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Guide

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Guide to Inclusive Practices in Participatory Research

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Introduction

Historically, individuals who consider themselves or self identify as disabled were (and still are, all too often) judged incapable of examining and reflecting upon their own realities. Thus, research was done **on** these people and not **with** or **by** them.¹ This context draws upon and also itself contributes to an overvaluation of academic and professional knowledge. To redress this injustice which those concerned have long denounced, participatory research is worth considering.²

This guide offers interested parties an introduction to the necessary conditions for carrying out participatory research projects. Those considering this type of research will, thus, be able to ensure the required conditions to facilitate an effective and, above all, respectful, process for all.

What is participatory research?

Participatory research is a type of research which integrates experiential, practical, professional and academic knowledge. It requires that those with experiential (or practical and professional) knowledge directly related to the subject of the study be involved in the research process as full members of the team.³ Their participation is valued and sought out at all stages of the research project, during the definition of the problem, the collection, analysis and interpretation of data, and up to the dissemination activities and knowledge mobilization.⁴

What is experiential, practical, professional or academic knowledge?

Experiential knowledge

Experiential knowledge differs from lived experience, from accounts or testimonials. Although it develops from personal experiences related to a given reality or situation, it also results from a journey, an analysis and a reflection.^{5,6} In other words, it is from the experience of a path in life or specific experiences that experiential knowledge is generated. In interacting with a person with specific experiential knowledge, it is possible to become sensitized to the experience of the other. Nonetheless, this process does not allow for the appropriation of this knowledge for oneself and the subsequent claim to possess this knowledge.

Practical knowledge

Practical knowledge allows for the possibility of coming up with concrete solutions to problems encountered.⁷ It is knowledge developed in action, in daily life.

Professional knowledge

Professional knowledge is common amongst members of a professional group. It is developed through work-related activities.⁸ This type of knowledge is constructed, amongst other paths, by formal or informal training, observation, and work-related experiences. It may sometimes be shared with colleagues or become the focus of practice guides.

Scientific knowledge

This type of knowledge is the result of a scientific process.⁹ This rigorous process, which may be shared and reproduced, is used to respond to questions and thus enhance the knowledge of a subject.

Intertwining of knowledge

We refer to the intertwining of knowledge when an individual has more than one type of knowledge or when the members of a team complement each other with their different knowledge.¹⁰ In Figure 1, the flowers represent the knowledge which it is possible to combine to form a bouquet (multiple experiences and skills). Moreover, this bouquet is more than the simple addition of all of this knowledge, since the experiences and skills develop over time and influence each other. In this way, there is an intersection of knowledge which is continually enriched and, ultimately, indivisible.

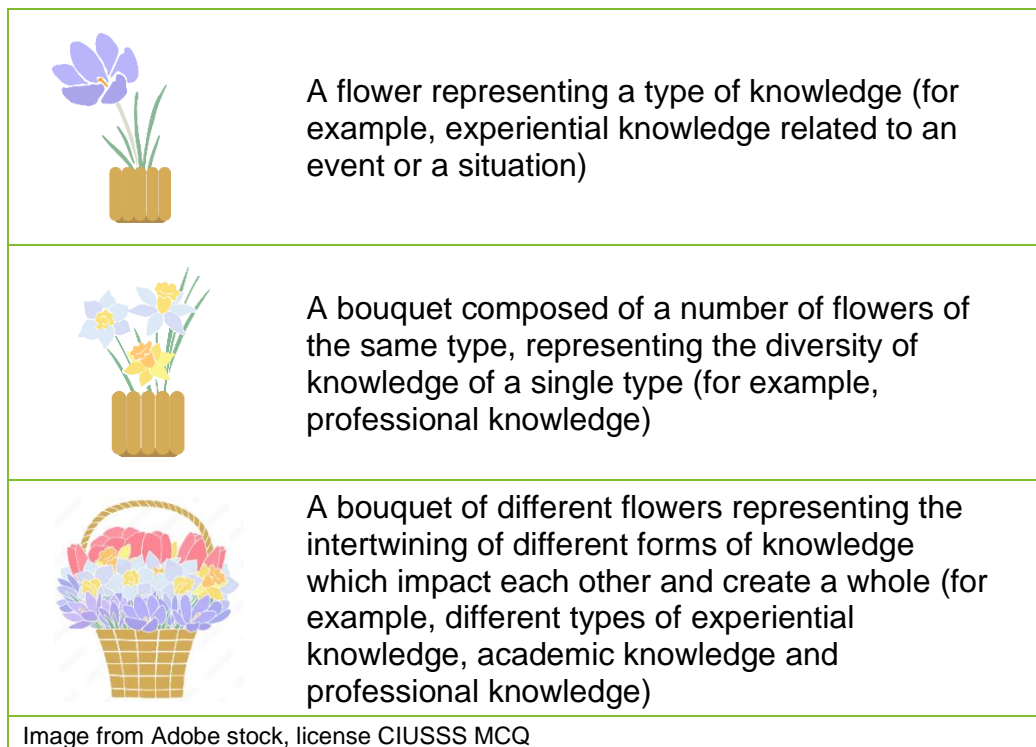


Figure 1. *Illustration representing an analogy between flowers which can form a bouquet and knowledge which can intersect.*

Why create a guide on inclusive participatory research?

A number of convictions led the authors to conceive of this guide. Here are several of them:

- It must be recognized that a/Autistics^a or people who have been labelled with an intellectual disability,^b due to their experience, have much to offer to the research concerning them. They may enrich the project, the research or the studies from beginning to end, because they are the best placed to discern the key issues regarding their own reality and needs.
- It is important not to reproduce the injustices experienced by these individuals in their daily lives and to suggest in a genuinely accessible and respectful manner to participate in research projects.
- It is possible to harm those with whom we work, despite the best of intentions. This is even more the case when these people have identities or experiences which differ from those of the other members of a team, as is often the case for a/Autistics or people who have been labelled with an intellectual disability.

How would you feel if...

- You invested a number of hours of your time in a research process without receiving just and equitable compensation?
- Your expertise was rejected, invalidated, or even denigrated because it is different?
- You were invited to take part in a project without your point of view being genuinely taken into account or without the means required for you to working accordingly to your needs and preferences?

Frustrated? Discredited? Discouraged? Sad? All of these responses?

These reflections led the authors to prepare this introductory guide to participatory research with a/Autistics or with people who have been labelled with an intellectual disability. They hope that the choice of becoming involved in participatory research is made freely and is clear for all parties involved. If missteps are made, the authors would like to see remedial actions offered. The authors hope that more and more research will be done with, indeed by, those most affected by the issues discussed. What is most important is, nonetheless, doing quality participatory research, in which individuals will feel that their knowledge is truly validated and in which relationships will be respectful and egalitarian.

^a In this document, we use the term “a/Autistic” to favour a language based on identity (rather than a language based on the person) and recognize that certain individuals: i) consider themselves autistic (with a small “a” to indicate that this is a state, a condition of a way of being), while others ii) self identify as Autistic (with a capital “a” to indicate that for them this is part of their identity and of their culture). Proposed by Désormeaux-Moreau and used by Autisme Soutien (n.d.), the utilization of the term “a/Autistic” as a common noun is inspired by an observed convention in d/Deaf communities.

^b In this document, and taking inspiration from People First Canada¹¹ and use the expression persons who have been labelled with an intellectual disability to refer to those whose intellectual functioning diverges from that of the majority.

What is the main objective of this guide?

This guide aims to provide information and to encourage reflection amongst those wishing to engage in participatory research with a/Autistic or with people who have been labelled with an intellectual disability.

This signifies research:

- In which the processes are consistent with the strengths, interests and needs of those with experiential knowledge related to the subject of this research;
- In which the division of powers is just and equitable; and
- Which responds to the requirements of scientific rigour.

How is this guide structured?

The first section of the guide lays out the necessary conditions for collaborative research with a/Autistics or people who have been labelled with an intellectual disability.

The second section illustrates how these conditions may be integrated within a process of participatory research. The guide approaches this process by dwelling upon the development of the intention of the research, research funding, the data collection, the analysis and interpretation of the data and, finally, knowledge mobilization activities.

Complementary and modifiable tools will also be progressively formulated and made available in order to support carrying out participatory research.

For whom is this guide intended?

Everyone involved in or interested in participatory research.

These individuals may be:

- ✓ Researchers
- ✓ Students
- ✓ Representatives of funding bodies
- ✓ Research partners, including those directly concerned in the study (for example, a/Autistic individuals and individual who have been labelled with an intellectual disability)
- ✓ Research professionals
- ✓ [...]

They may have knowledge related to the subject of the study:

- ✓ Experiential
- ✓ Practical
- ✓ Professional
- ✓ Scientific
- ✓ An intersection of more than one of these types of knowledge
- ✓ [...]

To the extent that they:

- ✓ Consider experiential knowledge important
- ✓ Consider diversity of benefit to scientific and social innovation
- ✓ Are aware of the efforts required in conducting participatory research (for example, in time or in relationships)
- ✓ Accept that the process and the research project may be modified on an ongoing basis, according to the needs and expectations of various participants
- ✓ Demonstrate openness to others' ideas, even when they conflict with their own

Section 1: Necessary conditions for collaborative work in the context of participatory research

The necessary conditions for collaborative work in the context of participatory research were grouped into four main themes: 1) valuing experiential knowledge; 2) clear and acceptable guidelines for all; 3) flexibility and openness; and 4) commitment to skills development. These themes are depicted in Figure 2 and described in this section. They constitute a common thread throughout the entire research process, that is, from the preparation of the project to its completion, as well as during the consideration of and reflection upon its repercussions.

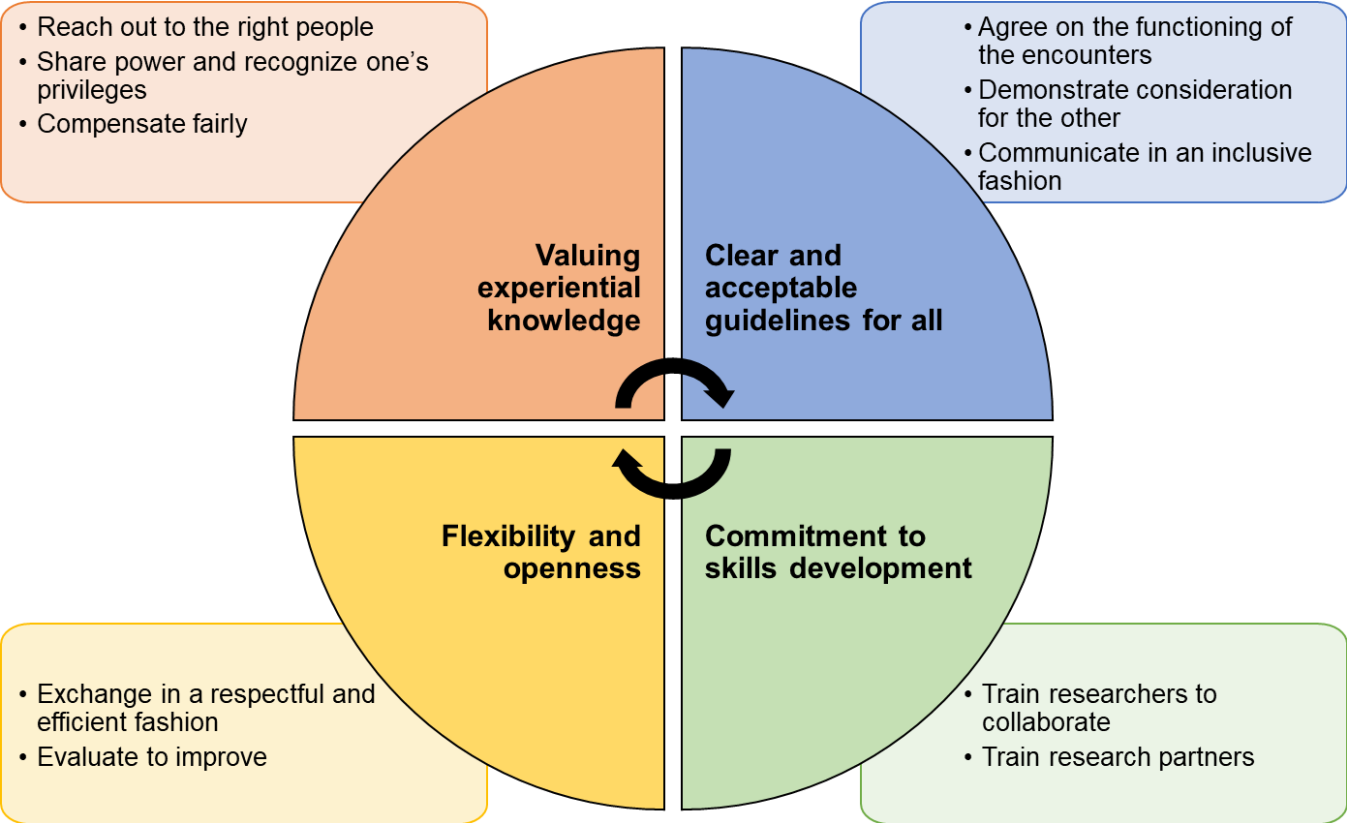


Figure 2. Necessary conditions for collaborative work.

1.1. Valuing experiential knowledge

Reach out to the right people

One of the first steps in the process of participatory research is to seek partners whose motivation and knowledge are in line with the needs of the research. This includes, in particular, those with experiential knowledge stemming from their significant experience in relation to the research theme,¹² and who are able to step back from this experience.

Participatory research supposes not only the involvement of those with experiential knowledge, but also the implementation of a process of co-construction throughout the study. In order to accomplish this, it is important to ensure that the research process and the mechanisms of work are accessible. To do so, it is sometimes first necessary to be creative regarding the research itself as well as regarding the implementation of measures allowing those with experiential knowledge related to the research theme to participate. Depending on the needs and resources of those involved in the participatory research, it may be useful to diversify the means and instruments established. For example, if one wishes to document the residential experience of non-speaking a/Autistic individuals (that is, those who express themselves by means other than orally) according to a participatory approach, it will be necessary to diversify the modes of communication (for example, schematic communication, assisted communication or online chat). Secondly, to maintain a process of co-construction throughout the entire study, one must consider the possibility of having to adjust, even needing to change, the subject of the study depending on the evolution of the participatory work. For example, it is possible that during discussions, those with relevant experiential knowledge place greater importance to another theme than that agreed upon at the outset. If this is the case, people must question themselves about: the way they (and especially those who have no experiential knowledge on the subject) approach the themes, the way they understand and interpret the perspectives of those with such knowledge, the ways of being, of expressing themselves and of acting... Finally, a co-analysis of the situation will highlight the means that need to be implemented to ensure the alignment between the perceived needs, the research objectives and the research method. It is important to remember that, if it is impossible to establish the necessary means for active participation of those with experiential knowledge, the subject, or even the research itself, should be questioned.

Is it relevant to invite informal caregivers or those with professional functions to collaborate rather than seek those who are themselves directly concerned with the subject of the research?

To respond to this question, it is essential to not simply remain in our comfort zone or stay with the tools available, which allow for participation. First, we must consider the availability of those with experiential knowledge relevant to the research focus. Then, one must determine the interest of these individuals in participating in the study envisaged. If it is not possible to find people with experiential knowledge with an interest in the research subject, one must then question the very relevance of the envisaged study or the perspective adopted.

Share power and recognize one's privileges

It is essential to be aware that certain people are more privileged than others due to characteristics that they possess and to who they are. Above all, it is vital to be conscious that these social privileges, which are not due to merit or effort,¹³ are present in all contexts, and that the research domain is no exception.

Power relationships establish themselves on the basis of a hierarchization of certain characteristics, some being socially valued, and sources of privilege and others being devalued or stigmatized. Concretely, power relationships can be established between individuals as a function of attributes which are more or less valued (for example, sex, gender, neurotype, age, skin colour, education, or profession). Certain people have more social privileges or advantages than others and the same person may be advantaged in certain circles and on the basis of certain characteristics, but not in others.¹⁴ Power relationships which are established on the basis of these privileges engender disadvantages, constraints and obstacles. It is through this prism of hierarchy that the observations and contributions of those who belong to marginalized or underrepresented groups are too often invalidated or devalued.

Allies

Those who have social privileges, notably due to their status or their function, have a major responsibility: that of using their power and associated resources to reduce these power relationships. These individuals may be allies.

Doing so is not a question of speaking on behalf of others but rather of taking a step back in relation to their own knowledge and social privileges. It means amplifying disadvantaged or underrepresented perspectives and supporting those who do not have the same privilege in their efforts to eliminate barriers (and not doing this in their place).¹⁴ It is the actions of one person that will determine the actual support and their allyship. In the end, it is based on someone's actions that people who face obstacles or barriers will determine if another as an ally (or not).

When conducting participatory research, particular attention should be paid to the composition of teams, since this may reinforce power relationships amongst the members, particularly if those with related experiential knowledge are in a minority position. One must be aware that it is often intimidating for someone with experiential knowledge to be in such a position, especially since there is often an overrating of professional, scientific and practical knowledge, to the detriment of experiential knowledge. This context can prevent the expression of experiential knowledge, particularly if not aligned with the knowledge, ideas or expectations of other members of the team. It may also increase discomfort with regard to revealing their identities.

Revealing identities?

Revealing certain aspects of one's identity can lead to fear of negative reactions or prejudice, depending on one's previous experiences. While certain aspects of identity may sometimes be hidden or camouflaged (for example the role of parent, mental health diagnoses, or sexual orientation), some are always very visible (for example, skin colour), while others may sometimes rightly or wrongly be inferred

from observation (for example, socioeconomic status, age, or gender). On the basis of various clues (for example, clothes worn by the person or their manner of expressing themselves), these deductions are often based on preconceived ideas (for example, those wearing skirts are women, and someone playing with a yo-yo is a child or an immature adult). To avoid discrimination, certain individuals devote considerable energy to concealing (hiding, masking or camouflaging) aspects of their identity, forcing themselves to be, act and communicate in a way which is not natural to them and, importantly, which does not respect their needs or their culture.

The choice to reveal one's identity

A white, Catholic, bisexual, cisgender researcher, diagnosed with an anxiety disorder, and the mother of three children, one of whom is a/Autistic, is conducting studies on the social participation of a/Autistics. This person may choose not to share some of these identities which are not apparent in a participatory research project involving a/Autistic partners, and to only reveal her status of researcher. At a different point in time, in a research context with parents of a/Autistic children, she might reveal her identity as the mother of an a/Autistic child, as well as that of researcher, to help creating a relationship of confidence with the parents, with whom she has points in common.

Dual status and questions of identity

An a/Autistic person with a doctorate (Ph. D.) and an academic position who is conducting participatory research with and for a/Autistics is confronted with a twofold rejection. On one hand, their expertise, their rigour and their skills are frequently questioned, discounted, indeed invalidated, within the academic community, due to their belonging to the a/Autistic community and their activism. On the other hand, significantly, they are sometimes reproached by certain a/Autistics for not doing enough to represent and defend the community's interests.

Assumed capacities

A young man who self-identifies and presents himself as having Down's syndrome, co-presents a knowledge translation with a researcher who corresponds to the predominant neurotype. During a question period, the members of the audience observe the physical traits associated with Down's syndrome 21. Based on assumed capacities, the audience only asks him simple and superficial questions. The substantive questions instead are directed to the researcher, who is considered capable of responding to them.

A person's sharing of intersecting knowledge, linked to that individual's different identities or to experiences related to each of them, favours the obtention of a wealth of data, and deserves greater recognition. One of the ways to recognize this is fair compensation for participants who are not affiliated with an organization who can pay for their time.

Compensate fairly

A just and equitable compensation allows for recognition of the contribution, but also the expenses and efforts invested by the partners with experiential knowledge, as well as taking into consideration their status.¹⁵ It is especially vital for funding agencies to better acknowledge the associated costs for these partners of their contribution to participatory research and to allocate the funds required for just compensation.

What are these costs?

Offering their time and spending their money for transport and lodging are possibly the obvious elements voluntarily granted by the partners. Yet, other elements may constitute significant concessions related to a profound and genuine commitment, such as physical fatigue and sensory overload, the emotions triggered by a reminder of more difficult situations, mental and emotional exhaustion, isolation, and the confrontation of their ideas or the silencing of their reality. Just and equitable compensation must take all of this into account.

Clear and acceptable paths for all are depicted in the next section. This allows, amongst other things, to render the way in which these may be invested within the context of participatory research more operational.

1.2. Clear and acceptable guidelines for all

This section covers the key elements which need to be discussed with partners from the outset of a research project and which should be re-evaluated during the project to ensure that each member of the team feels respected.

Agree on the functioning of the encounters

For inclusive planning of meetings, above all, it is best to reach agreement with the members of the group about the needs for accessibility.¹⁶ This includes, in particular:

- Explaining one's willingness to respond to the team members' accessibility needs;
- Announcing one's availability for individual preparatory meetings with participants who express the need for this before the team meeting;
- Proposing an agenda and transmitting the documents in advance (for example, by email);

- Using a written message model which highlights the key elements, thus facilitating the tracking of information, and which favours short sentences and simple words;
- Contacting those who express the need for this, before or after the team meeting, to explore possible needs so as to ensure their full participation (for example, tools and means of communication, and sensory tools) and to give feedback on the requested elements, all this in a way which suits them (for example, telephone, text, online chat, email or videoconferencing); and
- Ensuring equitable (and not equal) time to speak, so that everyone can express their ideas, accepting that certain individuals may need more time than others.

Figure 3 illustrates the idea that offering the same resources to everyone is not an acceptable solution, since each individual has their own needs and ways of being, acting and communicating, which correspond more or less to the most common ways. When one person's ways of doing things diverge more from the other group members' approach, it is essential that this person have the opportunity or the resources necessary for full participation.

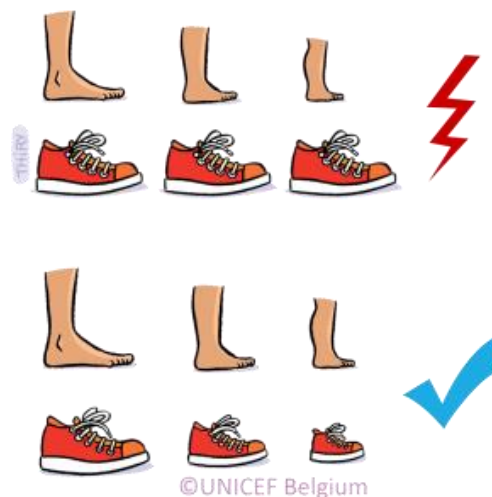


Figure 3. *Equity and equality: two concepts to differentiate*

Source: <https://kids.unicef.be/-Equity->

Similarly, different rules for inclusive functioning may be co-constructed with partners during meetings and members might be reminded of them at times. Some groups could agree on such modalities as:

- Each person's choice to open or close their camera during virtual meetings or when they speak;
- Only opening one's microphone during one's turn or when speaking (virtual meetings);
- The possibility of expressing oneself using speech, writing, images, schematic or any other means allowing for the communication of ideas;
- The availability of calm individual spaces and collective spaces during free time (i.e. the break and lunchtime);

- A maximum time period for work before taking a break (for example, at least a 10-minute break every hour);
- The raise of one’s hand (virtual or real) to have the right to speak;
- The AASPIRE method of five fingers for decision making (please see Figure 4) or any other method to facilitate the gathering of each person’s opinion (for example, thumb in the air, in the middle or lowered; a colour code for voting; or a confidential survey when required).











In Person	Virtual	Meaning
		Yay, I approve! Do it!
		Meh, I’m not thrilled, but I’ll approve.
		I am not sure, I need more information or discussion.
		I don’t like it, I won’t approve it, but I can live with it.
		I hate this so much that I can’t live with having my name associated with it.

Figure 4. Five finger method (adapted from Nicolaidis et al.¹⁷)

Moreover, it is necessary to sensitize the members of a group or a team and to invite them to be tolerant of different ways of being, of doing, of thinking and of communicating, including those which may seem unusual. For example, team members could be sensitized to the importance of strategies of self-regulation necessary to the management of anxiety or to maintaining attention which everyone could use (for example, chewing gum, manipulating an object, playing with one's fingers, shaking a foot, getting up, shifting one's chair, or rocking back and forth).

Sharing roles during meetings is also suggested, to diminish the power relationships and encourage active participation of group members. For example, the roles could be:

- Responsible for the animation (team leader);
- Responsible for time (time manager);
- Responsible for taking notes (scrib);
- Responsible for direction;
- Responsible for procedures.

The definition of responsibilities for each of these roles must be clear and explicitly understood by those involved.

Demonstrate consideration for the other

The expression of respectful vocabulary must be consistent with the preferences of those directly concerned and avoid terms conveying ableism.¹⁸ The best approach is to ask how each person would like to be addressed or to use their first name. When you refer to an a/Autistic person or a person who has been labelled with an intellectual disability, you can reference the formulations to avoid and those to favour, which are presented in Table 1. This table was created based on the proposals of the Guide des bénévoles d'Autisme Soutien,¹⁹ which itself draws from the recommendations of the organization Aut'Créatif²⁰ and from Bottema-Beutel et al.²¹ We have added here some suggestions inspired by the recommendations of the People first of Canada.¹¹ The word *persons* can be replaced by more precise terms according to the situation or roles, for example: children, adults, students, parents, or employees. It is best not to refer to people by acronyms or abbreviations.²² To learn more about the words to favour, do not hesitate to consult the web sites of these bodies.

Table 1.
Terms recommended to address people (inspired by Autisme Soutien,¹⁹ Aut'Créatif,²⁰ Bottema-Beutel et al.²¹ and the People first of Canada¹¹)

Language/(neuro)ableist discourse	Suggested alternatives
Biomedical, pathologizing /deficit-based language	
Autism Spectrum Disorder (ASD)	Autism, autism spectrum
ASD individual, individual having or with ASD, an ASD, person suffering from autism	a/Autistic, autistic, Autistic, autistic person
A person with ID, a mentally retarded person or a mental retard, a person suffering from an intellectual disability, a mentally handicapped person	Person who has been labelled with an intellectual disability
Disorder, illness, pathology	Condition, state
Disability, incapacities, symptoms	Characteristics (inherent to autism), particularities, traits
High/low level of functioning, high/low level of support, severe/mild autism or ASD	Description of specific needs, acknowledgement of the fact that the support needs probably vary across activities and contexts.
Treatment of autism (or of ASD)	When relevant: support, services, educational strategies ...
Normal individuals VS autistic individuals (or ASD)	Allistic individuals (or non autistics) VS a/Autistic individuals (or simply a/Autistics)
Patronizing language	
Specific needs, particular needs	Description of specific needs or challenges encountered
Disturbing behaviour, disruptive behaviour, problematic behaviour	Depending on what applies: autistic meltdown, autistic shutdown, self-stimulation (<i>stimming</i> – abbreviation for <i>self stimulatory behaviour</i>), description of behaviour
Obsession, limited interest, special interest	Fields of interest, fields of expertise, specific interests, key interests, passions
Tic, mania	Depending on what applies: description of the gesture, self-stimulation (<i>stimming</i> – abbreviation for <i>self stimulatory behaviour</i>)
Verbal/nonverbal	Speaking/Nonspeaking
Abnormal/normal	Difference, variation
Absence or lack of empathy	Different feeling and expression of empathy

Above all, it is important to remember to listen to the way in which people wish to be identified and to favour a vocabulary which reflects an openness, as well as a validation of diversity. Also, if a common vision of the subject of the study is necessary for a genuine co-construction, the vision and the identity preferences of different team members do not have to be shared. For example, a research team could agree to use the expression “a/Autistic individuals” to refer to the intended population for their study, all while agreeing that the members of the team who were directly and personally concerned could express themselves freely and be identified as a function of the terms and identity they choose (for example Autistic, Aspi, person on the spectrum, or merely their first name).

Communicate in an inclusive fashion

There is no single way to communicate research results so as to respond to the needs of all. It is essential to ensure that the results are accessible to various publics, including the population most concerned with the results.²³ The guide *One Idea Per Line: A Guide to Making Easy Read Resources*²⁴ offers a number of approaches to communicating in an accessible fashion. In participatory research, the active participation of partners is also encouraged in choosing, co-creating or validating the tools selected to distribute the research results.^{23,25}

To do so, it is recommended to plan diverse means of sharing the results, in collaboration with the partners with experiential, practical or professional knowledge, to determine the most effective means to reach the group which they represent. While academic communications and articles remain important, other modes of distribution must also be considered and, as much as possible, prepared with the partners with experiential, practical or professional knowledge. Here are some examples:

- Lay summary;
- Luncheon/Dinner--conference;
- Subtitled video capsule;
- Podcast with full transcript;
- Podcast;
- Computer graphic;
- Lay article;
- Open letter in a newspaper;
- Radio or television interview.

Usually, they must focus on the use of everyday language accessible to a public outside of the academic world.

1.3. Flexibility and openness

Exchange in a respectful and efficient fashion

Flexibility and openness are especially reflected in the use of means of communication which are familiar and comfortable for those involved. There are a number of ways to get in touch. It is important to take the time to discuss means of communication which will be used between and during meetings with team members. With respect to the diversity of needs and the preferences of each person, one must be sure to offer a number of means and to be open to making changes en route if a partner feels the need. One must consider relevant privileges, in order to understand that this is not a question of according the same importance to each person's preferences; instead, one must offer more resources and opportunity to those facing greater obstacles in expressing themselves and communicating their ideas. Here are some examples of ways to get in contact:

- Email;
- Text or vocal messages;
- Written or vocal messages on Messenger or Teams;
- Telephone calls;
- Brief individual encounters, virtual or live.

Evaluate to improve

Even when everything is in place, it is essential to continue to listen to the needs of each person. Needs evolve and take shape progressively. Thus, it is important to demonstrate openness in modifying, if appropriate, the markers established at the outset. Here are some recommendations to allow for the continuous improvement of processes on which participatory research may rely:

- Adopting a humble attitude, open to criticism;
- Being alert to nonverbal indications of discomfort;
- Proposing various means of offering constructive criticism or expressing oneself if there is a source of discomfort, including ways in which to do this in real time or later, anonymously, or not:
 - Feedback form online available at various points in time;
 - Conversation (using speech or writing) at the end of meetings;
 - Physical or virtual suggestion box;
 - Individual meeting;
 - Etc.

It is particularly important to regularly reiterate the means in place and your openness to modifications.

1.4. Commitment to skills development

Train researchers to collaborate

It is essential for researchers, students, and research professionals to also train themselves in the conducting of participatory research with a/Autistics or with people who have been labelled with an intellectual disability. The present guide may serve as an introduction. The authors encourage those who wish to invest in such projects, as well as those who are currently doing so, to evaluate their strengths and weaknesses in order to identify other guides, training or reading material which would allow them to further their development of skills. Moreover, some resources are suggested at the end of this guide if you would like to learn more. As we have already mentioned, a humble stance is encouraged to establish and maintain lasting partnerships in your projects. Do not hesitate to question yourself, to step back and to make adjustments, if needed.

Train research partners

It is also important to train partners with experiential, practical and professional knowledge in the basics of research.²⁶ Encouraging partners' development of skills contributes to their involvement in the research. It is recommended to consider their strengths and weaknesses and, together, to choose the training content and methods that could reinforce their self-determination and make their contribution even more significant.

To enhance partners' comprehension of the research process, it is important to present to them its different stages in clear and accessible language. The following section on the research process (presented in Figure 5) might prove useful for your partners in clarifying the stages of an academic project.

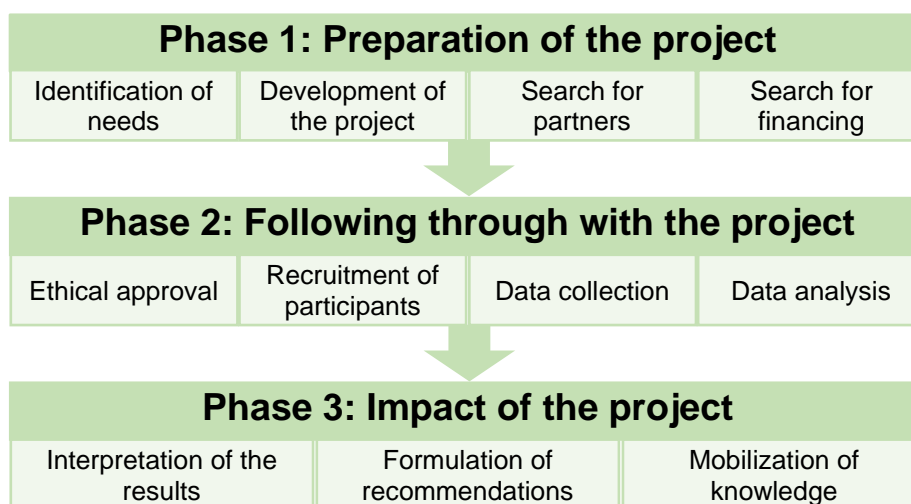


Figure 5. *The research process*

Section 2 : How to integrate these conditions into the research process

At all stages of the process, the research must be aligned with three guiding principles: respect for the persons involved, concern with their well-being, and justice.²⁷

2.1. Preparation for the project

Before even thinking of writing a grant application or a research protocol, it is vital to discuss the research needs with people with experiential knowledge related to the subject under study. For example, they should be involved in exchanges about the orientation of the theme, of objectives, of the conceptual framework and of approaches or methods to favour. Moreover, depending on their interest, their availability or their previous training, such partners can play various roles in a research project (for example, that of co-researcher, collaborator, partner, or research professional) according to their interests and skills. Given equal skills, the involvement and hiring of those with experiential knowledge is strongly encouraged. This involvement could be part of an academic path, an internship, or a job as an assistant or as a research professional. As with all members of the research team, it will be necessary to specify with these individuals their precise roles and responsibilities, as well as the training or support that they will need.

Frequently, those with experiential knowledge who are involved during the conceptualization of ideas (the concern or problem) and of the research project are not equitably recognized and compensated. Indeed, before the attribution of financing, there are a number of stages without any directly associated budget. It is the responsibility of the researcher to come to an understanding with the partners to recognize contributions of each person to the development of the research protocol, notably through attaining financing to carry out the research project.

Seeking funding

While looking for funding, it may occur that themes suggested by a granting agency are formulated in a way that does not align with the values and priorities expressed by the communities concerned. If the team still wants to move forward, discussions must take place with those with experiential knowledge to choose the ways to broach the theme.²⁶ Also, organizations have strict rules which candidates must respect. For example, the person responsible for the project must generally be employed by a body (usually a university) able to manage the funds granted (for example, with a finance department).

Once the theme and the team are selected, a research protocol is prepared following the criteria of the funding body and the research ethics committee. This research proposal must be written with a consideration of the knowledge of each member of the team. This comes back to the individual who will

carry out the project and will submit, the plan to reach agreements with co-researchers, collaborators and with partners, to identify their motivation, their availability and their interest according to their expertise. Discussions between members of the team may take place to allow them to identify the ideas which must be in the forefront of this protocol. Once this is accomplished, an initial version of the protocol drafted by the principal candidate is submitted to members, according to the modality which best suits them (for example, a written version by email, an audio version, or an illustrated version...) with directives in tune with each member's expectations.

Once the proposal is considered satisfactory by all those involved, this document is submitted, according to the directives and before the deadline set by the funding body. The evaluation of the proposal by the organization may take a number of months and it is possible that the proposal will be refused. If so, and once the decision of the body has been shared by the principal candidate with members of the team, a decision must be taken in consideration of the comments of the evaluators as to whether the team wishes to submit an application once again (revised or not, according to the position of the team).

2.2. Carrying out the project

Once the financing has been obtained, agreements may be reached regarding the roles and responsibilities, as well as the compensation, for each member of the team. It is possible that some will join the team for specific periods when their expertise will be required and that others will contribute throughout the study.

One of the initial stages of research which involves collecting data from human beings is to submit a request for a certificate of ethics approval from a research ethics committee. This process might take a certain amount of time. The committee members will require, amongst other things, information about the data collection tools that will be used and a number of other points of information about the recruitment of participants for the project, in order to be assured that individuals' rights will be respected. It often happens that exchanges between members of the research ethics committee and the research team occur to respond to certain concerns and to be assured that the study will be conducted in an ethical manner (for example, with kindness, respecting the free and clear consent of those involved). According to the policy statement of three research councils:

“Respect for individuals assumes that those who participate in the research do so voluntarily, with a sufficiently thorough reasonable comprehension of the objective of the research, its risks and its potential advantages. When individuals are able to understand this information and able to act as a consequence, of their own free will, their decisions to participate are generally perceived as expressions of their autonomy.”^{27(p. 35)}

The research ethics committees

It may happen that members of ethics committees emphasize or discuss the place of those who are partners in the research project and tend to consider them participants in the study, although they are, in fact, fully members of the research team. In this case, further explanation should be provided to the ethics committee to clarify the expected roles.

Regarding the process leading to ethical approval by the human research ethics committee, those with experiential knowledge may be involved in the understanding of a number of key issues. For example, they could respond to the following questions:

- Are the information and consent forms for a/Autistic participants or those who have been labelled with an intellectual disability sufficiently practical and clear?
- Are the advantages and disadvantages representative of what the participant will experience?
- Does the information provided allow for free and clear consent?
- Are the chosen modes of recruitment or data collection tools appropriate?
- How could they be improved to better reach those sought?

Research with those with experiential knowledge

It is important to remember that researchers with experiential knowledge related to the subject of the study (for example, a/Autistic researchers when the focus is on the a/Autistic experience; a researcher who is the sibling of someone who has been labelled with an intellectual disability if one is interested in the experience of siblings of these individuals) cannot substitute for lay partners (i.e. partners with no academic training). While the perspective of these researchers is particularly important, based on the intertwining of their academic and experiential knowledge, these people do not bring a lay perspective to the project. One must avoid “shortcuts” by claiming to be doing participatory research because the team includes researchers with experiential knowledge regarding of the subject of the study.

Also, it must be remembered that the experience of each individual is unique and that the experiential knowledge of one a/Autistic person or of on person who has been labelled with an intellectual disability cannot represent the perspectives of all a/Autistic people or all those who have been labelled with an intellectual disability.

“When you have met one autistic person, you have met one autistic person.”

Stephen Shore (free translation²⁸)

Also, it must be remembered that including a person in a participatory research process must be done based on the alignment between that person’s experiential knowledge and the object of the study – rather than being part of a given social group or community. It would be disrespectful and scientifically invalid to include, for example, any person who has been labelled with an intellectual disability in a participatory study to document the experience of learning to drive as perceived by people who have been labelled with an intellectual disability. Rather, depending on the focus of the study, it would be more appropriate to recruit individuals who have experienced or would like to experience learning to drive.

Finally, the interest and motivation of a person with experiential knowledge related to the subject of the study should not be confused with a desire for advocacy or activism. While it is possible to combine these commitments (i.e., participatory research and activism), it would be inappropriate for a research team to press for this.

2.3. Implications of the project

Experiential knowledge is particularly useful when the qualitative or quantitative data offered by a/Autistic participants or participants who have been labelled with an intellectual disability must be interpreted. Indeed, findings often takes on a different meaning depending on the knowledge that colours its understanding.²⁹ Thus, frank and open discussions about analyses between those with diverse types of knowledge and with different perspectives will permit an interpretation which is fairer, and more relevant and valid. At the same time, recommendations resulting from this analysis of results will be enhanced by the intersection of these various forms of knowledge and prove more useful for those directly concerned.

Finally, during the mobilization of knowledge, the intersection of different types of knowledge will support the choice of strategies to distribute the results and favour access for the population concerned (for example, via a short video, a computer graphic, a podcast, a popularized text or a letter to politicians). Evidently, all those involved in this process of mobilization should be recognized in a fair and equitable fashion in line with their contribution.

Conclusion

This guide offers an introduction to participatory research with a/Autistic individuals or those who have been labelled with an intellectual disability. It is vital to remember that quality participatory research must be prioritized over quantity, in order to ensure the integrity of those with experiential knowledge who commit themselves in order to advance knowledge and practices. It is crucial to express respect for their time and their contribution. Researchers who want to do participatory research must demonstrate humility and seek advice from those with experiential knowledge. They must also show flexibility in adjusting to their needs. In short, one must not only keep in mind, but also genuinely abide by, the key values of inclusive participatory research: transparency, equity, inclusion, diversity, reciprocity and openness.

We invite readers to consult the references and bibliography in order to further their knowledge. In particular, we would suggest the guide developed by an Australian research team, *Participatory and Inclusive Autism Research Practice Guides*,²³ which we found very interesting.

We would also invite contributions to the development of tools to support the carrying out of quality participatory research. Please do not hesitate to share your examples.

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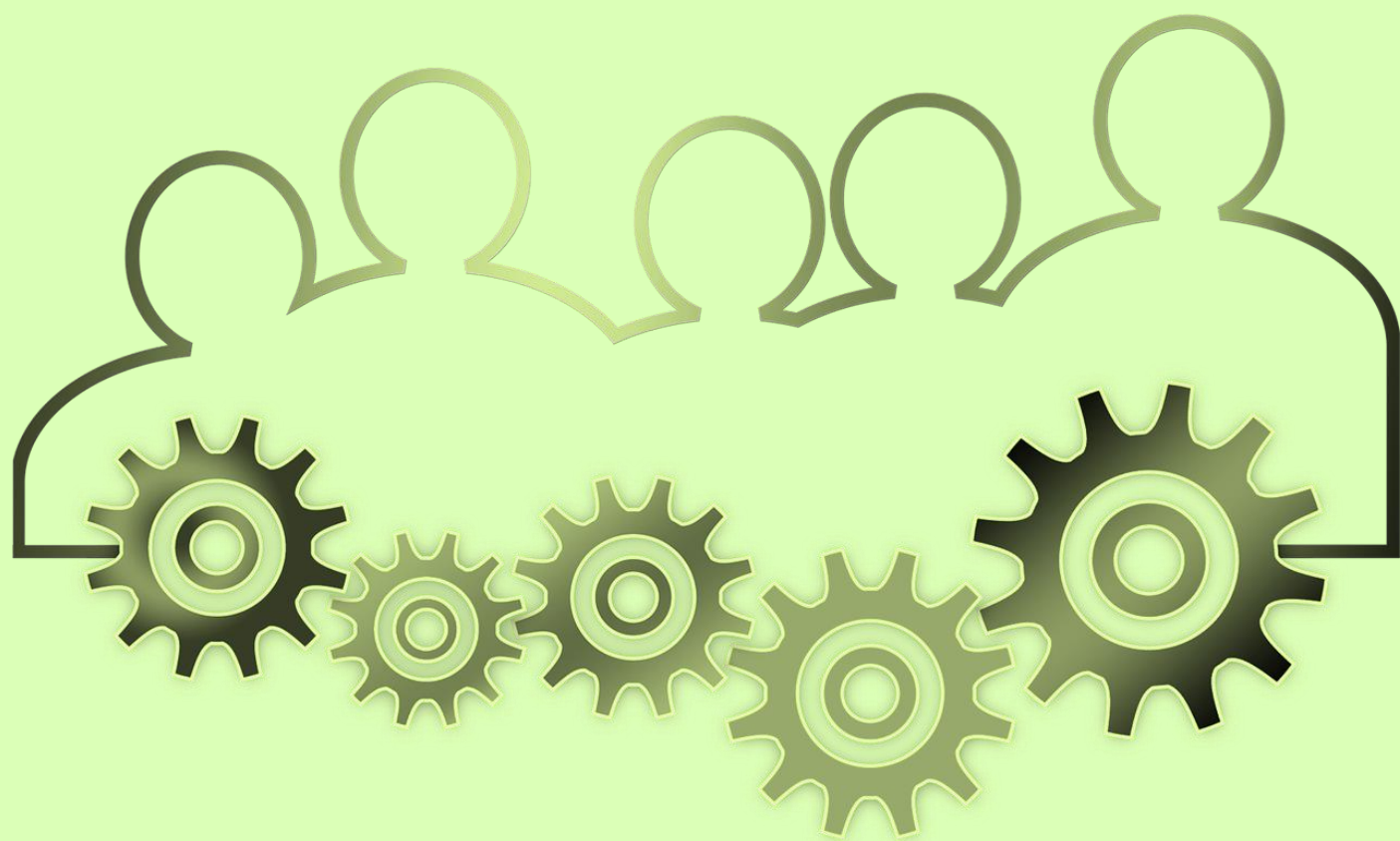
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