speak
better health, together

A Guide for Accessible Co-design

Tips for designing with people who have diverse ways of thinking, communicating, and sharing ideas.

AlfredHealth

South West Healthcare

Acknowledgement of country

Worimi man, Damian Griffis of the First Peoples Disability Network, says there is no word for disability in his people's language, which is wonderful. The focus is on "what we need to know about that person so we can ensure they can participate in the community," he says. "The Western approach to disability labels people and finds the deficit." We have a lot to learn from the traditional custodians of these lands. Alfred Health acknowledges the people of the Kulin Nations. We pay our respect to their Elders, past and present. We recognise and uphold their continuing connection to land and waterways.

Welcome

Hello, and thank you for your interest in making co-design accessible and inclusive.

When we say The Guide, we mean A Guide for Accessible Co-design. **The Guide** is for anyone who wants to bring people with and without disabilities together to improve services. **The Guide** is to help make co-design accessible and inclusive for:

- People with lived experience of disability
- Support people (such as carers or family members)
- The disability community
- Disability researchers
- Healthcare and other community services staff

The Guide shares practical advice and tips for accessibility and inclusion. It is not a step-by-step instruction on how to co-design.

You can use **The Guide** with other great resources about co-design.

The Guide uses Creative Commons Licence 3.0 AU. That means you can share it, change it, and update it. All you need to do is include Alfred Health as the original author.

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Part 1: Introduction

1.1 About the guide

What is co-design?

Every day, people with disability use services and take part in activities that support them and help them live their lives. But most of the time, the services are made by people who don't have direct experience of what it's like to need or use them. Decisions are made **for** people, not **with** them.

There is a better chance of improving services when people with lived experience of disability and people working in the services come together. Services can include:

- Hospitals

- Healthcare

- Mental health

- Disability support

Co-design is more than asking people with disability what is good or bad. Co-design is about working with people to have a say in:

- What services do we need?

- How are services made?

- How can we deliver services?

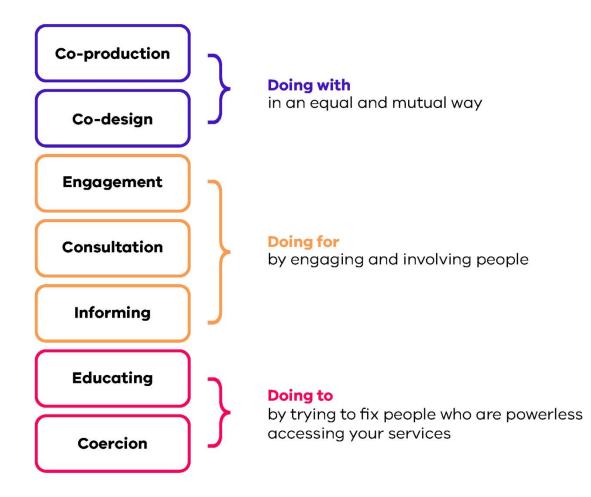## Participation is important. But not all participation is co-design.

All types of participation to improve services are a good thing. But not all participation of people with lived experience is co-design. For example, co-design is different to consultation. Consultation is when we ask people for ideas, but others make the decisions. Co-design is when we ask people for ideas and include them in decisions.

It is vital to be clear with people about how you work together. By being open, people know what is being asked of them. People also know how much of a say they have in making decisions.

The image above is the Co-Production Ladder. It has 7 levels. Each level is a different type of participation. Co-production and Co-design are at the top. It means doing things with people in an equal way. It also means both sides feel the partnership.

The Co-Production Ladder comes from Arnstein's Ladder of Participation (1969)

Access and equity

Access and equity are about treating people fairly in the work we do. It is more than treating everyone the same.

Access is making it easier for people to be involved. Equity allows everyone to share their stories and ideas in co-design.

By changing a few things, we can make it easier for people with diverse ways of thinking, communicating, and sharing ideas to be a part of co-design.

How we made The Guide

We made **The Guide** to help the SPEAK Project team at Alfred Health. The SPEAK Project uses co-design to improve hospitals for people with intellectual disability, communication support needs, and autistic people.

We made the guide by:

- Doing workshops with people with disability who had done co-design before

- Learning from books and articles about co-design

- Having meetings with university disability researchers who use co-design

- Adding things we learned doing co-design in the SPEAK Project

We want people to use and change this **Guide**. Add or take away parts that work for you, your team or your organisation.

Our aim is that more people will make co-design accessible to everyone. Accessible co-design helps practice the idea of making things better for people with disability and our community. "Nothing for us, without us."

1.2 Our 5 most important things

Below are 5 of the most important things we would like you to take away from **The Guide**.

1. Centre lived experience of disability

Often, "experts" make all the decisions about things that affect people with disability. But people with disability are experts too. They know what it's like to use your service.

If you place people with lived experience of disability at the centre, you increase the chances of your service meeting their needs.

Ask your project team, "How can we make sure people with disability are included whenever you are making decisions about them?"

2. Access and inclusion

Many people are excluded from sharing their stories and ideas. Often, the people left out are the people we need to learn from the most. When co-design is accessible, you include people with disability to participate meaningfully. This includes having people with disability on your project team.

Ask your project team, "How can we create a safe, supportive and accessible environment for co-design?"

3. Being open and honest

People with lived experience of disability said that openness and honesty are essential in co-design. They recommended the following:

- Being open about what we can change
- Being honest about the things that get in the way of change
- Doing what you say you're going to do
- Being honest when things change

- Be yourself and not only a 'facilitator' or 'professional'

4. The power of diversity

We are more likely to find solutions that benefit everyone when we include people with diverse backgrounds and experiences.

5. Value people with lived experience

In co-design, we are asking people to share their experiences of disability. We also ask them to share what overcoming barriers in our services are like. We must **reimburse** people for their time and effort to show that we value this expertise. When we say **reimburse,** we mean pay people in a way that is flexible. For example, paying people as casual workers may adversely affect other support payments. Reimburse people in a way that does not make it hard. For example, gift cards that do not work online may be inconvenient for people who don't like going to busy stores.

Ask your project team, "how can we reimburse participants in a way that works for them?"

1.4 Extra information about co-design

This Guide is not a step-by-step instruction about co-design. We have made this guide to give tips on how to make co-design accessible for people with disability.

There are lots of things written about what co-design is and how to do it. We recommend the following resources to learn more about co-design:

Beyond Sticky Notes: Co-design for Real

Beyond Sticky Notes teaches you what co-design is and how to do it. It includes useful tips, clear diagrams, and practical frameworks. This book will help you lead collaborative design work and share power.

Visit the [website at this link.](website)

Co-design. tools: Practical tools for radical collaboration

A work in progress. Includes good articles about co-design and why it's important.

Visit the [website at this link](website)

The following links have information about co-design and disability:

Purple Orange

The Purple Orange Co-Design Guide has practical tips and advice on co-design. It includes how you can use co-design in disability.

Visit the [website at this link.](website)

Accessible Co-Design: A guide for facilitators, designers & researchers.

This a short and easy-to-use guide with good tips for accessible co-design. The downloaded PDF size is 1.2 megabits. Download the guide at this link.

PWDWA Connect with me

This Co-design Guide shares information on engaging, connecting and co-design with people with disability.

Visit the website at this link.

1.5 Should we be doing co-design?

Collaborating and engaging with consumers is a great way to improve services and systems. However, not all collaboration is co-design.

Examples of things that are a part of co-design:

- We need to understand people's support and accessibility needs to make sure everyone can be an active part of co-design

- If you are making decisions about people with disability, more than two people with disability need to be involved (at an absolute minimum)

- Make time to get to know people you invite to co-design

- Reimburse people for their time and expertise

1.6 Jargon explained

We have added some definitions of words that are often used in co-design. Please add your own to the Guide.

Discrimination

Discrimination is when we treat people less favourably because of their disability. It also includes not giving people the same opportunities because of their disability.

"When you make it impossible for me to do stuff or join in, you're discriminating against me."

A participant with lived experience of disability

Access

Access is making things useful and meaningful for as many people as possible. Things that need to be accessible are:

- information
- communication
- activities
- environments

People with disability experience discrimination when we don't make things accessible.

Models of disability

1. Medical model of disability

The medical model sees people as disabled by something wrong with their body or mind. In the medical model, disabled people need a cure to make them like everybody else. It can

be useful when treating the symptoms of a disabled person's impairments. But it often misses what the person needs as a part of society.

2. Social model of disability

The social model says that people are not disabled by their impairments. People are disabled by the world around them. It is not an individual's problem. The problem is that society is not accessible or inclusive.

3. Human rights model of disability

The human rights model is more than removing barriers for people with disability. We should value disability as a natural part of human diversity. Everyone needs to respect people's rights and choices. The model also emphasises the pride, community and identity that come from being a disabled person.

Lived experience

People with disability who have used your service notice things you will have missed. They know what it's like to use your service. They experience when it works and when it doesn't. Your service can have a poor effect on them that you will not experience. They are experts in what it's like to use your service. We call it lived experience because people have time to think about how and why services didn't work. Lived experience knowledge and expertise are so important in improving services.

"Partnering with lived experience is like me being a peer researcher like my lived experience is being used in researching the project. Then we are asking people with lived experience questions, we are partnering with people with lived experience."

A participant with lived experience of disability

Trauma-informed

It is easy to want to improve your service quickly. You know things are not working, and you want people with disability to help you fix it. But often, people with disability have had bad experiences. Sometimes the bad experience is because of your service. We need to spend time building relationships and earning trust. We need to make co-design a welcoming and inclusive place. We need to create safe spaces for people to share their experiences. This is a part of being trauma-informed.

Strengths-based

Strength-based means learning about what skills and interests people have. Then making co-design activities that build on these strengths. Strengths-based is about focusing on what people can do and what people like to do – not what they cannot do.

Informed consent

Informed consent is not just saying yes to being a participant. Informed consent is making sure participants fully understand what they are being asked to do. Participants also need to understand their rights and that they can stop whenever they want.

Power imbalance

"For mainstream, society, and parliament, they've got power. For us with disability, people judge us, they shouldn't, and this is what this word means. You know, we with disability and mental health and stuff don't have power, the mainstream and government have power... We've all got good ideas."

A participant with lived experience of disability

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Equality and equity

"When everyone is given the same opportunities and the same ability to share their voice. This means that sometimes you have to support particular people more than others to share their voice. To make it equal, you must provide an inclusive and equal environment…. even if providing support to one person and not to another sounds like it's unequal, but then if one of those people is disadvantaged and the other person isn't, it's actually an act of equality to give them a chance to participate in the same way as the other."

A participant with lived experience of disability

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1.7 Involving people with disability

Improving a service or making something has different stages. Try to find ways to include people with disability at every step. This increases your chances of solving the right problems. It also increases the chances that what you create meets the needs of our diverse community.

Coming up with a project

- What are we trying to fix?

- Why is it important that we fix it?

Planning and getting funding

- How are we going to do the project?

- Reasons why we should get money and people to do the project

Research and sharing information

- What questions are we asking?

- Who is asking the questions?

- What answers are most important?

Coming up with ideas

- How are we going to make things better?

- What ideas are most important?

Trying ideas and seeing if they work

- What ideas should we test?

- Who are we asking to test our ideas?

- Who helps with testing our ideas?

Delivering (making it happen)

- What ideas are made into services that people with disability and other people use?

- What changes should come first, and what changes come later?

Reviewing and improving

- Are the changes or new ideas we made working?

- Who are the changes or new ideas helping?

- Who is reviewing if the changes or new ideas are working?

Part 2:
Accessible Co-design Tips

2.1 Getting ready

Information about your project

- Make sure information about your project is in plain language and Easy English.
- Write and test your project description, aims and objectives with diverse people with different disabilities and support needs.
- An accessible project description will benefit everyone who reads or hears about your project.

Project team

- Including people with lived experience of disability starts with your project team.
- When recruiting lived experience team members, make sure the process is accessible, for example:
  - The position description is in plain language
  - Test your plain language position description with people with disability
  - Share the position description as a video with captions
  - Give people extra time to apply for the position
  - Offer different ways to apply for the position, not just a written application
- Think about hiring more than one person with lived experience of disability.
- Make sure your workplace is accessible. This is more than physical access. An accessible workplace includes making changes that meet individual support needs.
- Think about having different skills in your team, including someone who has done co-design before (e.g., a designer or someone with community advocacy experience).

Project team skills and training

It is recommended that the project team know about accessible communication, including:

- How to make Easy English documents
- How to write in plain language
- Using different ways to communicate information, including images and videos

Budget planning tips

Essential things to include in your budget for accessible co-design are as follows:

- Reimbursing people with lived experience of disability who participate in co-design
- Making and testing Easy English documents with people who have lived experience of disability
- Support for online and in-person workshops, for example, Auslan interpreters
- Booking workshop spaces that are accessible to meet both physical (e.g., accessible bathrooms) and sensory support needs (e.g., quiet rooms with the ability to change lighting).

Planning who will be a part of co-design groups

Make sure your co-design groups are not too big.

Between 6 and 8 people is a good number of people. Smaller groups make it easier for everyone to be supported and have time to participate. Fewer participants can also lead to less visual and verbal stimulation for people with sensory needs.

If your project needs a larger group of participants for diversity, consider dividing people into smaller groups.

2.2 Finding and inviting people to take part in co-design

It is essential to be accessible and inclusive when finding people to join your co-design groups. If you have a diverse group of participants, you are more likely to get diverse ideas and solutions.

Think about connecting with:

- Self-advocacy groups (e.g., Voice at the Table and SARU)

- Disability organisations (e.g., AMAZE, Scope, VALID, NEDA, First People's Disability Network, Expression Australia, LGBTIQ+ Health Australia, and Carers Australia)

There are many ways to share your project information. It is vital to make the content clear and easy to understand. Examples of ways to share your project information include:

- Accessible presentations with images and text

- Accessible web page or website

- Videos with captions and accessible transcript to read in Word

- Emails in plain language

- Plain language and Easy English flyers

- Social media posts with short and clear messages

Inviting people to join your co-design group

Asking people to be a part of your co-design group is the first step in building relationships with people. Think about how to be welcoming and friendly from the start.

- Include a welcome message

- Be straightforward and clear about what you are asking of people. Answer common questions, such as:

- What is the project about?

- Why are people being invited?

- What will people be doing?

- How many hours are people needed?

- How will people be reimbursed?

- How will people's access and support needs be met?

2.3 Care and consent

Care

People with disability experience barriers to equal access to mainstream services, including healthcare. Many people with disability have experienced discrimination and trauma. Our society has a long way to go in respecting and celebrating diversity. It is essential to recognise this and make sure co-design is safe, welcoming, and caring.

Care and safety tips for co-design participants can include:

- Avoid activities that ask people to retell negative experiences in lots of detail. Instead, focus on what could be done differently to make it less negative.

- When someone shares an upsetting experience, listen and validate their feelings.

- Check-in with participants at the start and end of workshops. If people are upset, offer support and encourage them to access their support network.

- Make a 'how we treat each other' guideline with co-design participants and the project team. This can be an excellent activity to bring the group together.

It is also essential to check in regularly with project team members. Co-design can be challenging and emotionally draining work.

Consent

Participants must understand and agree to be a part of co-design activities. Consent is more than saying yes. People must understand what the project is for, how their information is shared, and their rights. This is called **informed consent**.

All project information must be available in accessible formats (e.g., plain language and Easy English).

Consent forms must be available in accessible formats (e.g., plain language and Easy English).

We recommend making a version of your consent form in Easy English. It is vital that people understand what they are saying yes to. This includes the following:

- What are their rights in your project

- How will you use their information and ideas

- How they can stop being a part of your project – and that it's ok to stop at any time

- Who can they talk to if they have a complaint

A clear and accessible consent form should be focused on participants as well as your organisation's ethical requirements.

Check with participants if they need support understanding what they are saying yes to and offering extra help.

Consent is not a once-off activity. **Ongoing consent** means project team members should regularly check with participants that they are happy to be involved and remind them they are free to say no.

Ongoing consent also means checking that people have what they need to participate. For example, their access and support needs are met in all your workshops and communications. It also means creating an honest relationship with participants so they feel comfortable to give positive and negative feedback.

2.4 Getting to know each other

Building relationships and trust is a big part of co-design. A great way to gain people's trust is to show that you care about them as an individual. Seeing the person and not the disability requires taking the time to get to know each other.

Getting to know each other means the project team and participants are both given chances to share different things about each other.

Make sure you set up both individual and group activities that help build relationships, such as the following:

- Learning about each other's interests and things you care about

- Understanding individual access and support needs

- Learning about people's strengths and what they like doing

- Avoid focusing on asking people to share negative experiences they've had

Plan and prepare meetings and activities based on what you've learned about participants.

Spend time with individual participants to learn about their specific support needs. This helps make co-design inclusive for every participant. It also shows you respect each person as an individual.

Plan your meetings and activities to build on the strengths of your co-design participants.

2.5 Co-leading and co-facilitating

Accessible co-design is finding ways to centre the voices of people with lived experience of disability.

Think about having your meetings and workshops run by people with disability. Find ways for people **without** disability to play a support role when needed.

There are many benefits of people with lived experience of disability co-leading or co-facilitating workshops, including:

• Recognising the ability and strengths of people with disability

• Building a sense of belonging and trust between facilitators and participants

• Showing that accessibility and inclusion are a priority

Like any facilitation team, ensure your facilitators with lived experience of disability know they can access support and additional training.

2.6 Working together online

This section gives tips and advice for running online co-design workshops. Aim to run a series of workshops that are 3 hours at maximum (including several breaks). Avoid running only one or two workshops with too many activities. Co-design is a journey, not a one-off workshop or meeting.

Think about having two or three facilitators. Each facilitator can have a different role, including someone to follow messages in the chat. It can also be helpful for one facilitator to make sure everyone is getting a chance to participate.

Before online workshops

- Choose a platform the disability community is familiar with, not what you use at work. For example, the disability community stayed connected during the COVID pandemic by meeting on Zoom.

- Book AUSLAN interpreters at least 4 weeks before each workshop (if relevant for your participant group)

- Decide on the date and time for the event, then send invitees a 'save the date' email or a placeholder calendar invite.

- Make plain language and Easy English documents that include 'how to join and use Zoom.'

- Plan and create your agenda for each workshop in plain language and Easy English.

- Create a simple document about the team facilitating the workshop. Use photos and include their role in the workshop (e.g., lead facilitator, supporting facilitator, or note taker).

- Email the agenda about the facilitation team and any important pre-reading information at least one week before each workshop.

- Create the invitation email in plain language. List out important information in bullet point format. Clearly show the Zoom link to join.

- Ask participants how and when they would like to be reminded.

- Some participants might need to be reminded the day before and on the day of the workshop. Include the Zoom link for easy access.

- Some participants may need to be reminded by email, and others by text message.

During online workshops

- Ask for permission and record each workshop.

- Making sure there is plenty of time to do different activities. Don't rush participants and allow for questions or reframing activity instructions.

- Remind facilitators to be inclusive in their approach and to speak directly, clearly, and at a good pace for Auslan interpreters and captioning.

- Remind facilitators to introduce themselves and their preferred pronouns, and describe their appearance.

- Don't rely solely on visual aids such as presentations and online whiteboards. Always clearly describe the visual aids you are using during workshops.

- Offer different ways for participants to join in discussions and activities, such as:

- Raising hand before speaking

- Adding messages to the chat

- Visual cards (red card for jargon, yellow card for slow down, green card to ask to talk)

- Encourage participants to say their names before talking.

After online workshops

- Share with workshop participants the following:

- Workshop notes or a summary in plain language and dot points for each idea or concept

- A transcript from the workshop recording

- Follow up with emails or texts after each workshop:

- Thanking people for participating

- Ask if people need any access or support changes to be made for the next workshop

- Be open to feedback and any ways to improve access or engagement for the following workshops

2.7 Working together in person

This section gives tips and advice for running in-person co-design workshops. Aim to run a series of workshops that are 4 hours at maximum (including several breaks). Avoid running only one or two workshops with too many activities. Co-design is a journey, not a one-off workshop or meeting.

Think about having two or three facilitators. Each facilitator can have a different role, including someone available for support. It can also be helpful for one facilitator to make sure everyone is getting a chance to participate.

Before in-person workshops

In-person workshops need extra planning time for accessibility. Things to think about include transport, venue accessibility, booking access support, catering, and accessible activities that meet the needs of your participants.

Booking the workshop

- Before you choose a date for the event, consider whether it will coincide with school or university holidays or exams, major religious or cultural celebrations, events in and around the city for larger events, or public transport works.
- Decide on the date and time for the event. Send invitees a 'save the date' email or a placeholder calendar invite 4 weeks before the workshop. Include the venue, date, and time.
- Create a spreadsheet that includes participants' support and access needs.

Accessible venue

When choosing a venue, always check the following:

- The venue is accessible. This includes an accessible bathroom free of obstacles (make sure the way in and out of the space is clear)

- There is accessible parking available at or near the venue

- There is a quiet space open for people with sensory needs

- Wheelchairs and mobility aids can move easily through the venue. It must be easy to move around the room and can fit under tables.

- Lighting in the room that you can adjust. For example, adjustable curtains, dimmable lights, or on/off switches.

- You can adjust the temperature of the room

Transport

- Talk with each participant to find out how they are getting to the venue
- Give participants public transport directions
- If participants are coming to the venue by public transport, offer to meet them at the train, tram or bus stop.
- If participants come to the venue by taxi or car, offer to meet them at the drop-off point.

Signage

Create signs in large type and symbols for your venue, including the following:

- Signs out the front of the venue
- Signs to find the bathrooms
- Clear signs out front of the room you are using

Catering

Make sure you have food and drinks available to keep people energised. When thinking about food check:

- Dietary requirements are available if needed. This can include:

- o vegan

    - o vegetarian

    - o FODMAP (a diet that eliminates certain types of foods to help people with digestive symptoms)

    - o gluten-free is available if needed.

- Add easy-to-read signs for different types of food.

- Participants may bring their drink bottles and straws. Provide straws if needed.

Agendas and pre-reading

- Plan and create your agenda for each workshop in plain language and Easy English.

- Create a simple document about the team facilitating the workshop. Use photos and include their role in the workshop (e.g., lead facilitator, supporting facilitator, or note taker).

- Email the agenda about the facilitation team and any important pre-reading information at least one week before each workshop. Make sure your pre-reading information is accessible. For example, all pictures and graphs have alt text (see Creating accessible Word and PDF documents for more details).

- Think about sending workshop activity instructions before the workshop. This gives participants a chance to prepare questions and think about ideas.

Follow up

- Follow up with participants the day before. Make sure people know:

- what is being asked of them

- how to get to the venue and travel time

- the start time of the workshop

During in-person workshops

- Set up an open and safe environment to encourage people to share what they need throughout the workshop

- Encourage all participants to ask questions at any time during the workshop.

- Be flexible and allow people to manage their engagement. For example, some may want to talk through ideas. Others might like to engage in hands-on making activities. Encourage and celebrate both types of participation.

- Print out activity instructions for participants. Have instructions in large type. Break down activities in clear steps and present them in dot point format. Include images with text to support different ways of learning.

- Offer different tools and materials to choose from. For example, if you use cut-out pictures to make a collage, offer tape, glue sticks, blue tack and Velcro. Also, avoid asking everyone to write on sticky notes. It can be hard to write clearly, or spelling can be challenging.

- Take plenty of breaks.

- Making sure there is plenty of time (don't rush participants)

Transport at the end of workshops

- Offer to help with ordering taxis
- If participants leave by public transport, offer to go with them to the train, tram or bus stop.
- If participants are leaving by taxi or car, offer to go to the drop-off point.
- Remember, everyone is different. Your role is to meet their needs individually.

After in-person workshops

Within 2 weeks of the workshop, consider the following:

- Share workshop notes or a summary in plain language and dot points for each idea or concept

- Follow up with emails or texts after each workshop:

- Thanking people for participating

- Ask if people need any access or support changes to be made for the next workshop

- Be open to feedback and any ways to improve access or engagement for the following workshops

Part 3:
Extras to get you started

Introduction

Part 3 gives tips and examples to think about with your team. These are just a few ideas to get you started. Part 3 also includes website links for more ideas to think about when doing creative workshops.

3.1 Accessibility conversation starters

Consider having accessibility conversations with your project team when planning your co-design project. We have created draft cards in A5 size for you to use (access-conversation-starter-cards-A5.docx). The cards include the below topics.

Access conversation cards

- Sharing information

- Communication

- Diverse teams of participants

- Agendas and instructions

- Workshop venues

- Online workshops

- Making things

- Visual designs

A great resource for conversation starters is KA McKercher's Model of Care for Co-design cards. Learn how to care for yourself and others before, during and after co-design. Find out more about these cards at this website link.

3.2 Creative activities conversation starter cards

The creative activities cards can be used to plan or start conversations. We have created draft cards in A5 size for you to use (activity-conversation-starter-cards.docx). When you are planning activities, consider the following:

- The activity examples are given to help get you started.

- Try and find other activities that work for your project and participants.

- Look for activities and ideas that help your participants think in different ways.

- Find ways to change activities to build on the strengths of your participants.

- We have added links to websites that have ideas for activities.

The cards include the below topics.

Activity cards

- Getting to know each other

- Warming up

- Looking at research

- Coming up with ideas

- Testing ideas activities

Website links for design activities

The following websites can help research types of design activities. But, it is essential to think about how to make them accessible to your participants. Please add any websites you find helpful to **the Guide**.

Service Design Tools

Service design tools are an open collection of tools and tutorials that helps deal with design challenges.

Visit the website at this link.

Design Kit is a website with ideas for using design and creativity in making services or things better for people.

Visit the website at this link.

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