



# Guidelines for Inclusive Research

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## Introduction

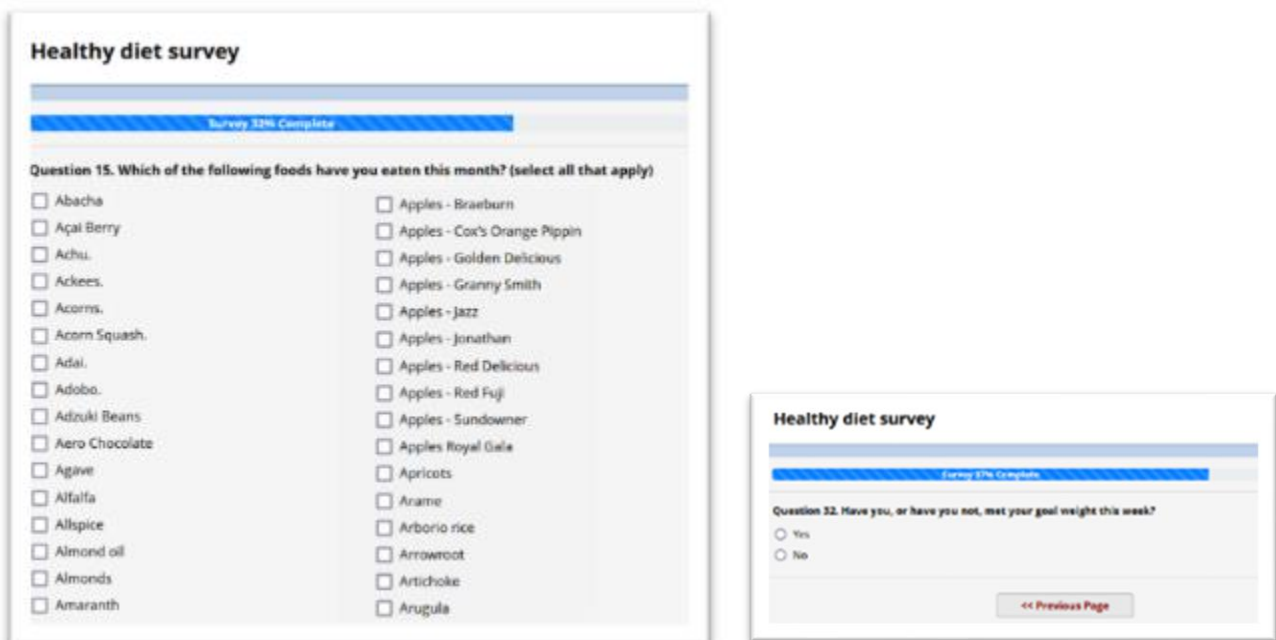
This project has provided many insights into what makes assistive technology research inclusive, feasible, and successful. An important aspect of this is working in partnership with consumers – you can read our reflections about this in the briefing document *“Impact of and Factors Supporting Collaboration and Participatory Design”*.

Inclusive research also requires close attention to the experience and access needs of participants. In this document, we share what we have learned about making research tools and materials user-friendly and inclusive. You are welcome to adapt these ideas for your own work.

## What is “usability” and how does it relate to research?

Do you remember the last bad survey you took? Perhaps it took longer than advertised or was too complicated. Were the questions confusing, or badly structured? Did the topics or terminology lack relevance to your own life? If so, Figure 7 may be relatable!

**Figure 7:** Examples of long and confusing survey questions.



The term “usability” refers to how easy something is to use. Usability is important for successful services, products, and environments. Common principles associated with good user experiences include:

- Usefulness:** Meeting an existing need
- Consistency:** The user experience is predictable and familiar
- Simplicity:** Being simple and intuitive to use
- Efficiency:** Minimises effort and time-costs
- Clarity:** Offering clear information and instructions
- Durability:** Preventing and resolving any errors in use
- Accessibility:** Accommodating diverse user needs

Usability principles hold just as much significance for the design of **research experiences** as they do for other products and services.

## Why is usability important to research?

If your research processes or materials have poor usability, research participants are more likely to leave your study. This limits the quality and quantity of your data, and the strength of your research findings. Frustration with research tools or activities can also harm the relationship that participants have with the academics or services that are conducting the research. Good usability creates better experiences for all research participants, but is especially important for some populations including: People with busy schedules, such as parents, carers, or busy professionals; people with disability or health conditions; people with language differences or low literacy, and people who are experiencing personal or situational stress. These groups represent a significant portion of the general population and are important voices to include in research. To capture these perspectives, good usability of research tools and processes is essential.

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- *People who are experiencing personal or situational stress.*

## Improving usability through co-design

Put simply, co-design involves “making things and learning what works” and requires “working with the people who are closest to the solutions” (McKercher, 2021). In the case of research, this means working with people who are similar to your target research participants (e.g., community members, service users, or professionals).

In our project, the university researchers worked closely with the My Active Life National Project Managers and Lived Experience Advisory Group (LEAG), to co-design our research questions, tools, and activities. The LEAG included six people with disabilities and supporters / carers of people with disability, who were involved or invested in inclusive recreation. Working with this team improved the overall usability of our research.

We undertook several steps as part of the co-design process:

- The university researchers read and summarised published articles and guidelines about inclusive research design and research participant experiences.
- The LEAG members critiqued existing research tools (e.g., Quality of Life questionnaires, consent forms), and provided feedback.
- The whole research team co-designed new research tools (e.g., recreation and health resource use measures; satisfaction measures, and dynamic consent processes).
- LEAG members tested and provided feedback on each tool, using a “Think Aloud” user-testing method. You can learn more about this method [here](#).
- We used accessibility testing tools such as [Accessibility Checker](#) to ensure our tools met international accessibility standards such as the [Web Content Accessibility Guidelines](#) (WCAG 2.1).



## Finding a compromise

Sometimes we had to find a compromise between usability and other priorities, such as research sensitivity, accuracy, or cost. For example, we noticed that some standardised tools (e.g., for measuring Quality of Life) had poor usability, but changing these was not easy. Standardised tools have been tested with large groups of people to enable researchers to compare results from a group of participants to a general population. Changing the tools makes the comparisons less accurate. We talked about the benefits and drawbacks of making changes, and decided which changes were the most important for these tools. Some suggested usability measures (such as translating tools into multiple languages or having someone to assist participants in completing surveys over the phone) were too expensive or resource intensive for the current project. Explaining the nature of standardised research methods to the LEAG participants and having transparency about project resources helped us to make informed and balanced decisions as a team.

## What we learnt

We have gained several insights about usability and inclusion through our work in this project. The following guide outlines nine principles that we have identified for inclusive research, and the ways these can be achieved.

### Principles of Inclusive Research

1. Usefulness
2. Flexibility
3. Choice and Control
4. Consistency
5. Efficiency
6. Clear Communication
7. Accessibility
8. Respect
9. Resilience

# Principles of Inclusive Research

## 1. Usefulness

Research questions and outcomes should always have value to the populations at the centre of the research. This means **only undertaking research that is necessary and important**.

Here are six things you can do to improve the usefulness of your own research:

1. Conduct a **comprehensive literature review** to identify what topics have already been studied enough, and how your research can update or fill gaps in existing knowledge.
2. Talk to members of the community that you are researching, to identify their **priorities and needs for information**. Does your research match these aims? If not, why not?
3. **Explain why you are collecting sensitive information** (e.g., financial data; questions about gender, age, or culture), or information that will be arduous for participants to report (e.g., recalling detailed information about activities or resources). Avoid asking these questions if the information will not be useful or informative.
4. **Explain how the research findings will be shared and applied**. For example, how do you expect your research to impact services or products in the future?
5. Ensure you **share your research findings via accessible formats and channels**. For example, in our project we have made plans to share our findings through mainstream media, social media, and with local politicians. Other examples of accessible knowledge sharing could include practice resources, checklists, pamphlets, posters, and advocacy guides.
6. Consider the **individual value to participants** of engaging in the research and communicate these honestly. Look for opportunities to increase this value, for instance by building in opportunities for participants to grow their networks, access resources, or build and document their skills. Where individual value is low, consider if reimbursements are appropriate, and what form these should take. For example, we have learned that in some communities it is culturally inappropriate to provide gift vouchers in lieu of money, due to the way that finances have been historically controlled for those groups. In other instances, gift vouchers may offer the most flexible and accessible solution. Conversations with diverse community members and advocates can guide these decisions.

## 2. Flexibility

No research method is the perfect fit for all participants. When working with diverse communities, we have found it valuable to **provide people with a choice in how they want to participate**. For example:

- Choosing to participate individually or in a group
- Choosing how people would like to communicate their perspectives, for example through spoken or Auslan (signed) interactions, written submissions, creating photographs or drawings, or using augmentative and alternative communication (AAC) tools.
- Choosing if they want to participate in further or continued research.

An online interface that we have used for this process can be viewed in more detail in a [blog post from Research Assistant Dion Williams](#).

## 3. Choice and Control

It is important that research participants understand the study before they agree to participate. This is called giving *informed consent*. In traditional research, participants are given a written *Plain Language Statement* (containing information about what the study will involve) and will be required to sign a consent form. This approach can be problematic for several reasons:

- **Accessibility:** Printed consent forms can be difficult for people with vision impairment to read and sign.
- **Convenience:** Signing a consent form as a printed or electronic document often involves several time-consuming steps (e.g., printing, signing, scanning, uploading or posting/emailing a document)
- **Clarity and language:** When we have tested standard information and consent forms with some research participants, they have told us that not all of the information is important to them. Participants may skim or ignore lengthy research documents and can easily miss the information that's most important. Complex language can also make the forms harder to understand.

There are several ways that you can adapt your consent process for participants. For example, you can:

1. Use **simple language combined with meaningful pictures**, as shown in the screenshot below (figure 8a). This format is easier for people with lower literacy or language skills to understand. It can also be useful when a participant and a researcher/supporter are having a less formal conversation about the study.
2. Provide a **participant information video** (see figure 8b). We usually record our videos using Microsoft PowerPoint. They are a combination of simple spoken language, simple text, and pictures. You can also add captions or sign language, depending on the audience. Consider including a lived-experience partner in the videos if relevant.
3. Provide a **supported decision-making option** for young children and people with significant cognitive impairment, instead of proxy consent. Supported decision making is defined as an interdependent and continuous process shared between the participant and supporters who know them well (Watson, 2016). Young research participants and those with significant cognitive disability can express their preferences and feelings about the research through a range of means including facial expression, body language, gesture, physiological reactions, and behaviour. Familiar supporters can then acknowledge, interpret, and act on these expressions (e.g., by helping the person to engage in the research, or by recommending changes or discontinuation).






To learn more about these accessible approaches to consent and how we have used them in our own practice, please see this blog post: <https://blogs.deakin.edu.au/inclusivehealth/doing-inclusive-research/>





Figure 8a and 8b: Accessible online consent form with supporting pictures and video.

### How do I get involved?

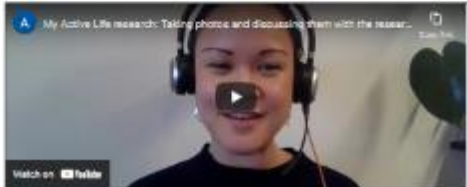
You can choose to:




-  Have a 1-hour interview on a video call
-  Have a 1-hour interview over the phone
-  Write your answers to interview questions and send them in an email
-  Draw 3-5 pictures and talk about them with someone from the research team
-  Take 3-5 photos and talk about them with someone from the research team

You have chosen that you would like to **support someone to take 3 - 5 photos and talk about them with someone from the research team.**

If you like, you can watch the video below which has Closed Captions. It will let you know all the information in the consent forms about **taking photos** for this research. It also lets you know about the information in your photo manual. This manual includes important information about what types of photos can be included in this study and some rules to follow when taking your photos. [Please click here to download and save a copy of the photo manual for your use.](#)



Watch on   

## 4. Consistency

The research experience should be **consistent, familiar, and predictable**. You can achieve this by:

1. Ensuring that any documents or surveys in your study **look and operate the same way**. This means that returning participants will know what to expect.
2. Follow a **consistent and predictable structure** in your surveys and documentation – e.g., keep your headings, formatting, instructions, and controls (e.g., survey buttons and labels) consistent across different research activities. Group related information or questions, and use clear section breaks when transitioning between different concepts or topics.
3. Organise surveys and interviews in a **logical order**. For example, if you want to know about a service experience, ask questions that follow the timeline of a person’s engagement, such as finding/waiting for the service → intake process → initial appointment → receiving the service → leaving the service. This helps to make recall easier and more efficient.
4. Use **appropriate language and terminology** for the community you are researching. For example, describe health conditions, services, and procedures using the language your participants will be most familiar and comfortable with. You can learn about these terms by reading public documents from relevant services, by observing services in action, or by asking community members such as a LEAG.
5. Provide **practical examples** to help people recognise a familiar concept – for instance:
  - “Do you use a mobility aid (e.g., a walking stick, wheelchair, scooter, frame or walker) to move around?”
  - “Have you used a digital health resource (e.g., a health website, mobile health app, or wearable health sensor) during the last month?”



## 5. Efficiency

Participants' time is precious. To ensure maximal efficiency and reduce workload for participants, consider the following strategies:

1. **Only show important information.** Reduce clutter and eliminate any unnecessary or irrelevant elements, such as lengthy background text.
2. Allow participants to **seek additional information** if they are interested. Some participants need lots of information about a study, and others want very little. In an online survey or document, pop-up boxes or links can be used to define terms or explain concepts that some participants will know, and others won't. For in-person activities, improve efficiency by provide essential information about the study and asking if participants want to know more.
3. Use a **screening survey before an interview** to improve efficiency and make the interview questions for each participant personalised and relevant.
4. **Build in short-cuts** to make survey completion faster. For example:
  - Provide drop-down or multiple-choice options for common responses.
  - Use text prediction to auto-populate fields such as addresses.
  - Allow participants to duplicate or save data that they would need to enter multiple times (e.g., to record repeated activities, or the same data for multiple family members).
  - Allow participants to skip questions or activities that are not relevant or important to them, unless these are essential to your research.
  - Allow participants to provide a range or an estimate for numeric data (e.g., activity frequency, travel time, income, cost, etc.), instead of asking them to recall an exact number.

## 6. Clear Communication

Technical words or complex language can be confusing for research participants. Written documentation can also be a barrier for people with limited English proficiency, or those with low literacy skills. Approximately 40% of Australians have literacy abilities below the level needed to participate comfortably in work, education, and society.

To improve the clarity of your research documents and activities, you can:

1. Provide **clear and simple instructions** at each point of engagement. For example, include relevant instructions at the start of each survey section, rather than including them all in the survey introduction.
2. Include **visual prompts** if required. For example, we have found it helpful to include pictures to represent the specific topics or technologies that we want to know about. We also found it useful to include visual images on scales or yes/no questions (i.e., a tick and a cross).
3. Offer a **“read aloud” (text-to-speech) or recorded version of written text** where possible.
4. Where possible and relevant, **translate project materials** into additional languages that are common in the community you are researching, and allow participants to engage in the language that is most comfortable for them.
5. Regularly **remind participants of the task requirements**. For example, if you are asking questions about a specific recall period (e.g., “in the past 7 days...”), include this in every question.
6. Provide **clear and quick feedback to participants**, so they know what is going on. For example:
  - Include progress indicator bars or section numbering on surveys, so participants can plan their time and monitor the workload of the survey.
  - Confirm that you have received project documentation (e.g., consent forms, survey responses).
  - Provide an option for participants to view or save their own contributions, and to receive a summary of the project findings. This allows them to see the impact of their input.

## 7. *Accessibility*

There are many considerations for accessibility in research. Some of the most important principles are as follows:

- Ensure adequate visual accessibility: this includes using an appropriate font size, colour contrast and background. For more information, see Vision Australia’s blog post on [inclusive design and legibility](#).
- Ensure that electronic resources be read and accessed using a screen reader (software that reads screen contents aloud) for those who cannot see or read. For more information, see this online lesson from W3 Schools: [Accessibility Screen Readers](#).
- Ensure that electronic resources can be navigated through and accessed using an alternative to a standard keyboard or mouse. For example, you may need to provide an alternative to on-screen signatures for those who cannot use a finger or stylus to sign.
- Enable any “read-aloud” features that are provided by the system.
- Integrate meaningful pictures or symbols where this can support understanding.

## 8. Respect

It is important that all users feel respected as they engage with your research materials. To ensure that your content is respectful and inclusive, consider the following:

1. **Use health or disability terminology that is preferred** by the community you are studying. For example, should you use the term “diabetic” or “person with diabetes?” Should you use the term “neurodiverse”, “Autistic”, or “person with Autism?”. Sometimes you may need to provide multiple terms to ensure everyone feels included and respected.
2. **Avoid making assumptions** about participants’ lived experience. For example, phrases like: “do you suffer from [health condition]...” or “are you dependent on [equipment]...” imply that all people will have a negative experience of their disability or health condition. Neutral terms like “do you experience...” or “do you use...” are more empowering and accommodate a wider range of perspectives and experiences.
3. If you need to ask about a person’s gender identity, **provide a range of inclusive gender options** such as “non-binary”, “other”, and “prefer not to say”. Provide room for participants to describe their preferred terminology if it’s not listed.
4. Consider the **implications of requesting and reporting on cultural heritage**, such as a participant’s identification as Aboriginal or Torres Strait Islander. These questions can be sensitive, so consult with relevant community members before you ask.
5. Consider the **impact of visual imagery**. For example, are the pictures used age appropriate, culturally appropriate, and relevant to participants? Do they represent the diversity of your participant groups?

For more information and guidance, we recommend consulting your community advisors and following the guidance of the Australian Government Style Manual: <https://www.stylemanual.gov.au/accessible-and-inclusive-content/inclusive-language>



## 9. Resilience

No matter how careful your design is, research participants will still make mistakes in their use of research tools. They may also interpret instructions or provide input in unexpected ways. Your research process needs to be able to accommodate these errors and variations, to ensure that participant data can still be used accurately.

Some of the ways you can improve the resilience of your research tools and processes include:

1. **Undertake testing** (trial-runs) of research activities, documents and tools with people who match your target participant group. This will help you to identify common errors, points of confusion and possible alternative responses ahead of time.
2. **Warning participants when an action will result in a major consequence.** For example, warning them that selecting a response or clicking a button will end a survey or remove them from the research.
3. Giving participants an **option to remove, undo, or correct a response** after they have provided it. This will help to reduce participants' anxiety around making errors.
4. Creating an easy process for participants to return to a survey or research activity if they get interrupted or need to take a break.
5. Using **text validation to detect typographic errors** in important information – for example, if a numeric answer contains letters, if a date is outside of the expected range, or if an email or phone number appears incomplete. If you are using validation, please ensure that the checks accommodate the full range of valid entry options (e.g., phone numbers with and without country codes), to reduce participant frustration.
6. Where possible, **provide a clear explanation when something has gone wrong, and clear instructions on how to fix it.**

## Summary

Just because a research tool or approach has been used for decades, this does not mean it is the best tool for every project. With co-design and better attention to usability we can humanise the research process, empowering participants to share their valuable perspectives without draining their energy or dignity in the process.

## References

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