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**Citation:** Manni, S., Barros Pena, B., Vines, J., Koteyko, N. & van Driel, M. (2023). Co-Designing online platforms with autistic users. .

This is the published version of the paper.

This version of the publication may differ from the final published version. To cite this item please consult the publisher's version.

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# Co-Designing online platforms with autistic users

A toolkit for UX designers, researchers, developers

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## Last updated

# April 2024



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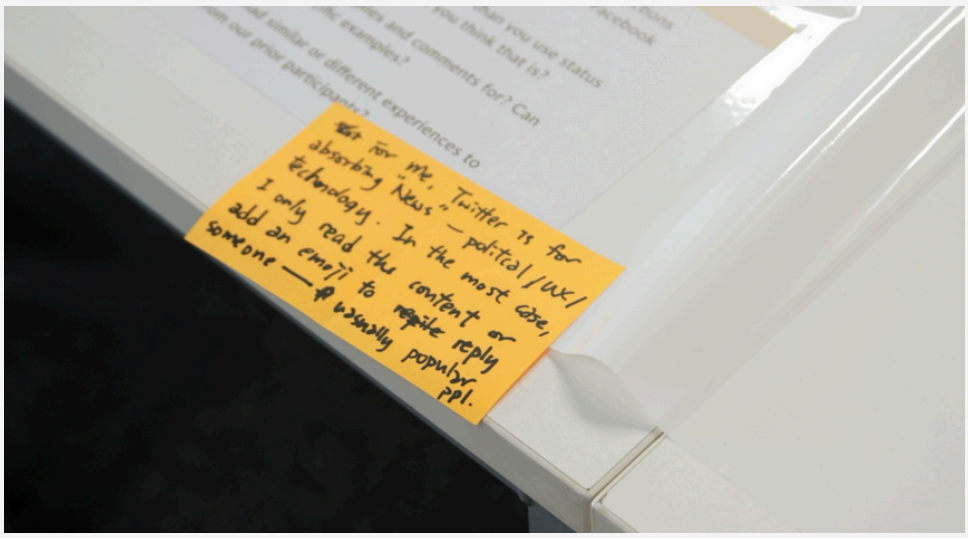
# Welcome

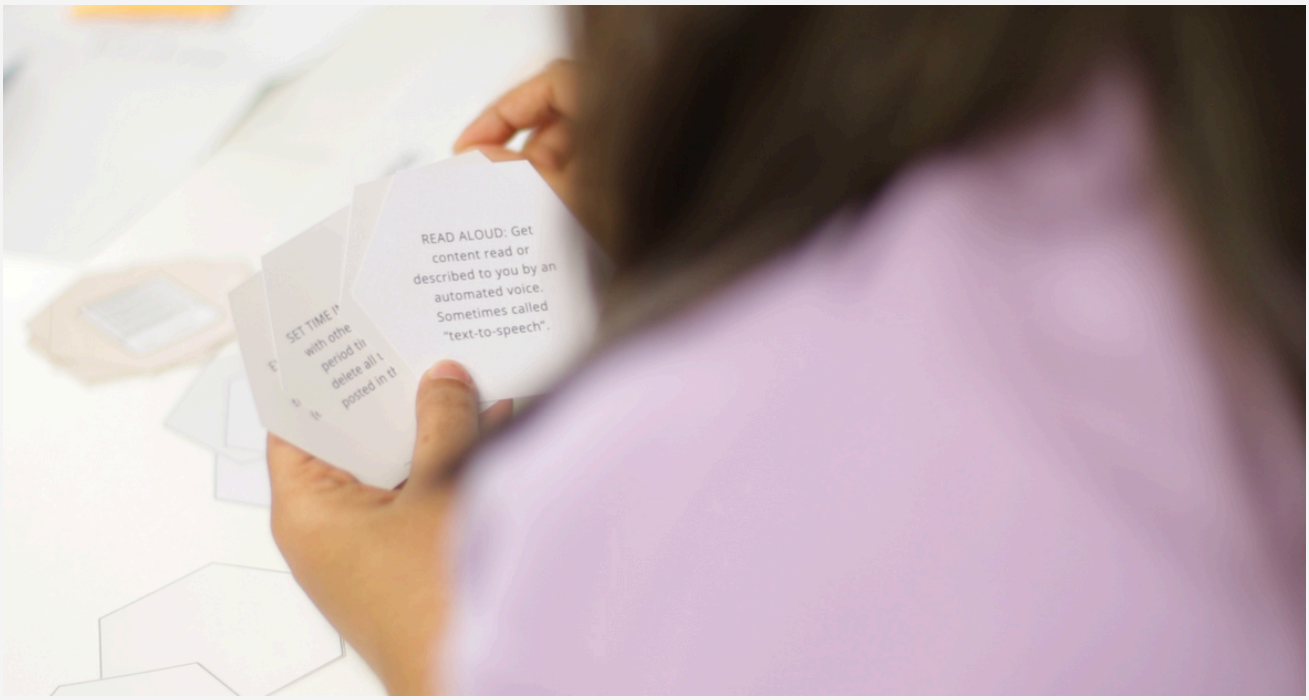
Welcome to co-designing online platforms with autistic users.

## About this toolkit

This toolkit offers methods and good practice tips for UX researchers, designers, and developers who would like to use participatory approaches to the design of social media and digital networking platforms that are more inclusive to neurodivergent users and better understand the needs of autistic users.

The toolkit is based on the research project Autistic Adults Online (www.autisticadultsonline.com), which looked at how autistic adults use social media, how they feel about the way the platforms work, how that impacts their interactions with social media and other people, and how design could better support them in their social media use.






Using linguistic analysis of social media data, interviews, co-design workshops and then thematic analysis of this material, Autistic Adults Online uncovered a wealth of information on autistic needs and preferences when they use digital platforms, and when they interact with autistic and non-autistic users on these platforms.

The research methods developed and the findings and insights emerged from Autistic Adults Online have informed this toolkit. We hope that by engaging with this information, designers can apply some of the preferences expressed by our research participants to their products and services, while also being equipped with methods that can support participatory design with neurodivergent users.

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# Chapter 1
# Autism and Neurodiversity

**In this chapter you can find general information on what autism is, and on neurodiversity as a framework to design more inclusive social media and digital networking sites.**

**What is neurodiversity?**

Neurodiversity is a concept which  starts with the perspective that **the way people experience and interact with the world is varied and neurological differences should be embraced** rather than being treated as illnesses.

Neurodiversity as a term was adopted in the late 1990s to indicate the emergence of a **social justice movement** which advocates for more inclusive conditions in a variety of contexts.

There are many forms of neurodivergence, including: Autism, ADHD, Dyslexia, Dyspraxia, Dyscalculia, Dysgraphia, Irlen Syndrome, Hyperlexia, Tourette's Syndrome, OCD, and Synesthesia.

**Why is neurodiversity important?**

Thinking in terms of neurodiversity can help reflect on the fact that autism and other conditions are not illnesses, but rather ways of perceiving and experiencing the world to support and make space for.

# Chapter 1 Autism and Neurodiversity

Neurodiversity as an approach also highlights how many disadvantages that neurodivergent people experience are induced by the fact that **the environment around them is shaped by and for neurotypical people**. This includes online spaces.

By adopting neurodiversity as a framework, designers can start reflecting on how to design social media and digital networking sites where the needs of neurodiverse audiences are taken into account. This usually ends up improving conditions for neurotypical users too.

**What is autism?**

Autism is a form of neurodivergence which can affect **how people communicate and interact with the world**.

**What are some of the characteristics of autism?**

Each autistic person is unique. The list of characteristics you can find here is generic and only offers a superficial overview of some autistic traits:

- Hypersensitivity to sound, touch, taste, smell, or light.
- Attention to detail and precision, tendency for literal thinking.
- Difficult interpreting and expressing one's own feelings and those of other people (alexithymia).

- Appreciating patterns, repetition, and predictable situations, while disliking unexpected events and routine changes.

- Difficulty socializing and interacting with others, although this only tends to happen in interactions with neurotypical people (Crompton *et al* 2019).

**A note on inclusive language:**

We use the term '**autistic people**' instead of 'people with autism' as identity first language is preferred within the autistic community in the UK (Kenny *et al*, 2016). We acknowledge, however, that differences in the use of terminology exist.

Our research found that many digital and social media platforms are not doing enough to support the communicative and sensory needs of autistic users. With this toolkit, we intend to offer resources to help designers ensure that social media and digital networking sites are designed to be inclusive of neurodiversity.

# Chapter 2
# Participatory Design

**In this chapter you can find a brief introduction to participatory design as a collaborative approach which involves end-users in shaping the products and services they use in their daily lives.**

**What is participatory design?**

Participatory design is an approach where professional designers collaborate with end-users to co-create products that accommodate the users' needs, values, and aspirations.

> [an] approach towards computer systems design in which the people destined to use the system play a critical role in designing it.'
>
> Schuler & Namioka, 1993

In participatory design, technology users are not positioned as passive customers or consumers. They are also not just a source of information for technologists, nor evaluators of a final product. Instead, they become active contributors of design ideas, and decision-makers in the technology design process.

# Chapter 2 Participatory Design

While the priority is to address structural injustice and the different vulnerabilities it creates, participatory design helps to realise an important imperative of involving groups that have been excluded from shaping the product and services they use.

People have **diverse experiences, skills, hopes, and aspirations**, and they also have a distinct awareness of what is not working well for them in the environments that surround them. Incorporating this **insight in the design** of new and existing systems means creating products, services, and systems that better suit their needs.

In Autistic Adults Online, participatory design was used as an approach to help us better understand the challenges social media spaces can pose for neurodivergent users and to elicit ideas and suggestions from participants about the kinds of design features that could support their social media use.

The role of the designer/researcher in participatory design is to **create and facilitate spaces** for participants, people, designers, and researchers to come together. This is often done through workshops.

In the next chapters, we will present the stages and methods of the participatory design process created for Autistic Adults Online, with a view of allowing you to replicate or adapt them to your own design practice.

# Chapter 3
# Autistic Adults and Social Networking Sites

**In this chapter you can find information on how autistic adults tend to use digital networking sites according to our research, and how these can be improved for better support.**

Our research found that many digital services and social media platforms are **not doing enough to support the communicative and sensory needs of autistic users**.

Many social media platforms and digital networking sites are designed for and by neurotypical people, with often implicit neurotypical norms and expectations, overwhelming amounts of unorganised content, excessive visual and auditory stimuli.

Our participants spoke about the uncertainty and anxiety they felt during online interactions and highlighted the lack of control over the different audiences their content could reach.

We identified **seven challenges** that online platforms can pose to autistic users. We also found that autistic users develop **coping mechanisms** to mitigate these challenges.

## Chapter 3 Autistic Adults and Digital Platforms

### Possible challenges posed by social media platforms and digital networking sites to autistic users

| | |
|---|---|
| 1 | **USE OF EMOJIS AND GIFs:** these can be difficult to decipher, especially when their emotional meaning is nuanced and contextual. |
| 2 | **SENSORY OVERLOAD:** when there is an overwhelming amount of moving images, sounds, pictures or colours, and diverse and often unrelated content (social, adverts, news, etc.) being presented at the same time. |
| 3 | **AUDIENCE UNCERTAINTY:** it can be difficult to understand who is able to view content that is shared on some platforms and how to control privacy. |
| 4 | **CONVEYING AND INTERPRETING MEANING:** being understood and understanding others on social media might requires extra effort compared to neurotypical users and there is a risk of being misunderstood by neurotypical contacts. |
| 5 | **LACK OF SPACE FOR INTEREST-BASED INTERACTIONS:** many online platforms don't do enough to facilitate structured and purposeful conversations around shared interests. |

# Chapter 3 Autistic Adults and Digital Platforms

## Possible challenges posed by social media platforms and digital networking sites to autistic users

| | |
|---|---|
| 6 | **POOR CONTENT QUALITY:** irrelevant, harmful, or hostile content in online platforms can be particularly distressing for autistic users. |
| 7 | **COMPULSION TO USE:** autistic users can feel an obligation to keep up with online responses and interactions. |

While some of these challenges affect any user of social media platforms, they can have a **particularly lasting and distressing impact** on autistic users.

Autistic users develop **coping mechanisms**, which can include disengaging from social media platforms altogether, or investing considerable amount of time and energy in controlling privacy, establishing  boundaries, composing and double-checking content.

## What should change

According to our research, social media platforms and digital networking sites can **improve** autistic users' experience by taking some initiative so that users don't need to rely solely on their own coping mechanisms. This can be achieved by:

- Providing functionalities that enable people to form connections with others around **common interests**.
- Clearly explaining online communities' rules and **expectations**, avoiding jargon, and providing tools that explain the potential **meaning** of emojis, GIFs, memes or other expressive devices.
- Making **privacy** settings more visible and **simpler to control**.
- Helping protect **mental health** and establishing boundaries on usage.
- Giving users **more overall control** over the social media user experience, in particular over the content they see on the platform and how that content is presented and organised.

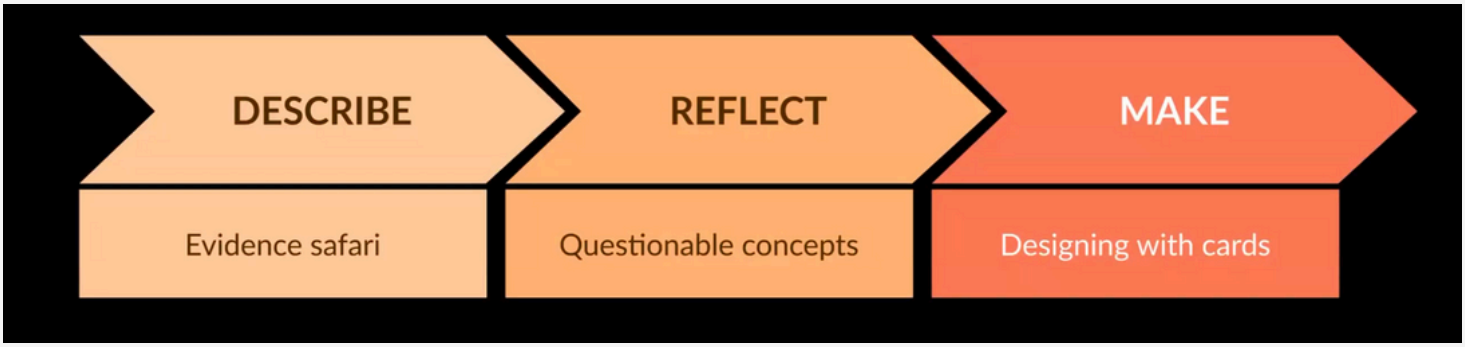
We hope that the methods presented in this toolkit can support co-design efforts and ideation processes to create products that embed some of changes desired by neurodivergent users.

# Chapter 4
# A Suggested Workflow

**In this chapter you can find information on the different phases of the participatory process developed at Autistic Adults Online.**

During the research project Autistic Adults Online we worked with autistic adult participants to explore their use of social media through a series of participatory design workshops.

Researchers developed a **participatory design process** where a series of three online workshops led participants from **describing** and **reflecting** on their own usage of social media to the **development** of ideas for new social media features that could better support their social needs. Each workshop was dedicated to a specific phase of our design process and supported by custom designed methods.



# Chapter 4 A suggested workflow

- Phase 1: **Describing.** During this workshop participants are invited to describe their own social media practices. This happens through the engagement with findings emerged from a previous portion of the research project in an activity called **evidence safari**, which is described in chapter 4.

- Phase 2: **Reflecting**. During this workshop participants are encouraged to think critically about social media practices and platforms. This is facilitated by using **questionable concepts**, provocative design proposals assembled to motivate creative critique.

- Phase 3: **Making**. During this workshop participants are asked to re-imagine social media platforms. They are guided to do so through the use of sets of **design cards**, which intuitively represents key building blocks of any social media platforms. The use of design cards is described in chapter 5.

We believe that this workflow can be particularly useful to designers and researchers who wish to start a co-design exploration by grounding their work in existing data, to engage critically with it, and to then use it as a basis to create new designs.

# Chapter 4 A suggested workflow

In the next chapters, we describe two core methods used in Phases 1 and 3: evidence safari and design cards. You can use these materials in three ways:

- You can **use the methods yourself**, to actively engage with the experiences of participants from the Autistic Adults Online project, relate them to your own experiences of social media, and use them as the basis for the design of new features of existing or new social media platforms.

- You can use the methods as they are **with participants in workshop** settings, to facilitate discussion and support participatory design activities.

- You can use the methods as the basis to **design your own evidence safari and design cards**, personalising them to different sets of data, different platforms, and different groups of participants.

Chapter 6 contains good practice tips on how to run inclusive online workshops based on the experience of researchers and participants at Autistic Adults Online.

# Chapter 5
# Exploring data: Evidence Safari

**In this chapter you can find information on using evidence safaris as a way to engage with data and use it as a starting point for discussion.**

The evidence safari is a group activity that helps participants **engage with evidence** by presenting it with summarised and structured data, usually arranged in sets of cards.

This method is popular for policy design activities within UK governmental bodies (openpolicy.blog.gov.uk/2016/03/07/exploring-the-evidence/) and it can be adapted to different sets of data.

**Key steps** for the development of an evidence safari activity are:

- **identifying** relevant **sets of data** that can be used as a basis for discussion with participants, according to the questions you are trying to address through the workshops.
- **identifying** main **themes and trends** in the data.
- **organising the themes through sets of cards**, each dedicated to a theme. Each set of cards can contain bite-sized chunks of key information on its theme. The last card in the set can be a review card, offering prompts to relate the information explored in cards to participants' views and experience.

# Chapter 5 Exploring data: Evidence Safari

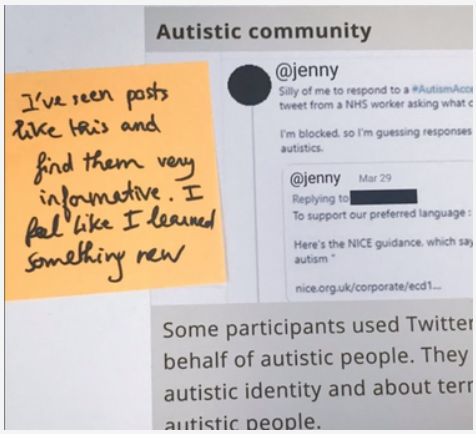
You can use the sets of cards created for Autistic Adults Online as reference to produce your own evidence safari.

For Autistic Adults Online, researchers created an evidence safari which would encapsulate the key social media experiences by autistic participants who took part in different phases of the research.

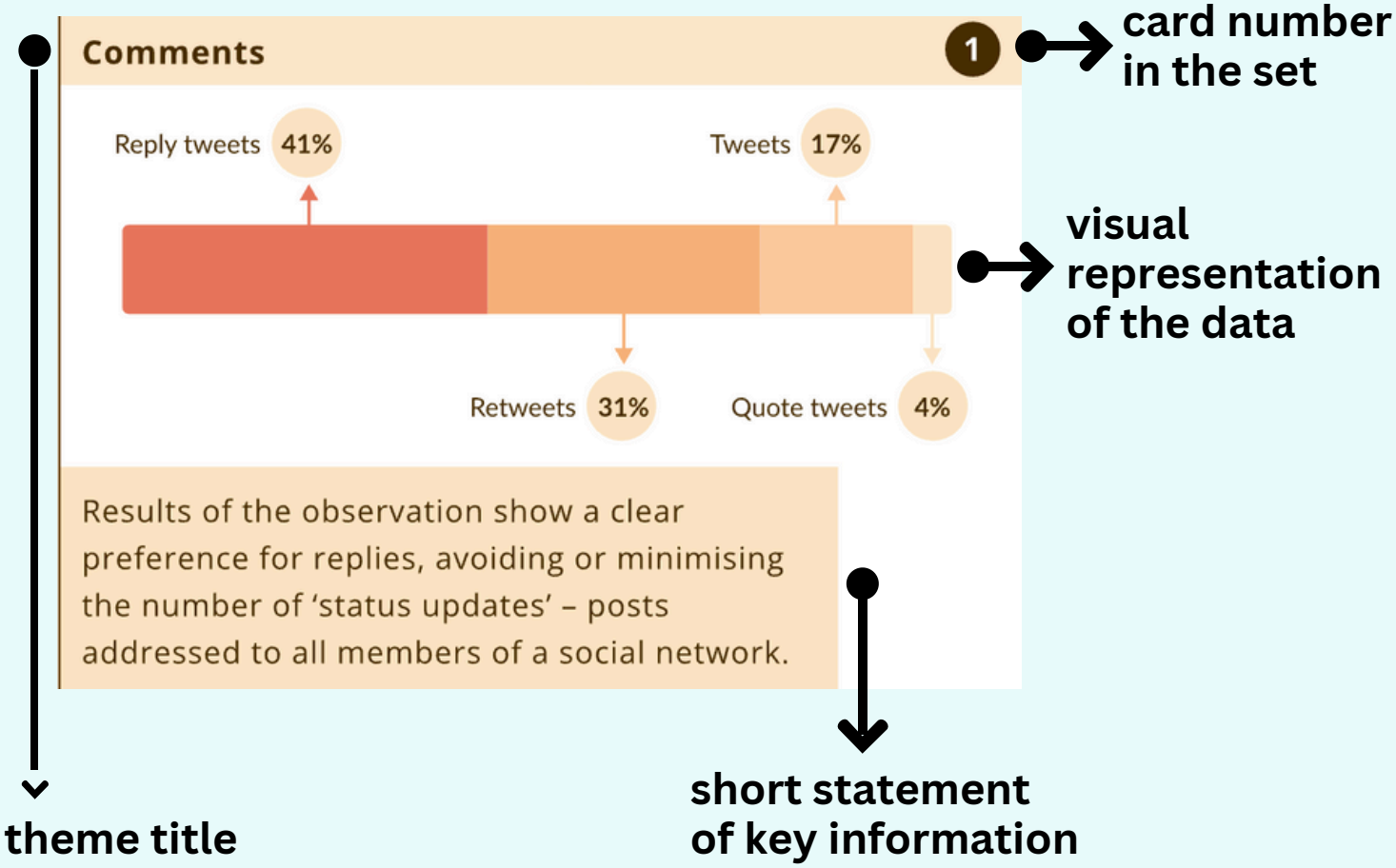
The Autistic Adults Online Evidence Cards are organised in nine sub-sets of five cards each. The sub-sets are divided in two main groups, one exploring social media practices of our research participants, and the others unpacking some of the challenges social media can pose:

- **Social media use cards** (theme cards): five sets of cards exploring aspects of the social media practices of Autistic Adults Online participants  grouped around themes such as comments, avoiding conflict, social media features, autistic community, special interests.

- **Challenges cards**: four sets of cards exploring social media aspects Autistic Adults Online participants found challenging, and coping mechanisms they developed to meet these challenges (themes: conveying and interpreting meaning, audience uncertainty, compulsion to use, sensory overload).



Here you can find an example of an evidence card for the Comments theme, which shows how research participants may tend to prefer using the comment function to interact with others' content, over composing their own content anew:




Not all evidence cards need to contain recaps of information or graphs. They can contain images, quotes, and any other useful type of information.

Here you can see the review card for the Comments set:

**Review card - Comments**

Do you use replies on Twitter, or similar functions on other social media like comments on Facebook or Reddit?

If you comment or reply more than you use status updates or tweets, why do you think that is?

What do you use replies and comments for? Can you think of specific examples?

Have you had similar or different experiences to those from our prior participants?

You can browse the Autistic Adults Online evidence cards to start exploring how research participants use and interact with social media.

You can download the cards, in printable quality, at https://tinyurl.com/43zz6dr8.

You can print and use these cards in your own workshops. When using cards with participants, you can select sets of cards that you think explore themes that particularly relate to your product or service, or if time allows, you can use them all.

The cards can be printed for in-person workshops, or used on online boards as Miro. Participants can be asked to comment using post-its or through live discussion, with review cards offering prompts.

# Chapter 6
# Designing new features: Design Cards

## In this chapter you can find information on using design cards to imagine new features for social media and digital networking platforms.

Once the use of evidence safari has generated engagement with aspects of data related to the issue or area of practice you are unpacking in the workshops, participants can be guided through a design activity which helps them envision new digital features in response to their reflection. This can be facilitated through the use of design cards.

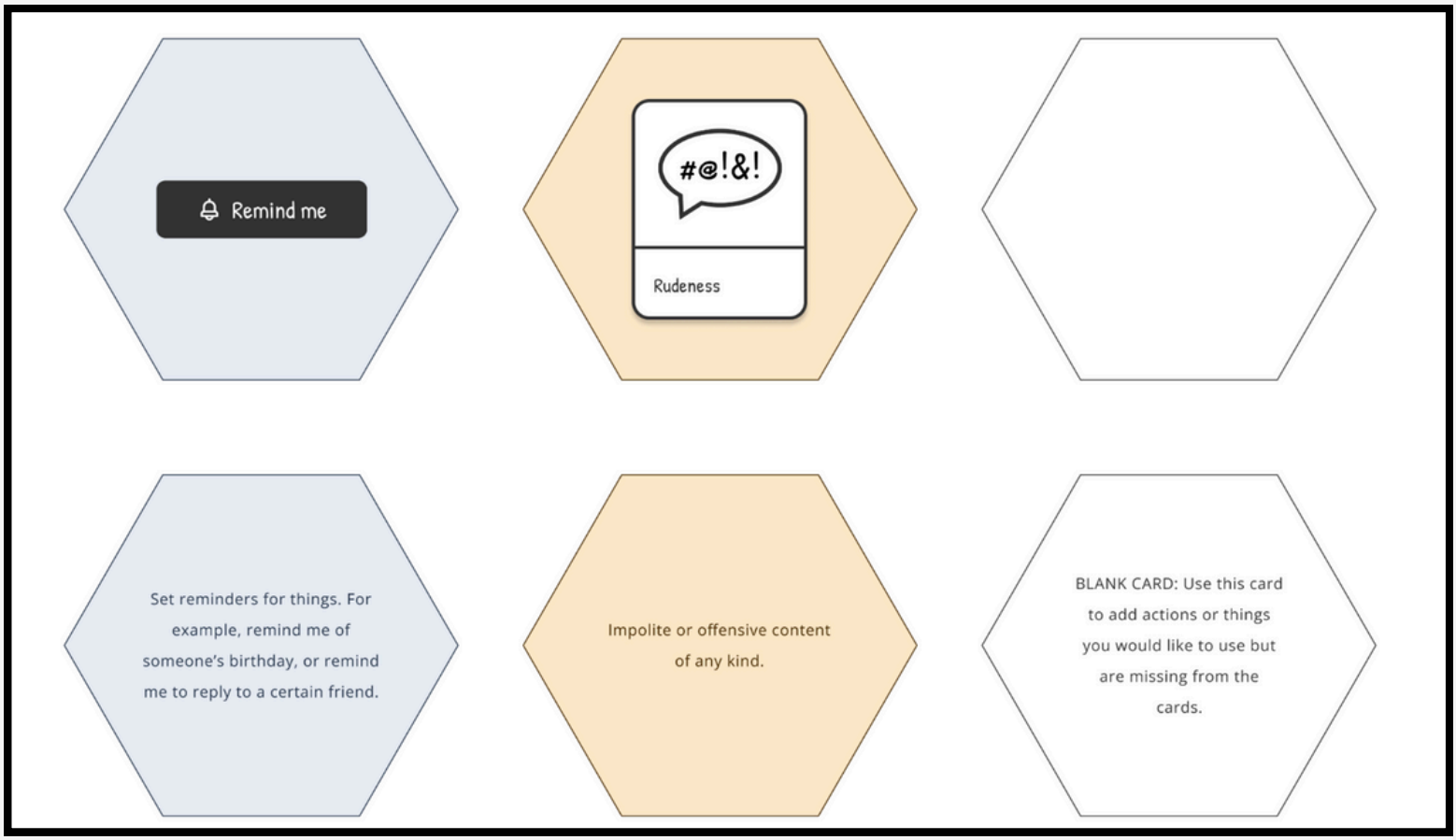
Design cards can be an intuitive and accessible way to co-design with participants who may not necessarily have design experience. Cards can, in fact, act as carriers of ideas (even when used online), can stimulate combinatorial creativity, helping participants coming up with new ideas, and can foster collaboration (Lucero et al 2016).

# Chapter 6 Designing new features: Design Cards

For Autistic Adults Online, researchers created a set of design cards which break down the foundational element of most social media platforms by dividing them in two main categories:

- **Action cards** (blue): 17 cards that describe actions users can perform on social media (e.g. delete, remind, send).
- **Object cards** (orange): 17 cards that describe objects users can interact with on social media (e.g. post, people, posts that contain rude content).

Each card has the name of its action or object on the front side and its definition on the back. The set of cards also include a number of blank cards which participants can use to describe their own entities or actions.



# Chapter 6 Designing new features: Design Cards

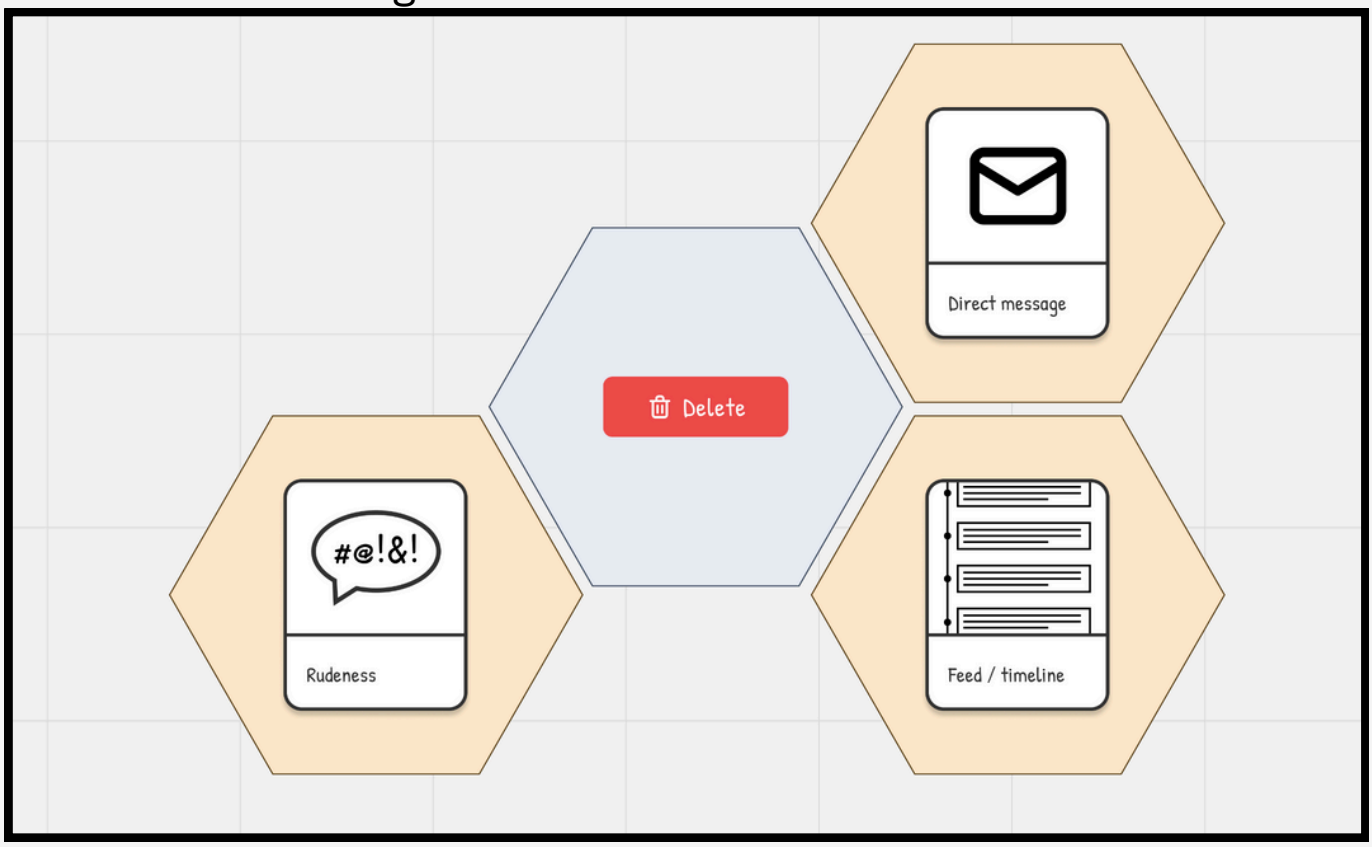
You can access **printable copies** of the design cards at https://tinyurl.com/54zjrkfu.

As per the evidence cards, design cards can be printed out for in person workshops or used for on-line workshops. The design cards in the Autistic Adults Online set cover most building blocks of common social media platforms. However, if you are working with a specific platform or service, you might want to adapt them by **adding your own actions and entities**.

Participants can be given the task to design a feature that would address an issue, challenge, or dynamic explored through the evidence cards.

For instance:  how to mitigate exposure to rude content.

By combining relevant cards participants designed a feature which would block (action) rudeness (object) from reaching either the user's direct messages or their feed.



# Chapter 6 Designing new features: Design Cards

At times participants may initially struggle to translate their thoughts into a design feature, even using cards. In this case, you can encourage participants to pick a small number of random cards for each pile (objects and actions), and then explore how to combine them, perhaps placing the evidence cards they discussed in the previous activities alongside their new designs.

Autistic Adults Online participants imagined 38 new social media features that in their view would better support the needs of autistic users.

A selection of these features are described in the research paper “My Perfect Platform Would Be Telepathy" - Reimagining the Design of Social Media with Autistic Adults” (https://doi.org/10.1145/3544548.3580673).

You can also access the research paper at https://openaccess.city.ac.uk/id/eprint/29923/1/CHI_23.pdf

# Chapter 7
# Good Practice for Inclusive Online Workshops

The good practice tips offered in this chapter were developed based on the experiences of researchers and participants at Autistic Adults Online. They specifically apply to running **participatory workshops online**. The choice of working online was in our experience the preferred modality of interaction for the group of autistic participants researchers worked with.

It is always good practice to have **conversations** with participants in advance of the start of the project to discuss preferences on whether to work online or in person. We supply these recommendations as participatory workshops have traditionally happened in person and fewer resources address good practice for inclusive online workshops.

## Good practice tip 1: provide detailed guidance

Clearly communicate with participants **ahead of the start** of the workshops and ensure they can access clear information on **how to join** the workshops and **breakdown of activities** which will happen in the workshops, with detailed timing, content, and information on facilitators. It is good practice to send slides, videos, activities breakdowns ahead of time, so that participants can join the workshops knowing exactly what will be asked of them and have a chance to prepare if they wish to do so.

Make sure that instructions are provided in **different formats**. A simple explainer video with a voice over alongside text slides can help those who cannot engage with a long written explanation.

Give participants a chance to communicate with facilitators and to express any accessibility need before the start of the workshops.

## Good practice tip 2: offer alternative forms of engagement

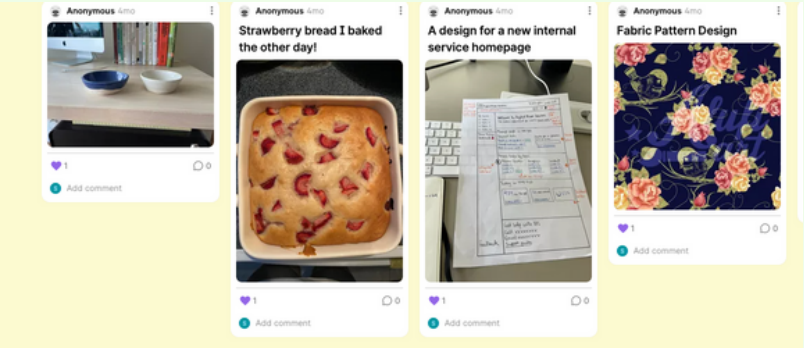
Make sure to schedule **plenty of breaks** (at least 15 minutes for every hour of online presence) and offer participants **alternative forms of engagement** in online workshops (camera off, using chat only, using online digital boards, such as Miro), not expecting all participants to interact with active camera and sound. Make sure to discuss with participants different ways of contributing to the workshop beforehand, so to be aware of and able to support personal preferences.

## Good practice tip 3: design inclusive written materials

Ensure that any written material (cards, guidance, etc.) is designed according to **accessibility standards** and mindful of dyslexia and other conditions. This might include careful consideration on the choice of fonts, spacing, background colour, and other. In the Additional Resources section of this toolkit you can find links to guidance at this regard.

## Good practice tip 4: offer interest-based icebreakers

Offer an icebreaker based on **passions or interests** that participants can share. For instance, we asked participants to upload an image of a hobby, interest, or passion to a an image-based blog before the start of the workshop. This allows participants to begin their workshop experience sharing something they care about. Being able to prepare this activity in advance further reduces possible anxieties often induced by feeling on the spot during icebreakers.




## Good practice tip 5: make sure the workshop follows a solid structure

Design a precise structure for the workshop, and once this has been communicated to participants, make every effort to follow it throughout the event. **Avoid** leaving too much space for **improvisation**.

## Good practice tip 6: share a code of conduct

It can be helpful to design and share a code of conduct in advance of the meeting. This can contain general rules on **mutual respect and inclusivity**. The code of conduct can include a note on use of inclusive language and short guidance on what to do in case the workshop is disrupted, a problem arise, or a participant is made to feel uncomfortable.

## Good practice tip 7: avoid feeling-based questions

Some autistic people may experience alexithymia, a condition which makes it difficult for them to interpret feelings and emotions. For this reason, some of our research participants told us that they prefer not to be asked questions based on feeling, e.g. “how do you feel about this issue?”, in favour of more **specific questions**.

# Chapter 8
# Additional Resources

**In this chapter you can find a collection of references and supportive resources on some of the topics discussed in this toolkit.**

**Online resources on autism:**

**Autistic Adults Online Website:**
www.autisticadultsonline.com
It offers an overview of the research project, the research team, a blog, and a collection of resources.

**Autistica Webinars**:
www.autistica.org.uk/get-involved/join-an-expert-webinar
A range of expert webinars on topics affecting autistic people, including accessibility of physical and online spaces.

**Other design toolkits and guides:**

**The Inclusive Design Starter Pack**:
www.inclusivedesignjam.com/learn/starter-guide
A beginner's guide to inclusive design which provides a solid foundation in concepts such as diversity & inclusion, accessibility, equity & justice, care & healing.

# Chapter 8 Additional Resources

**A range of resources on participatory design by MakeTools:**
https://maketools.com/downloads

**The Design Justice Network**
https://designjustice.org/
Offers resources, events, and courses on design practices that center those who stand to be most adversely impacted by the outcomes of non-inclusive design processes.

**The British Dyslexia Association**
https://www.bdadyslexia.org.uk/
Offers advice on how to create dyslexia friendly materials and environments.

**Quick links to workshop materials**

Link to **evidence cards**: https://tinyurl.com/43zz6dr8

Link to **design cards**: https://tinyurl.com/54zjrkf

## Publications:


- Barros Pena, B., Koteyko, N., Van Driel, M., Delgado, A., & Vines, J. (2023, April). " **My Perfect Platform Would Be Telepathy"- Reimagining the Design of Social Media with Autistic Adults**. In Proceedings of the 2023 CHI Conference on Human Factors in Computing Systems (pp. 1-16).

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- Van Driel, M., Vines, J., Barros Pena, B. and Koteyko, N., 2023. **Understanding Autistic Adults' Use of Social Media**. Proceedings of the ACM on Human-Computer Interaction, 7(CSCW2), pp.1-23.

# Thank you!

Thank you for exploring with us what can be done to make platforms more inclusive for autistic users.

We would welcome your **feedback** on this toolkit to keep improving it in the future.

Please use this link:

https://forms.gle/Siubc3Su3NijEAMB6

to tell us your thoughts.

A **special thank you** to the people who made this project possible:

- Our autistic research participants from all sections of this research.
- All the staff at Autistica who supported this project.
- Autistic Nottingham and our Advisory Board.

Follow project updates on our **website**: www.autisticadultsonline.com

or on **Twitter** at @Online_Autistic