

The Research Passport Guidelines for Participants and Researchers

Table of Contents

<i>What is the Research Passport?.....</i>	<i>2</i>
<i>What types of research can the Research Passport be used for?</i>	<i>2</i>
<i>How will the Research Passport benefit participants?</i>	<i>2</i>
<i>How will the Research Passport benefit researchers?</i>	<i>3</i>
<i>What is the process of using Research Passport?</i>	<i>3</i>
<i>What you can and cannot expect from using the Research Passport.....</i>	<i>3</i>
1. Take the Research Passport seriously.....	4
2. Try your best to make appropriate accommodations for participants.....	4
3. Always strive to incorporate good research practice.....	4
4. Encouraging and supporting other researchers to use the Research Passport.	4

The Research Passport Guidelines for Participants and Researchers

What is the Research Passport?

The Research Passport is a document that participants can complete before taking part in research. Participants can complete as much or as little of the Research Passport as they wish. This document can include personal information (e.g., name, age, gender identity), communication preferences, how autism affects the participant (e.g., how to minimise distress) and any other information the participant would like to share (e.g., sensory sensitivities).

The Research Passport aims to improve autistic participants' experiences of taking part in research, by supporting and empowering the participant, and enabling researchers to be better prepared to meet their participants' needs. The Research Passport is a structured way for autistic people and researchers to have a conversation about their preferences, needs and the research environment before participation, which can sometimes be difficult conversation to have in person on the day of the research.

What types of research can the Research Passport be used for?

The Research Passport can be used for research that involves any type of interaction with a researcher. This could be in person 'face-to-face' research, including (but not limited to):

- Interviews.
- Focus groups.
- Studies where the participant completes a number of tasks with the researcher.

Or, the Research Passport can also be used for research that involves virtual interactions with researchers, including (but not limited to):

- Video calls.
- Telephone calls.
- Online focus groups.

The Research Passport is not suitable for online surveys, as these are usually completed without any interaction with a researcher.

How will the Research Passport benefit participants?

The Research Passport aims to improve the experience of taking part in research and relations between the participant and researcher.

The Research Passport gives participants the autonomy to express as much or as little about their needs and preferences as they would like in advance of taking part in research. This can avoid sometimes awkward or uncomfortable conversations at the time of the research.

Completing the Research Passport can also help participants feel reassured that the researcher has familiarised themselves with their needs and will do their best to make them feel comfortable. Similarly, the participant may also feel more confident that the researcher will notice things like stress or anxiety, and will know how to manage such situations appropriately.

How will the Research Passport benefit researchers?

The Research Passport allows researcher to familiarise themselves with their participants' needs and preferences before they take part in the research. This can help the researcher feel more prepared for working with their participants. The researcher can carefully consider any possible reasonable adjustments in advance so that the research environment is as pleasant, and suited to the participants' needs as much as possible.

Researchers familiarising themselves with the participants' preferences may help build rapport and trust with the participant, and can demonstrate that the researcher has taken time to learn about the participant and how best to support them.

These factors could make the research process more enjoyable for both the participant and the researcher, and, in facilitating a positive research experience, participants may wish to take part in more research in the future. Improved interactions can also improve the quality of research, and can also help build networks with communities through a good reputation.

What is the process of using Research Passport?

Below is a general outline for the process of using the Research Passport, however this may vary between research studies depending on the research protocol, or whether the Research Passport has been used before by participants:

1. Participant signs up to participate in research study.
2. The researcher may ask the participant if they would like to complete a Research Passport, or the participant could approach the researcher with the Research Passport they have already completed.
3. The researcher receives the completed Research Passport before the participant takes part in the study.
4. The researcher familiarises themselves with the Research Passport and carefully considers the possible reasonable adjustments.
5. If certain reasonable adjustments are not possible, the researcher informs the participant and tries to find a suitable alternative.
6. On the day of the study, the researcher is mindful of the content of the Research Passport and endeavours to make the experience as pleasant for the participant as possible. The researcher and participant may wish to have a conversation about any aspect in the Research Passport, but this is at the discretion of the researcher and participant.

The Research Passport is the participants' to keep. Participants can feel free to bring it with them to other research studies they may be involved in.

On the last page of the Research Passport there is a section that the researcher can complete to share some information about their research background and why they do autism research. Researchers can complete this fill this in before giving the Research Passport to their participants to complete, or participants can ask the researcher to complete the information if they approach the researcher with the Research Passport.

What you can and cannot expect from using the Research Passport

While the Research Passport should be a helpful tool (for researchers and participants), it will not be able to solve every problem in research. Therefore, it is important that participants and researchers are aware of what they can and cannot expect from using the Research Passport.

When using the Research Passport, researchers should adhere to these four core expectations, and participants should feel reassured that researchers will abide by them. The core expectations are:

1. Take the Research Passport seriously.

Researchers must take the time to read Research Passport carefully, being sure to familiarise themselves with the participants' individual needs and preferences. Researchers must endeavour to make the research experience as pleasant as possible, ensuring appropriate considerations are made.

2. Try your best to make appropriate accommodations for participants.

Researchers must carefully consider all reasonable adjustments and make every effort to provide appropriate accommodations. Where this is not possible, researchers must inform the participant ahead of time, and try to find a suitable alternative.

3. Always strive to incorporate good research practice.

Researchers must always strive to incorporate good research practice elsewhere in their research protocol. For example, following guidelines for accessible, inclusive research.

4. Encouraging and supporting other researchers to use the Research Passport.

Researchers must encourage and support other researchers (peers or junior researchers) to use the Research Passport fairly and appropriately.

Whilst participants should expect researchers to follow the above guidelines, participants should also be aware that it may not always be possible for the researcher to accommodate all needs even if they tried to. For example, a preference for rooms with natural light could be impacted by researchers being restricted by the rooms they can use due to room booking availability or if research equipment cannot be moved from a specific location. In such cases, you can expect the researcher to inform you about what is not possible and you can discuss what is available.

In addition, participants should also be aware that researchers may be restricted in what they can offer due to funding or logistical constraints. For example, while some researchers may be able to provide refreshments such as water, tea or coffee, this will not be possible for all researchers (e.g., due to limited/no access to facilities or funds). Similarly, it is not always possible for researchers to subsidise travel to the research venue, as this is reliant on external funds. Therefore, food, refreshments or monetary compensation cannot be expected from all researchers who use the Research Passport.