and language], primarily among academic researchers, prevents partners from voicing opinions. »*

*(ENGAGE committee member)*

Then, **respecting each person's pace** is important. The pressure to perform in the academic world often imposes a very fast pace that doesn't always correspond to the reality of community stakeholders (Bird et al., 2020). They generally need time to absorb all the new information to which they have access during the course of the project and to develop the skills necessary for real inclusion.

### TIPS FOR INCLUSIVE WORK MEETINGS

- Respect partners' valuable time by ensuring that their presence at the meeting is really relevant.
- Ensure that community stakeholders are well represented at meetings and that there are enough of them to put them at ease.
- Involve partners in the preparation and facilitation of meetings.
- Don't overload the agenda, and allow for a discussion period at the end of the meeting for feedback.
- Try to support the preferences of the people involved, in terms of the meeting format (face-to-face or virtual) in line with their current situation (transportation, illness, etc.).
- Use the means of communication preferred by the people involved; for example, remind them of the time of the meetings a few days in advance by email or telephone (ATD Fourth World, 2021).
- Before a meeting, clearly communicate its objectives and send out all useful materials so that everyone has the information they need to participate in the discussion (PCORI, 2021).
- Provide informal time at the beginning of the meeting so that people can socialize.
- Use language that is accessible to everyone, and be sure to explain more complex terms or concepts.
- Present a diagram of all the stages of the research project at each meeting so that everyone can see how the project is progressing and identify the next steps to be taken.

*It can also happen that life problems catch up with them and they can no longer participate for a while. If they want to, continue to invite them, maintain a connection, make phone calls, send reports, etc. This can help people continue to participate in a project, even if there is an interruption at some point.*

(Florence Bernard)

To maximize the contribution of people who are socially excluded and to strengthen their power to act, it's helpful to show flexibility and to provide them with personalized support (Ibáñez-Carrasco et al., 2019; Loignon et al., 2018).

## TYPES OF SUPPORT POSSIBLE

Types of support	Description	Concrete examples
Material support	Providing the necessary materials and compensation to encourage the inclusion of socially excluded persons in the team and, where appropriate, ensuring access to a physical space and the means to get around (Ibáñez-Carrasco et al., 2019).	<ul style="list-style-type: none"> <li>Covering transportation costs: car, taxi, adapted transport, public transport, etc.</li> <li>Tailoring all the documentation needed for the research to the specific needs of the people involved by considering the use of videos, photos, or audio formats, and not just written materials.</li> </ul>
Educational support	Supporting the development of skills in research and knowledge transfer, but also in leadership, communication, project management, and any other relevant skills (Feige & Choubak, 2019; Ibáñez-Carrasco et al., 2019; Learning Difficulties Research Team et al., 2006).	<ul style="list-style-type: none"> <li>Providing training on informed consent, EDI principles, data collection and analysis, and confidentiality issues.</li> <li>Writing a scientific article with the community partners.</li> <li>Encouraging the partners to take the lead in various dissemination activities.</li> </ul>
Emotional support	Taking into account the emotional burden of participation, ensuring the emotional well-being of those involved, and actively seeking ways to adapt our practices in more difficult moments and to avoid subjecting partners to negative experiences (Ibáñez-Carrasco et al., 2019; Roche et al., 2020).	<ul style="list-style-type: none"> <li>Establishing a support network that is accessible to all as needed (e.g., working with a community organization that can provide assistance, bringing in an experienced IPPR partner to act as a facilitator or liaison).</li> <li>Opening up a dialogue about how people feel on a regular basis and providing a variety of ways to give feedback (e.g., email at the end of meetings, phone call, group discussion, etc.).</li> </ul>

Cultural support	Taking into account the cultural identities, customs, and beliefs of the people involved in the project (Ibáñez-Carrasco et al., 2019; INVOLVE & NIHR, 2012).	<ul style="list-style-type: none"> <li>Opening up a dialogue to give team members the opportunity to share their cultural and spiritual customs and beliefs in an atmosphere of recognition and respect.</li> <li>Respecting elements associated with the individual's culture, including diet (e.g., vegetarian, halal), religious practices (e.g., respecting times of prayer), and style of dress.</li> </ul>
Peer support	Putting in place tools, informal activities, or working groups among peers so that people can talk about the project, their experiences, their emotions, and their knowledge, or good practices to be implemented (ATD Fourth World, 2021; Loignon et al., 2014).	<ul style="list-style-type: none"> <li>Creating a space for conversation (e.g., a social media group) among community partners from different participatory or partnership-based research initiatives.</li> </ul>

*With the principal investigator, it was a matter of sending her an already finished article and submitting it to her for review. With the two female peer researchers, it was a matter of sending them sections of the article on a regular basis to get their feedback, so that it wouldn't take too much of their time, as they were already very busy with their community involvement. You have to find the way that works for everyone on the team.*

(Nadia O'Brien)

*« Each person must be able to express themselves in accordance with all facets of their identity – cultural, religious, gender, etc. – without fear of judgment or feeling the need to censor themselves. Likewise, each person must accept people as they are, respecting all aspects of their identity. »*

(Membre du comité ENGAGE)

Finally, it's useful to regularly evaluate not only one's own processes (e.g., meeting procedures, management practices, task allocation), but also the needs, skills, and well-being of the others involved, which may change over the course of the project (ATD Fourth World, 2021; Leblanc et al., in revision; NIHR, 2021). This can be done through informal discussions between the researcher or facilitator and the community partners, or through individual self-assessment or a group log, for example.

*We created a phone tree to guide the peers. If they wanted to vent after the interviews, they were matched with another peer. If it was more serious, they could call the coordinator or the principal investigator. They could also call a social worker, paid for by the research funds, who followed up within 24 hours.*

(Nadia O'Brien)

## FACILITATING FACTORS FOR A GOOD IPPR PROCESS

- Having the support of a researcher, a community partner with IPPR experience, or a community ally working within the communities involved.
- Engaging a facilitator who is knowledgeable about the people involved in our research and about the academic community, and who can also help build and maintain trust, and act as a coach, facilitator, and cultural translator to ensure a common understanding (e.g., by rephrasing the academic rhetoric) (ATD Fourth World, 2021).
- Establishing different sub-working groups (e.g., groups comprised solely of researchers, or of lived experience experts) (ATD Fourth World, 2021; Fillion, 2011; Godrie et al., 2021, Introduction; Loignon et al., 2014, 2018, 2020).

Several advantages have been noted with respect to working groups reserved solely for lived experience experts: ensuring understanding of the project and academic jargon; developing self-confidence; fostering mutual support and a sense of belonging; exchanging without constraints; and creating collective experiential knowledge that can be communicated to the other team members (ATD Fourth World, 2021; Fillion, 2011; Loignon et al., 2014, 2018, 2020).



## ENDING A COLLABORATION AND SUSTAINING COMMUNITY PARTNERS' ENGAGEMENT

### THE IMPORTANCE OF PREPARATION TO END A COLLABORATION SUCCESSFULLY

Maintaining a genuine dialogue about the end of the project throughout the process allows for a common understanding of the expectations of all those involved in the research and minimizes the potentially negative effects experienced while participating in a research project or when it ends.

First, to be well prepared for the end of a project, it would be wise to budget for results dissemination in the community from the beginning of the project and to think together about meaningful ways for the community partners to spread the knowledge developed by the research. It can also be very rewarding to encourage them to lead these activities themselves, thereby promoting greater epistemic justice. Ideally, all members of the team should be equipped to present and use the results in whatever way they wish to follow up on the research.

Several of the lived experience experts on poverty expressed a sense of emptiness at the end of the project. They explained that they had lost a group to which they belonged, and they felt they had lost a significant activity in their lives that gave them a great deal of self-esteem and a sense of usefulness. For them, the project was a space in which their experience was recognized and valued. They also emphasized the void with respect to social relationships... after three years, many of us had developed close ties.

(Sophie Dupéré)

The project went out and got additional knowledge transfer funds and the peers were able to decide how they wanted to pass on the new knowledge developed in the project. For example, there was a presentation in a hair salon with a chocolate fountain!

(Nadia O'Brien)



Next, it's advisable to take some time to celebrate the end of a collaboration and to envision potential further actions together. This celebration can take the form of a special ceremony to acknowledge the development of skills, the accomplishments of all involved, and the successes of the research project. It is also beneficial to look back on the challenges encountered and lessons learned, and to make room for the mourning sometimes experienced at the end of a project.

## SUSTAINING COMMUNITY PARTNERS' ENGAGEMENT

Beyond the life of an IPPR project, it would be important to think about and put in place ways to sustain community partners' engagement in research, which means taking the time to establish meaningful relationships with them and then to maintain those over time (Macaulay et al., 1998). Researchers' continued presence in the community beyond one-time research projects fosters the development of trust among community stakeholders and partners, and makes it possible to observe the medium- and long-term impacts

“  
*One of the lived experience experts had the idea of documenting our research project 'differently': Produce a portfolio to document our research process, notably with photos, caption bubbles, and artifacts that could illustrate our approaches and values, as well as the results and impacts of the project. In fact, this portfolio often attracted more attention than our traditional research report.*  
”  
(Sophie Dupéré)

of research and maintain an open dialogue with those affected by the research about certain activities they would like to pursue, thereby creating an environment conducive to the emergence of new participatory research projects.

The following are examples of suggested strategies to sustain the positive impacts of community partners' participation in research and help them become further empowered.

## STRATEGIES FOR SUSTAINING COMMUNITY PARTNERS' ENGAGEMENT

- Focus on strengthening partners' skills and developing their leadership to empower them to participate in other research, express themselves with confidence in other contexts, and use the skills they have developed in new employment or civic engagement (Dupéré et al., 2022).
- Identify potential avenues for partners to be involved in projects around similar themes (e.g., by suggesting other research projects or opportunities for civic engagement in community groups).
- Become active more broadly in improving institutional conditions for community partners' participation in research (e.g., by engaging in efforts to have the learning achieved by non-academic actors officially recognized, including recognition by the organizers of scientific conferences or by editorial committees) (Dupéré et al., 2022).
- If possible, provide support for lived experience experts that can be sustained through partnership with community groups.
- Find opportunities to work with community partners on an ongoing basis outside of grant-based funding periods.
- Get involved in developing communities of practice on participatory or partnership-based research geared towards community partners, where they can come together, unite, share expertise, and network.
- At the end of a project, enable a transfer of leadership by supporting the handover of responsibility for certain objectives coming out of the research project to community partners, who are sometimes the best equipped to pursue the options arising from the research results.

“  
*I've been working with a women's group for seven years. We're not always in research mode, we don't always have grants. Sometimes we're more into disseminating results or working to educate the general public.*  
”  
(Jacinthe Rivard)



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# The ENGAGE Committee



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