



The Research Passport

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Introduction

The Research Passport is a tool to improve the experience of taking part in research. Participants can complete information and share it with the researcher so the researcher can be better prepared to support the participant during the research process.

Before using the Research Passport as a participant or as a researcher, please read the Research Passport Guidelines (provided in the supplementary material of the Research Passport paper).

When developing the Research Passport, participants particularly favoured some items within the National Autistic Society's (NAS; an autism charity in the UK) [Passport to individual autism support](#) and [Health Passport](#). As such, permission was obtained from the NAS to use some of these items for the Research Passport as endorsed by the NAS.

The Research Passport contains the following sections:

- Personal information
- Contact information
- Communication
- My diagnosis
- Other needs
- Participating in research
- Distress
- Transport

We would like to remind you that the aim of the Research Passport is to make the research experience as welcoming and respectful as possible. Therefore, you can choose what information you would like to share with the researcher. If you do not want to complete any aspect of the Research Passport, you do not have to.

There is also a section on the last page that the researcher leading the study can complete to share some information about their research background and why they do autism research.

[Keep up to date with further developments of the Research Passport at the CRAE website: crae.ioe.ac.uk.](#)

Research Passport

Personal Information

- I am completing the Research Passport on behalf of... (please select the most appropriate answer)

Myself

My child/young person or a child/young person I am supporting

An adult that I am supporting

Other (please specify): _____

- My name is...

- I like to be called...

- I would like to be referred to by these pronouns...

He/him/his

She/her/hers

They/them/their

Other (please specify): _____

- Date of Birth (dd.mm.yyyy)

Contact Information

- Contact details

Address: _____

Email: _____

Telephone: _____

Mobile phone: _____

- I would prefer to be contacted by ... (please select as many as you feel appropriate)

Speaking on the land line phone

Speaking on my mobile phone

Text message

Email

Post

Other (please specify): _____

Communication

- I prefer to communicate in the following ways...

(Please rank your preferences of communication, with 1 being your ideal way of communicating and 5 being your least preferred way of communicating. If any methods do not apply to you, leave them blank.)

_____ Face to face using oral speech

_____ Face to face using augmentative and alternative communication

_____ Signed language

_____ With someone supporting me

_____ By telephone

- Other things I would like a researcher to know about my communication preferences...

My Diagnosis

This section is optional if participants would like to comment on their outlook on autism and share this information with the researcher.

- I prefer this type of language...

(Please tick as many as apply)

- Person first (i.e. a person with autism)
- Identify first (i.e. an autistic person)
- Combination/I don't mind
- Other (please specify): _____

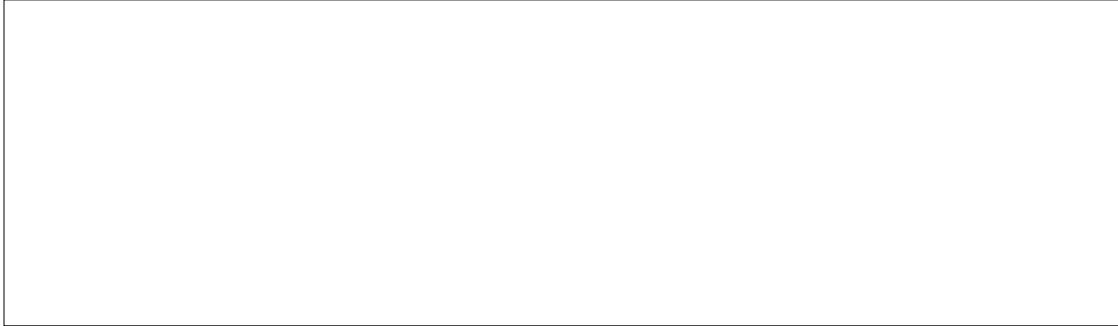
- Please tick as many as apply

- I have an official diagnosis of autism
- I self-identity as autistic
- Other (please specify): _____

- I started to self-identify with autism at age... (Please insert age)

- I was diagnosed at age... (Please insert age)

- I would like to share these feelings about my identification/diagnosis...

A large, empty rectangular box with a thin black border, intended for the user to write their response to the prompt above.

Other Needs

- Sensory reactions

	Under responsive	Average	Over responsive	Both under and over responsive
Light	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Sound	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Touch/ Pain	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Smell	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Taste	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other (please specify):	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

- Please use this space to provide any further explanation about your sensory reactions...

- Being autistic affects me in the following ways... (Please tick as many as you feel appropriate)

	Tick or leave blank
Balance	
Co-ordination	
Concentration	
Filling in forms	
Following complex instruction	
Multi-tasking	
Procrastination	
Sense of direction	
Short-term memory	
Sleep	
Social conversation	
Speed of responding	
Time management	
Other (please specify):	

- I also have these other conditions and/or medical issues...

- These other conditions and/or medical issues may affect me in the following ways...

- Other strengths I would like you to know about...

- Other difficulties I would like you to know about....

Participating in Research

- When I arrive to do the research...

- I would like some time to transition
- I do not need time to transition
- It depends on other factors. I have explained more here:

- When I arrive, I would like to transition by:

- Breaks in the research

- I do not need breaks during the research
- Breaks during the research would be helpful for me
- I would like to be offered breaks during the research and then I can decide
- It depends on other factors. I have explained more here:

- If you would like a break during the research, when would you like your break?

After every task

every 30 minutes

every 40 minutes

every 60 minutes

Other (please specify): _____

- Difficulties that might affect my ability to do certain tasks in research

	Yes	Yes, but I might be masking this	Sometimes	No
Busy/noisy places are stressful				
Being with others is tiring				
Bright or flickering lights upset me				
Being touched upsets me				
I am anxious with strangers				
It's hard to be brief				
I need time to plan what I am doing				
Changes of plans make me anxious				
I find it difficult to switch between tasks				
I find it difficult to work under time constraints				
I get overwhelmed by too much information				
I find it uncomfortable to sit for too long				
I find it uncomfortable to stare at a screen for too long				
I find it difficult to fill in consent forms or questionnaires with no verbal explanation or clarification by the researcher				
Other (please specify in the space below):				

- Other things I would like you to know about me that might affect my ability to do certain tasks in research

- The areas of research I am most interested in...

Distress

****Trigger Warning****

This section asks about stressful situations.

Please skip to page 18 if you do not want to complete this information.

You may want to discuss this section with someone close to you to think about what you do in distressing situations and what helps you in such situations.

- When I am distressed, I may (please tick as many as you feel appropriate)

- Get loud, agitated and upset
- Become passive, possibly non-verbal and seem to shutdown
- Become verbally/physically aggressive without meaning to
- Make noises
- Flap my hands
- Become unable to speak coherently
- Become bad tempered
- Other (please specify): _____

- You can help me avoid stress by...

- What to do if I am distressed (please tick as many as you feel appropriate)
- Talk quietly and give simple instructions
- Give me time to calm down

- Provide me with a quiet room, with low lighting
- Do not touch me
- Other (please specify): _____

- Other things you can do when I am distressed include...

- This stim is a distress signal...

- This stim is not a distress signal...

Transport

- I am happy to take part in research (please tick as many as you feel appropriate):

At a University

At home

At my school/college

Service provider (e.g. clinical setting, centre etc.): _____

In another place (please specify): _____

- Transport requirements

	Agree	Sometimes	Disagree
I can make my own travel arrangements			
I can travel alone			
I travel with someone else. This person is:			
I can travel by bus			
I can travel by overground train			
I can travel by underground tube			
I can travel by taxi			
I can travel in my own vehicle			

- Other things I would like you to know about my travel requirements

The End of the Research Passport

You have reached the end of the prototype Research Passport, thank you sharing this information.

This Research Passport is yours to keep. Please feel free to bring this with you to other research studies you may be involved in.

[Keep up to date with further developments of the Research Passport at the CRAE website: crae.ioe.ac.uk.](http://crae.ioe.ac.uk)

Information about the Researcher

This section can be completed by the researcher so participants can find out more about the person leading the study they are taking part in.

- Researcher's name

- What topics or areas does the researcher investigate?

- What research has the researcher done in the past?

- Why does the researcher do autism research?

- Is there anything else the researcher would like to say or would like the participant to know?