



Co-designing with people  
with disabilities

# Guide to ethical practice

## in inclusive innovation





**The APF France handicap TechLab** helps companies implement their inclusive innovation initiatives (through awareness-raising campaigns and training in inclusive design, co-design and product testing, etc.). Since its creation, the TechLab has focused on creating and sharing knowledge about inclusive innovation and the challenges it poses for organisations.

**[techlab@apf.asso.fr](mailto:techlab@apf.asso.fr)**

**[www.techlab-handicap.org](http://www.techlab-handicap.org)**



## TECHNOLOGY FOR CHANGE

The mission of the Technology for Change Chair, which is supported by a sponsorship programme established between Accenture and the Institut Polytechnique de Paris (IP Paris), is to explore and reinforce the links between technology and sustainable development, covering the social, economic and environmental dimensions of the latter. The aim of the Chair's work is to propose ways in which technologies can contribute to resolving various social and environmental problems, including exclusion. With this in mind, the Technology for Change Chair supports the TechLab's work in the field of inclusive innovation.



The H2i - *Handicap et Innovation inclusive* (Disability and Inclusive Innovation) network is a joint research network that brings together people with disabilities, researchers in different fields and business professionals. The network aims to promote inclusive innovation and participatory research. The H2i network supports the TechLab's activities aimed at sharing and promoting more inclusive innovation practices.

# Foreword

Inclusive innovation refers to innovation that is carried out with and for those who are generally "forgotten by innovation". Indeed, **innovation often excludes certain groups of people**, either because those people are not able to acquire a particular innovation, or cannot use and benefit from it, or simply because those people are never actually represented on the innovation design teams. Consequently, people with disabilities, the elderly, people in vulnerable situations, children, women or people from different cultural backgrounds sometimes find themselves excluded from innovation.

The recent health crisis highlighted some of these cases of exclusion: people with disabilities and the elderly found themselves all the more isolated during the crisis because they could not use digital technology; certain pupils were unable to attend school remotely because they did not possess the necessary equipment; entire population groups were deprived of access to vaccines.

Inclusive innovation aims to resolve these inequalities by involving every population group in the design of innovative products and services. Since 2018, the APF France handicap TechLab has been working to get people with disabilities actively involved in the companies' product and service design processes. This is known as **co-design**. Co-design clearly makes sense when it comes to designing solutions to improve the quality of life of people with disabilities, but this principle is also essential when it comes to designing products and services for the general public.

By involving excluded population groups in the design of all products and services, we can actively work towards a more inclusive society.

**In partnership with the Ecole Polytechnique, the TechLab conducts research into what actually forms the basis of a truly inclusive approach to innovation.** Obviously, there are a certain number of challenges that must be addressed in order to get companies and people with disabilities (as well as other population groups that have been "forgotten by innovation") to work together. The first challenge concerns ethical issues; to be truly inclusive, an innovation process must respect and protect people. Above all, it must empower them and ensure they are treated with dignity. In terms of ethics, there is not always one simple answer; often, careful thought and questioning will provide the foundations for the approach to be adopted. Consequently, above all, this guide addresses the various questions that can be raised.

Enjoy reading!

*The TechLab would like to thank Harmonie Mutuelle for its financial support in producing this guide.*



# Contents

- 1. Voluntary participation with consent**
- 2. Participation for everyone**
- 3. Free and fully-informed participation**
- 4. Participants' safety**
- 5. Privacy**
- 6. Confidentiality & company data**
- 7. Non-manipulation**
- 8. Participation ecology and objectivity of the test**
- 9. Impact on the day-to-day lives and experience of the people involved**
- 10. Participants' compensation**

# Co-designing products and services

The co-design of products and services refers to the principle of "designing with someone". We also talk about co-creation or participatory design. More and more companies are choosing to involve consumers in their design process, through various approaches and levels of involvement: focus groups, co-creation workshops, interviews, product tests, etc.

Co-design enables companies to create products and services that meet the needs of consumers as effectively as possible. Over the last thirty years or so, there has been a significant increase in the number of "living labs" - places which bring together both designers and users. However, above and beyond this, co-design is happening all around us: in companies, associations and government departments. Indeed, in line with the development of the participatory approaches that can be observed in all walks of society, it has become almost inescapable.

Nonetheless, co-design involving people with disabilities is still a somewhat marginal practice. Even companies that work in the field of disability admit that it is not easy to bring together a panel of people with disabilities. How do you identify the appropriate people? How do you enable them to come to



codesign sessions ? How do you adapt the methods of co-design appropriately?

Moreover, people with disabilities are rarely involved in the panels set up by large companies. Disability is not one of the usual categories addressed by these panels (i.e. men/women, roughly 40 years old who live in urban or rural areas).

That being said, certain companies and organisations are actively committed to including people with disabilities in their study panels; TechLab's experience highlights the wide-ranging ethical questions that arise in these cases, which can be used to guide and inform co-design approaches involving every type of user.

**This guide is therefore aimed at all the organisations that involve people with disabilities in the design of innovative products or services** (companies, start-ups, living labs, incubators, etc.), as well as all those that involve everyday consumers in such processes.

It draws on the research carried out at TechLab in the field of inclusive innovation and analyses the interactions observed within 20 co-design projects. At the same time, the guide does not claim to be exhaustive and may be complemented and enhanced by the discussions that we hope it will provoke.



# 1.

## Voluntary participation with consent

**Participation:** noun. The fact that you take part or become involved in something

**Voluntary:** *adj.* Done, made, or given willingly, without being forced to do it

**Consent:** *verb (trans.)* To agree to do something, or to allow someone to do something



## Voluntary participation with consent

### “ Situation

An educator who works in a socio-medical centre is contacted by a start-up company that is developing a fun innovation for people with disabilities. The start-up wants to test its innovation with people at the centre. The innovation looks very interesting and the educator is enthusiastic about the idea. He decides to replace the next theatre workshop with a session to test the innovation. On the day of the workshop, he informs the participants about this change of programme.





## Questions to ask yourself



- Have the participants been properly informed about the process?
- Have they been encouraged to take part?
- Do they feel free to refuse?
- Have they explicitly given their consent to take part in the process?
- Are they in a position to be able to understand all the issues involved in the project? If not, who should be consulted concerning their consent?
- What measures have been taken to enable participants who cannot read/speak/write to express their consent? (Pictograms, signature by a third party, case of non-signature, etc.)
- If a communication campaign is planned using these videos or pictures, have the participants expressed their prior consent?

## Points to be considered



The fact that people with disabilities be involved in the innovation process is one of the legitimate demands made by a number of associations and individuals. This involvement will guarantee that the products and services designed will actually meet the needs.

However, there is a risk that such a demand could be taken as an obligation to participate. This is why it is important to ensure that people participate on a voluntary basis. It is therefore important to ensure that the people involved actually "want" to take part and do not feel obliged to do so.

The consent of minors and adults under guardianship must be duly confirmed by a legal representative or a trustworthy person. In the event a person is unable to express their consent themselves, the legal representative of that person, or someone who has a close and regular relationship with the person concerned, must confirm the latter's consent.

If a communication campaign is planned, consent must be requested for the recording of pictures or sound at the start of the process.



# 2.

## Participation for everyone

**Participation:** noun. The fact that you take part or become involved in something

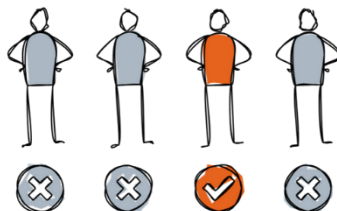
**All:** *adj.* Every one of, or the complete number of



## Voluntary participation with consent

### “ Situation

A person who works for an association is contacted by a start-up that has designed an innovative product. The start-up wants disabled people to give their opinions about the product. The person that works for the association sets up a survey group made up of people he knows will have no difficulty expressing their opinion about the product. Moreover, the start-up specified that they wish the group to be made up of people with a physical handicap, not a mental handicap.







## Questions to ask yourself



- Are all participants welcome to be part of the group, whatever their disability? If not, why?
- Is this selection justified? Does this create a situation of exclusion as regards the group?
- Have the organisers planned any adjustments to enable wider scope of participants (methodological adjustments)?
- Have the organisers checked that the place used to host the co-design sessions will enable everyone to participate (accessibility)?
- Is the diversity of consumers fully represented?

## Points to be considered



Ensuring that everyone can participate in the co-design process is one of the foundations of inclusive innovation. Consequently, questions should be raised if any group of people is excluded from participating in the process of designing products or services.

Sometimes, the decision to exclude certain people from the process stems from a well-meaning intention, for example, you do not want to place certain people in a difficult situation. However, the idea of protecting people should not result in "overprotection"; many people can decide themselves whether they will encounter difficulties or not. It is not for someone else to decide in their place. Moreover, they may prefer to have limited participation in the process, rather than be excluded from the group and the project.

Sometimes, we wrongly assume that certain people will not be able to contribute to the co-design process (e.g. people with mental disabilities or people who have difficulty expressing themselves). But the methodologies used can be adjusted, so that everyone can contribute effectively. The methodologies also need to be adjusted to ensure that no-one is excluded (for example in the case of sensory disabilities).

On the other hand, certain types of people may not be selected to take part in an inclusive innovation process for perfectly legitimate reasons; for example, if the innovative product is not aimed at those people because of their lifestyle, their age or even their disability (for example, there is no point involving people who cannot stand up in the tests for a walking frame).

# 3.

## Free and fully-informed participation

**Participation:** noun. The fact that you take part or become involved in something

**Free:** *adj.* Not limited or controlled

**Inform:** *verb (trans.):* To tell someone about particular facts; to give information or to teach someone about something



## Free and fully-informed participation

### “ Situation

Michèle accepted to take part in a co-design process. The process involves participating in four workshops. However, by the second workshop, she feels uncomfortable. She does not feel she is understood by the designers; she does not agree with the objective of their solution. She feels that the process takes up too much of her time and that she should have been paid for it. However, she does not dare to withdraw from the process.





## Questions to ask yourself



- Have the participants been properly informed about the project's objective?
- Have they been properly informed about the duration of the project and the financial conditions?
- Have they been properly informed about the possibility of withdrawing from the process?
- If so, what is the procedure that must be followed to withdraw?

## Points to be considered



The contract established between a company and a panel of users within the framework of a co-design process is a moral contract. It is generally not an employment contract.

However, the contract conditions must be properly set out. The participants must be informed about the product or service that will be dealt with during the joint work, as well as the objectives of the work : is the goal to design a new product to replace another? Is the goal to adapt an existing product to a certain disability? Is the goal to test a prototype and check its usability or accessibility?

Participants must be informed about how long the project will last: number of meetings, times, duration of meetings, overall duration of the project.

They must also be informed about the financial conditions: transport costs, compensation, product donations, etc.

Finally, participants must be free to withdraw from the project at any time and be clearly informed of this.



# 4.

## Participants' safety

**Safety:** *noun.* State in which or a place where you are safe and not in danger or at risk, notably in relation to physical attacks, accidents, theft



## Participants' safety

### “ Situation

A start-up is designing an innovative urban mobility device for people with disabilities. It invites people to come and test the device. The test goes well. At the end of the meeting, when the participants are asked to fill in a written questionnaire, the start-up realises that one of the people concerned is visually impaired and cannot fill in the questionnaire. The company realises that the test had put the participant in danger.







## Questions to ask yourself



- Has the product been certified in terms of safety?
- If not, is a product test really necessary, or would a demonstration be enough to obtain user feedback?
- Could using the product entail any risks for participants?
- Could the physical or mental health of the participants increase these risks?
- Are participants aware of the potential risks?
- Have all measures been taken to avoid injury?

## Points to be considered



Ensuring the safety of participants in a workshop is an essential aspect of the co-design process. Consequently, the risks linked to testing products and services must be analysed beforehand and take into account any vulnerabilities/disabilities that the people may have. Participants must be informed about the potential risks involved in testing the company's products or services. Every precaution must be taken by the company to protect the participants. If safety is an issue (uncertified product, etc.), a simple product demonstration may be enough to get feedback from participants.



# 5.

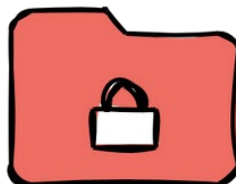
## Privacy

**Privacy** : *noun*. someone's right to keep their personal matters and relationships secret



## “ Situation

Juliette, who has multiple sclerosis, agreed to take part in a trial for an innovative technical tool. When she was interviewed by the company as part of the test, she was happy to share information about her disability and the difficulties it causes her on a day-to-day basis. However, she did not expect what she said during the interview to end up on the company's website in order to highlight the need that the company's solution responded to. When she complained to the company, they apologised, saying that their Communications Officer has used the video from the trial in an inappropriate way. The fact that most of Juliette's work colleagues were unaware that she had multiple sclerosis made the disclosure of her health data even more embarrassing for her.





## Questions to ask yourself



- What measures have been taken to anonymise the data?
- Are any videos recorded or photos taken during the trial?
- Are these necessary for the study?
- Can the videos or photos be produced without showing the people's faces or names?
- If a communication campaign is planned using these videos or pictures, have the participants expressed their prior consent?
- How will their personal data be used?
- Have the participants been informed about how their personal data be used?
- How long will the data be kept? Is the data storage area secure?

## Points to be considered



People who take part in an inclusive innovation process may disclose details about themselves, talk about their physical condition and share medical data.

The confidentiality of this type of data must be ensured at every stage of its use:

- during the data collection (all external people who attend the discussions must be identified and made aware of this point),
- when recording and storing data (records must be stored in a secure place),
- when using the data (data must only be used for the intended purpose).

At each of these stages, the data can be anonymised. For example, only first names could be used during a round-table discussion. Photos can be taken in such a way that people's faces are not visible.

Participants involved in a co-design process must be informed about how their data will be processed and that they are entitled to refuse to provide certain information.



# 6.

## Confidentiality & company data

**Confidentiality:** *noun*. The fact of private information being kept secret

**Confidential:** *adj*. Private, and intended to be kept secret



### “ Situation

Jean is taking part in a trial for an innovative product. He is very enthusiastic and takes a lot of photos. He then posts these photos on Facebook, explaining the company's approach, which he considers to be positive, and the qualities of the product he has tested. In doing so, he has revealed details about a new product, which the company was planning to launch at a major trade show during the following quarter.







## Questions to ask yourself



- Is certain information that the company aims to share confidential?
- Has this information been clearly identified?
- Have the participants properly been informed about the confidential nature of this information? Does the method used to inform participants about the confidential nature of certain information take account of any disabilities the participants may have? (Simple explanations, written, oral, etc.)
- Have the participants been informed about why it is important to keep the information confidential and how to ensure it remains confidential?

## Points to be considered



Products and services that are being tested as part of inclusive innovation process are often products/services that are not yet on the market. Participants must be informed about the confidentiality issues concerning the product or service being tested. The way in which this information is conveyed may need to be adapted in order to take into account the participants' disabilities. It may also be useful to clearly specify to the participants which elements are confidential: product features, choice of materials, associated services, product release date, etc. Edited information or materials – which comply with the confidentiality requirements – may be given to participants for their own use.



# 7.

## Non-manipulation

**Manipulation:** *noun.* The action of influencing or controlling someone or something to your advantage, often without anyone knowing it

**Manipulate:** *verb (trans.)* To control something or someone to your advantage, often unfairly or dishonestly



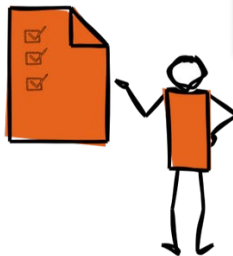
## Non- manipulation

### “ Situation

Claiming he wants to get user feedback, an entrepreneur has his product tested by people with disabilities in a socio-medical centre. He gives a long presentation about the advantages of his product to the participants in the trial.

After this, he distributes a questionnaire to the participants. In fact, the questionnaire is a market study that he needs to carry out in order to obtain financing from his bank. His lengthy presentation could clearly have an influence on the respondents answers to the questionnaire.

Two months later, the entrepreneur gets back in touch with the centre with a sales proposal for his product.





## Questions to ask yourself



- Are the expectations and objectives of each stakeholder (company, participants, etc.) explicitly explained and shared?
- Is the main objective to improve the product or service?
- To what extent can the product or service still be modified at the start of the co-design project?
- Are there any secondary expectations/objectives (marketing, financing, sales, etc.)? Are these expectations/objectives clearly shared with the participants and the other stakeholders? Are there other ways in which these secondary expectations/objectives could be met?
- What are the expectations/objectives of the potential intermediaries (associations, innovation labs, etc.)? Do these have an impact on the co-design process or the results?
- Do participants need to buy the product in order to test it? Why?
- Are the participants encouraged to buy the product?



## Points to be considered

The objective of a co-design project is to enable the designer to improve his/her product or service thanks to interactions with and feedback from the participants in the process. If the expectations are different, this must be clearly specified. While it is quite legitimate for companies to want to present their products to future customers in order to sell them, it is not legitimate to do so under the guise of "co-designing" the product. This is a form of manipulation.

Stating that the objective is to "test the product" is also ambiguous; is the aim to test the product in order to "show it" or to identify how it can be improved? If the aim is to improve the product, is the goal to use the feedback to improve the current version before going to market or to use the information for a future version?

Using a co-design session to influence participants' perceptions and responses to market survey is also manipulative.

Finally, it is also a form of manipulation to use a co-design session essentially in order to then be able to promote a product to third parties as being "designed/approved with the help of the users" or "designed/approved with the help of the XYZ association".

The company must be clear about its intentions and where the product is at in its development stage at the time of the co-design session. It must also clearly explain its intention to use the term "co-designed" to promote its product after the process.

# 8.

## Participation ecology and objectivity of the test

**Ecology:** *noun.* (in this context) study of the reciprocal relationships between human beings and their moral, social and economic environment

**Objectivity:** *noun.* Quality of something that conforms to reality, of a judgement that describes the facts accurately



## Participation ecology and objectivity of the test

### “ Situation

A group of people with disabilities is involved in a product testing process. One of the people has difficulty using the product. The person apologises for not being able to complete the test alone. Someone helps the person to carry out the next steps. The person feels a sense of failure because he/she wasn't able to carry out the actions requested. Moreover, the company seems to place more value in the opinions and comments of the doctor that was also involved in the process.







## Questions to ask yourself



- Are the participants put in a difficult situation during the test process?
- If so, what measures have been taken to ensure they do not experience a sense of failure?
- By being organised in such a way, is the test still representative of the difficulties people will encounter during actual use?
- Is the co-design project method adapted to people with disabilities (e.g. physical or cognitive impairments)?
- What measures have been taken to ensure that the opinions of the professionals involved in the process are not given greater weight than those of the users?



## Points to be considered

During a workshop, people may encounter difficulties. They may fail to carry out the action they are supposed to perform with the product being tested. They may not understand an instruction. It is important to take all necessary steps to prevent these situations from giving the participants a negative feeling.

However, a difficulty can also be due to the actual product being tested, and highlight a product's defects. Therefore, participants involved in product tests should not be given help in how to use the product too quickly, since this would distort the results of the test. Consequently, participants should be informed that, if they have difficulty carrying out certain tasks, it is the product's usability (ease of use) or accessibility (adaptation to the needs of people with disabilities) that is the problem, not their abilities. The methodologies used in co-design should also be adapted to avoid putting participants in a difficult position. For example, people with physical disabilities should not be asked to provide written feedback.

Professionals who work in the field of disability often have very valuable opinions concerning the design of disability products and services. Their work exposes them to a wide range of situations. However, this professional knowledge does not replace people's experiential knowledge, i.e. the experience of living with a disability on a day-to-day basis. These two types of knowledge complement each other. A professional's input and knowledge may be more noticeable than the participants' experiential feedback in a co-design session, since professionals often have a more assertive stance. The process needs to ensure that both types of knowledge are taken into account in a balanced way.

# 9.

## Impact on the day-to-day lives and experience of the people involved

**Impact:** *noun*. A powerful effect that something, especially something new, has on a situation or person

**Day-to-day:** *adj*. Happening every day as a regular part of your job or life

**Experience:** *noun*. Something that happens to you that affects how you feel



## Impact on the day-to-day lives and experience of the people involved

### “ Situation

Léonard is helping to test an innovative device that will greatly improve his mobility. Since he has been using the device, he can walk more easily and has even started to leave his wheelchair behind when going out in his neighbourhood. The device has been loaned to him for 6 months. The company that designed the device collects feedback from Léonard every month. After the test period, Léonard will have to return the device. He cannot afford to purchase it.





## Questions to ask yourself

- Will the participants have access to the service or product after the project (can they afford it)? If not, could there be problems linked to allowing them to benefit from the product/service over a short period?
- Will the test have a significant impact on their lifestyle? Could this be unsettling? What impact will this have on their health?

## Points to be considered



The products tested, particularly medical devices, can have a major impact on people's day-to-day lives. When the expected benefits are significant, you need to consider the question of how long those benefits are going to last. If it is unlikely that the participants in the test will be able to afford to buy the product, it is important to specifically discuss the effect that abandoning the use of the product at the end of the test period will have on them (consequences for their health, their daily lives, their morale, etc.). Care must be taken not to over-protect the participants or make decisions in their place. They must be given the opportunity to make an informed decision about whether or not to take part in the process.



# 10.

## Participants' compensation

**Compensation:** *noun*. The combination of payment and other benefits that a person receives for doing a job



## Participants' compensation

### “ Situation

Adeline is taking part in a co-design workshop in a neighbouring town. She pays for public transport to get there. She was told she could possibly receive remuneration for her participation from the company in charge of organising the test, but she refused because she was afraid it would affect her entitlement to her Disability Living Allowance.







## Questions to ask yourself

- How does the company reward the value created and the time spent by participants?
- Are participants clearly informed of the financial conditions before they enrol to take part in the process?
- Are participants reimbursed for their travel expenses?
- Will they be given any compensation? If not, can they be given the product free of charge or at a lower price?
- Is the compensation proportionate to the time spent?

## Points to be considered



Some companies may consider that involving associations in their product or service trials means that they are already sharing value with the participants, since the aim of the trial is to improve the product or service's accessibility, which is one of the key goals the associations are seeking to achieve. Nevertheless, improving a product/service's accessibility will benefit a large number of people (beyond the scope of the association) and help create products and services that are easier for everyone to use, thereby creating value for the company. Consequently, the issue of compensation needs to be addressed.

Moreover, people with reduced mobility may also have higher travel costs, which need to be taken into account. In medical research, the compensation is capped, in line with the principle that bodies cannot be used for the purposes of trade. Also, with certain methodologies, compensation is perceived as introducing a bias. However, this bias can undoubtedly be overcome, if it is made clear to the participants what is expected of them and how they will be rewarded for their participation.



# Conclusion

The process of inclusive innovation raises many ethical questions. And indeed, asking oneself questions is the first step towards achieving a more ethical approach. In this respect, co-design processes could draw on the idea of **Research Ethics Committees**, which are set up in the field of medical research.

These committees must issue a favourable opinion before any research involving human subjects can be carried out. The committee's opinion concerns the procedures that will be used to protect the people involved in the research, as well as the relevance of the research and the methodology to be used.

Research Ethics Committees are made up of healthcare professionals and people qualified in ethics, law and human and social sciences, as well as patients' associations.

The diverse profiles of the members that sit on this type of committee ensure that everyone's interests are taken into account.

In the same way, companies and organisations working on innovations with co-design processes involving people with disabilities could discuss the ethical aspects of their processes with this type of committee.



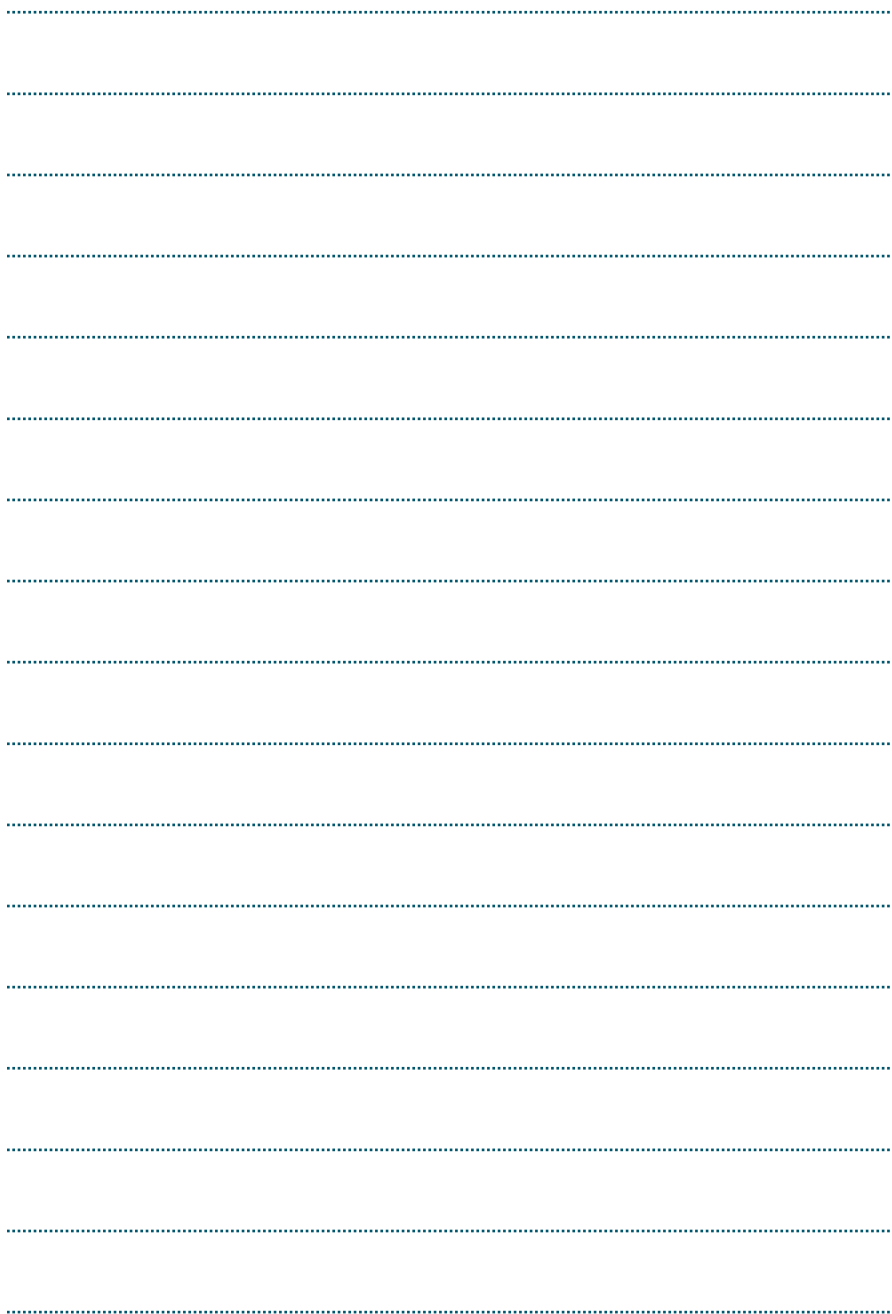
# Would you like to adopt an inclusive approach to design?

Get the TechLab involved in the design of your products and services

Le TechLab helps you set up and implement your co-design processes involving disabled people:

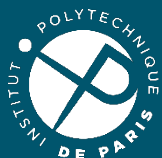
- the opportunity to design truly inclusive, ergonomic and useful products
- a network of 100,000 players involved in the disability sector
- a relevant methodology taking ethical issues into account





# ● ● ● The TechLab guides

**TechLab**  
Le hub de l'innovation  
technologique



**TECHNOLOGY  
FOR CHANGE**

Author: Estelle Peyrard

Graphics: Camille Chevrotton and Estelle Peyrard

Translation : CG Traduction

[techlab@apf.asso.fr](mailto:techlab@apf.asso.fr)

[www.techlab-handicap.org](http://www.techlab-handicap.org)