



MACQUARIE
University
SYDNEY · AUSTRALIA

Macquarie University PURE Research Management System

This is the accepted version of the following article:

Ashworth, M., Crane, L., Steward, R., Bovis, M., & Pellicano, E. (2021). Toward Empathetic Autism Research: Developing an Autism-Specific Research Passport. *Autism in Adulthood*, 3(3), 280-288.

which has now been formally published in final form at:

<https://doi.org/10.1089/aut.2020.0026>

This original submission version of the article may be used for non-commercial purposes in accordance with the Mary Ann Liebert, Inc., publishers' self-archiving terms and conditions.

**Towards empathetic autism research:
Developing an autism-specific Research Passport**

Maria Ashworth¹, Laura Crane¹, Robyn Steward¹, Melissa Bovis² and Elizabeth
Pellicano³

1. Centre for Research in Autism and Education (CRAE), UCL Institute of
Education, University College London, London, UK
2. Kings College London, London, UK
3. Macquarie School of Education, Macquarie University, Sydney, Australia

Running title: Research Passport

Correspondence to:

Laura Crane

Centre for Research in Autism and Education (CRAE)

UCL Institute of Education

University College London

55-59 Gordon Square

London, WC1H 0NU, UK

L.Crane@ucl.ac.uk

Keywords: autism, research, accessibility, participation, adults

Word count for abstract: 239

Word count: 4, 835

Word count for lay summary: 526

Funding:

A grant from the UK autism research charity, Autistica [grant number 7261] supported this work.

Authorship Confirmation Statement:

RS conceived the idea of the Research Passport. LC, RS, MB, and EP sought funding for the project, and designed the study (with input from MA). MA coordinated and collected all data for the project (under the supervision of LC). MA analyzed all data with LC (plus input from EP). All authors provided intellectual input throughout the study (via monthly team communications, as well as RS and MA having regular meetings). MA and LC wrote the manuscript with input from EP. All authors reviewed and approved of the manuscript prior to submission.

Author Disclosure Statement:

No competing financial interests exist.

Abstract

Autistic adults sometimes report negative experiences of research participation. People have developed *passports* or *toolkits* in other areas where community members report dissatisfaction (e.g., healthcare, criminal justice). We created a *Research Passport* that autism researchers and autistic adults could use to support the inclusion of autistic adults as research participants. We designed and developed the Research Passport via an iterative design process. First, we gathered ideas for a Research Passport via focus groups with autistic adults without an intellectual disability (ID) (n=9) and autism researchers (n=6; one of whom was autistic). We found that the Research Passport (1) was a useful idea, but not a panacea for all issues in autism research, (2) needed to be universal and flexible, and (3) could have a broad remit (e.g., to record scores on commonly used standardized tasks that could, with permission, be shared with different researchers). Next, we conducted a preliminary evaluation of a prototype Research Passport via usability testing in three ongoing research projects. Nine autistic participants without an ID provided feedback on the Research Passport (via a survey), as did three non-autistic researchers (via interviews). We found that the Research Passport: (1) promoted positive participant-researcher relationships, (2) provided a structure and framework to support existing practices, and (3) needed to be adapted slightly to facilitate usability and manage expectations. Overall, the Research Passport was useful in promoting empathetic autism research. Further design and development of the Passport are warranted.

Lay summary

Why was this research developed?

Autistic adults taking part in research do not always have good experiences. An autistic member on our team thought that a *Research Passport* could help improve people's experiences. This idea was inspired by 'passports' or 'toolkits' that autistic people can use when visiting professionals like doctors (so the doctor knows about the person and how to support them).

What does the Research Passport do?

The Research Passport lets autistic people tell researchers about themselves before taking part in a research study. Autistic people can decide how much, or how little, they tell the researcher. Autistic and/or non-autistic researchers can use the Passport to try and make sure that their autistic participants have good experiences when taking part in research.

How did the researchers evaluate the Research Passport?

First, nine autistic adults (who did not have an intellectual disability) and six autism researchers took part in group discussions. We asked what they thought about our Research Passport idea and what it should include. We made a Research Passport mock-up based on these discussions. Nine autistic participants who did not have an intellectual disability used the mock-up in one of three university research projects. Autistic participants completed a survey to tell us good and not-so-good things about the Research Passport. Also, we interviewed three researchers about using the Research Passport (asking what they liked and what could have been better).

What were the findings?

Autistic adults and researchers involved in designing the Research Passport thought the Passport (1) could be useful but could not solve all problems in autism research, (2) needed to be suitable for lots of different people, and (3) could have lots of different benefits (e.g., collecting participants' scores on tests that researchers use a lot, so participants do not have to keep doing the same tests each time they take part in a new research study).

Autistic adults and researchers who used the Research Passport in ongoing studies and told us that it (1) led to good relationships between participants and researchers, (2) helped researchers make sure that the way they did their research was acceptable, and (3) was useful. However, participants need to be told what the Research Passport can/can't help them with.

What were the weaknesses of this project?

This study involved a small group of autistic adults and researchers, and the results may not be the same with autistic adults and researchers who have different needs. Also, participants said the Research Passport was not very easy to complete, and a bit long. We need to change the Research Passport so that a wider range of autistic people (like those with intellectual disability) can use it.

What are the next steps?

The Research Passport needs to be professionally designed so it is easier to use by a wider range of autistic people. A bigger evaluation of the Research Passport could allow us to test it with more participants and in more research studies.

How will this work help autistic adults now or in the future?

Using the Research Passport could, with some changes and alongside other supports, improve the experience of autistic adults taking part in research.

Towards empathetic autism research: Developing an autism-specific Research Passport

Introduction

The amount of autism research funded and published over the past decade has increased dramatically¹⁻⁴. Greater knowledge and understanding of autism should lead to more positive outcomes for autistic people and their families. Yet autism research does not always align with community priorities³. This observation has led to calls for greater, and more meaningful, community involvement in research⁵⁻⁸. Despite an emerging body of research on involving autistic people as co-researchers⁵⁻⁸, there has been less attention given to the experiences of autistic people as study participants.

Experiences of autism research participation can be negative^{9,10}. Pellicano and colleagues³ reported that community members (autistic people, their family members, and the professionals who worked with them) had negative experiences of taking part in research, believing their participation to be tokenistic and undervalued. Participants highlighted poor management of expectations about the research process and reported receiving little or no feedback on the research process or its outcomes. Participants also reported “dehumanizing” (p. 7) interactions with researchers, reportedly feeling like “monkeys in a zoo” (p. 4).

Researchers have developed ‘passports’ or ‘toolkits’ in other areas that autistic community members report dissatisfaction (e.g., healthcare¹¹, criminal justice¹²). These context-specific tools typically include important information and resources, as well as opportunities for autistic people to provide information about themselves and their

needs. These tools aim to support and empower autistic people and their families, and enable professionals to meet the needs of those with whom they are working. Initial evaluations of these tools have been positive. For example, a healthcare toolkit decreased autistic patients' barriers to accessing healthcare, improved communication between patients and healthcare providers, and empowered patients to self-advocate for their needs¹³.

Similar tools have been created for other communities disenfranchised and/or harmed by research. For example, Kidney and McDonald¹⁴ collaborated with two research advisors who had intellectual/developmental disabilities to create a toolkit that fostered respectful and inclusive research. The toolkit covered aspects such as recruitment, consent, incentives, and interview locations. The toolkit also promoted principles including accessibility, individualization, flexibility, and responsiveness. The researchers did not systematically document or validate the toolkit development process. Nevertheless, the team reported learning valuable lessons from the co-creation process, including that participants were encouraging about the toolkit itself.

An autism-specific toolkit could complement existing practice-based guidelines to support the inclusion of autistic adults as research participants⁸. These guidelines advise that:

- 1) Participants should have maximum autonomy throughout the research process;
- 2) The informed consent process should be as accessible as possible;
- 3) Participants should be able to take part in research in different ways;
- 4) Research measures and materials should be adapted for participants;

- 5) Qualitative interviews should be accompanied with accessible guides;
- 6) Proxy reporters should only be used if the individual cannot directly participate themselves; and we must consider what a proxy reporter can reliably answer about a participant (e.g., they could report demographic facts but not the autistic person's internal states).

In the current project, we aimed to supplement and extend existing guidelines and toolkits for promoting research participation. Specifically, we used an iterative design process to develop a Research Passport that autistic adults could use when engaging in research as study participants. The Research Passport was a community-driven initiative, proposed by one of the authors, RS (who is autistic herself). The UCL Institute of Education Research Ethics Committee at University College London (UCL) approved the project (REC 1232). There were two phases of the project. In Phase One, we elicited the views of researchers and autistic people to iteratively design a prototype Research Passport. In Phase Two, autistic adults tested the prototype Research Passport. Our aim was to assess whether the Research Passport improved the experience of engaging in autism research, for both study participants and researchers.

Phase One: Designing the Research Passport

Method

Design

We investigated: (1) the utility of a Research Passport, and (2) what a Research Passport might 'look like'. We conducted focus groups with autism researchers and autistic adults, which focused on: (1) experiences of research; (2) views, if any, of

existing autism passports (e.g., healthcare passport); and (3) the type of information that a Research Passport should collect.

Participants

We recruited autistic adults and researchers (all of whom worked with autistic adults) through community contacts, social media, and word of mouth (see Table 1). Fifteen participants took part in either face-to-face focus groups (four autistic adults and six researchers) or online focus groups (five autistic adults). Participants gave informed consent prior to taking part and received a voucher for participating.

The autistic adults did not have an ID and were fairly highly educated. We did not directly ask autistic adult participants to quantify how much prior research experience they had. However, participants (in both the face-to-face and online focus group) self-reported varying prior research experience. Participants' experiences ranged from having only taken part in online studies, to having participated in only one or two in-person studies, to having "a lot" of research experience.

The six participating researchers (one of whom is autistic) had a background in psychology and conducted cognitive/behavioral autism research, including quantitative and qualitative research. The researchers' prior autism research experience ranged from three to seven years.

[Insert Table 1]

Materials and Procedure

Participants took part in focus groups (face-to-face or online) exclusive to their group (i.e., autistic adults only or researchers only). The groups followed this format: (1) Welcome and introductions; (2) Questions about positive and negative experiences of

research (why, and what could have improved it?), before, during, and after data collection; (3) A refreshment break; (4) Discussion about existing healthcare/support passports, and what a Research Passport might 'look like' (e.g., what information might it contain?); (5) Closing comments and thanks.

One researcher (MA) conducted the face-to-face focus group in a quiet, private room at UCL. Focus groups lasted for 1h 52m (autistic adults) and 1h 4m (researchers). We hosted the online focus group (lasting 1h 12m) via a messaging platform, Flock. Where appropriate, we followed published guidelines for the inclusion of autistic adults as research participants⁸. For example, we aimed to: (1) "make the consent process as accessible as possible" (p. 8) by using plain language and creating a simple and accessible process for providing consent online; (2) the online format maximized inclusion of participants who may not feel comfortable engaging in a face-to-face group interaction; (3) we developed the interview schedule with an autistic co-researcher (RS) to ensure it was accessible; and (4) we sent participants the focus group schedule in advance, so they could review the material and prepare answers if they wanted to.

We ensured participants felt comfortable sharing their experiences by: (1) establishing ground rules at the outset of the focus groups (e.g., respecting each other's experiences, not sharing information with anyone outside the focus group); (2) emphasizing that participants did not have to answer questions if they did not want to, or participants could answer questions anonymously; and (3) explaining that participants could take a break or stop entirely at any time without having to give a reason.

We made a quiet room available if participants wanted to take a break during the face-to-face focus group.

Data Analysis

We followed Braun and Clarke's^{15,16} process of reflexive thematic analysis, adopting a critical realist framework. We used inductive ('bottom-up') methods to identify themes, by identifying patterns in the data without integrating them within pre-existing codes or preconceptions. We recursively proceeded through the stages of: (1) data familiarization by reading the raw interview transcripts, (2) generating initial codes by highlighting key information in the transcripts, (3) searching for themes by grouping similar codes/data together, (4) reviewing data within themes to ensure it was appropriate and similar to the other data within its theme, (5) naming and defining themes by discussing and editing possible titles until the team was satisfied it reflected the content and meaning of the theme, and (6) report production. During data familiarization and initial code generation, we noticed that similar themes arose across both groups. We therefore analyzed data from autistic adults and researchers together. MA led the analysis, with input from LC (at all stages of the process) and EP (during the latter three stages of the process). A collaborative process ensured the trustworthiness of data analysis. For example, team members vetted themes and sub-themes, we sought team consensus on themes and theme names, and we conducted peer debriefing (with members of the research centre the project was affiliated with, and broader members of the research team including a researcher that worked for the organization funding the study)¹⁷. In terms of positionality, none of the three authors involved in the analyses identify as autistic, but we conducted peer debriefing with

autistic researchers. All authors of the paper view autism from a social model of disability perspective¹⁸, recognizing that autistic people are disabled by barriers in society that exclude/discriminate them, rather than as a result of within-person 'impairments' or 'deficits'.

Results

We identified three themes from focus group discussions.

Theme 1. The Research Passport could be a “very useful” tool for autism research but will not be a panacea. Participants considered the Research Passport to be a “really good idea” (R4¹) that could help avoid “awkward” (A2), tiring, and sometimes “embarrassing” (A3) conversations about needs and preferences. The Research Passport could “save time [and] energy” (A4) for the participant and could facilitate an opportunity to start a dialogue between participants and researchers about communication/environmental preferences: “Autistic people’s needs might vary depending upon the situation. I think it could be difficult to say, “Oh, I always need X, Y and Z,” ... it’s more about how, if something is going wrong, how would you like to communicate and agree on that” (R2). Participants felt that the Research Passport could help ensure that taking part in research was a welcoming, secure, and comfortable experience.

Participants acknowledged, however, that the Research Passport would not solve all issues in autism research: “[it] is a useful thing but not a cure-all” (A3).

Researchers highlighted that the Research Passport could not necessarily account for,

¹ Quotes followed by a bracketed *A* are by an autistic adult participant. Quotes followed by an *R* are from a researcher participant. The numbers indicate the participant number of the respective autistic adult or researcher.

and prevent, all difficult research scenarios. Autistic adults explained that the Research Passport could not overcome prevailing issues in autism research. For example, a Research Passport could not overcome inherent ideological and methodological issues in some research projects. These issues included researchers endorsing objectionable, derogatory views about autism, “language or hypotheses [that] indicate strong deficit models” (A3), or poorly designed research with ‘incorrect’ methodology. In these cases, a Research Passport would not encourage participants to take part or improve the research experience, and “the emphasis is really about the [research] environment and demonstrating values of respect” (A9).

Theme 2. The Research Passport needs to be universal and flexible.

Participants stressed that the Research Passport would need to be: “universal” (A4), having sufficient content and capability to be adaptable; flexible enough to be “inclusive” (R5) for a “diverse range of people with different needs” (R3); and functional to researchers (e.g., open spaces for people to add additional information). Similarly, participants emphasized that the Research Passport “shouldn’t be one format” (A3) and should be available in electronic/web and paper versions. Participants suggested “collapsible sections”, “because some projects will have medications be relevant and others won’t... some [projects] will have transit needs be relevant and others won’t. Like, it doesn’t matter for an online interview necessarily” (A3). Participants also noted the range of people who could complete the Research Passport, and the range of research people could take part in. Participants felt it would be “difficult to make a passport for every situation” and striving for universality would be “a struggle” (R5).

Theme 3. The Research Passport could have a broad remit. Participants highlighted other potential benefits of the Research Passport. For example, participants suggested that researchers could record commonly used test scores on a Research Passport, which participants could then share with “chosen” (A6) other researchers (avoiding participants repeatedly completing the same tasks in different studies). Yet participants felt that sharing data “would depend on the trustworthiness of the researchers” (A4). Participants felt that incorporating a Research Passport could signal that a researcher was “truly a good egg” (A4) and become a symbol of good research practice. Autistic adults also suggested that there could be space to add information about themselves. Providing such information could address autism stigma and ensure researchers had a holistic, human view of their participants: “[It would be good to have] sections that give us the opportunity to debunk the myths and stereotypes surrounding autism that students and early years researchers may have picked up along the way” (A4).

Summary and next steps

Participants thought the Research Passport was a promising idea that could benefit autistic participants, and autistic and non-autistic researchers. Participants wanted the Research Passport to be adaptable and useful for a wide range of autistic people. Participants felt that the Research Passport could potentially impact data collection, storage, and sharing between researchers, as well as becoming a symbol of good research practice that could be reassuring for prospective participants.

Based on information collected from the focus groups, we created an initial prototype of the Research Passport (via Qualtrics software). We circulated this

prototype by email to the focus group participants. Participants provided feedback by email or telephone. We made amendments to the prototype based on feedback, such as adding different response options (e.g., “I may be masking this difficulty”), changing wording of questions to improve clarity, or adding specific items or sections about interests. We evaluated the updated prototype (see Figure 1), as described next.

Phase Two: Evaluation

Design

We tested the usability of the Research Passport in ongoing research projects at UCL in 2019-2020. We conducted surveys with participants, alongside interviews with researchers, to assess (1) whether participants and researchers thought that the Research Passport was useful, and (2) if/how the Research Passport affected the research process.

Participants

Autistic adults. Nine (three males, six females) autistic adults, participating in one of three different research projects, completed the Research Passport. In total, we approached 16 adults (8 from project 1, 50% opted in; 6 from project 2, 50% opted in; 2 from project 3; 100% opted in). Like the autistic adults in Phase 1, the autistic adults in Phase 2 did not have an ID and were fairly highly educated (see Table 1 for participants' demographic information). Participants self-reported having varying amounts of prior research experience: two (22.2%) = a lot, two (22.2%) = moderate, three (33.3%) = little, two (22.2%) = none. Participants with in-person prior experience took part in experimental research (n=6, 66.7%), interviews (n=6, 66.7%), and/or focus groups (n=3, 33.3%).

Researchers. We interviewed three female researchers, all of whom were personal contacts of the research team, about their experience of incorporating the Research Passport into their research protocols (see Table 1 for participants' demographic information). All researchers were full-time (three-year) doctoral students in psychology departments at UCL (one in their first year, one in their second year and one in their third year). All researchers were conducting cognitive/behavioral research with autistic people, comprising experimental and non-experimental research. The researchers had 4–5 years of prior experience in autism research.

Procedure and Materials

Three doctoral researchers at UCL incorporated the prototype Research Passport into their research protocols. Autistic adults signed up to take part in the researchers' (independently ethically approved) projects. Researchers then sent their autistic participants additional, standardized information about the Research Passport evaluation. Based on this information, the adults voluntarily gave their informed consent to the Research Passport team. We contacted participants directly about taking part in the Research Passport evaluation. We collected completed Research Passports from participants and shared them with the relevant researchers. We instructed researchers to read the Passport carefully prior to their testing session and make any changes/accommodations to their research protocols. We deliberately kept guidance about how to incorporate the Research Passport into their protocols to a minimum, so that we could assess what worked best in practice. Participants completed the Passport then completed a feedback survey (via Qualtrics) about their use of the Research Passport. Researchers also took part in semi-structured interviews (with MA) about their

experience of implementing the Research Passport. The average length of interviews was 19 minutes (range = 13 – 25m).

Data Analysis

We used thematic analysis (as previously described) to analyze qualitative responses to open-ended questions in the feedback survey (completed by autistic adults) and the transcripts of the interviews (with researchers). We examined autistic adults' responses to Likert scale questions in the feedback survey using descriptive statistics.

Results

Autistic adults reported that they were interested in the Research Passport when they heard about it and said that their experiences of using the Research Passport were generally positive. For example, autistic adults found the content of the Research Passport useful, completed most of the Passport and felt happy sharing information in the Passport with the researcher. Participants also felt that the Research Passport would improve the research experience, and most said they would use it again. Nevertheless, our participants told us that the prototype was not entirely straightforward to complete, and there was not a high level of engagement with the researcher about the contents of the Research Passport (see Table 2).

[Insert Table 2]

We identified three themes from autistic adults' qualitative survey responses and in-depth interviews with researchers.

Theme 1. Positive participant-researcher relationships. Autistic adults and researchers told us that the Research Passport created positive participant-researcher

interactions. Researchers noted that the Research Passport helped them feel “more prepared” (R1) and “confident” (R3) about supporting their participants through the research process and gave them better insights into their participants’ needs and preferences: “It was super useful to know whether people needed more breaks or when they turned up whether they were difficulties in terms of transitioning, just getting started, providing additional support, how they wanted to be approached” (R1). Autistic adults commented on researchers’ preparedness and liked that “researchers [took] the time to learn about research subjects” (A5). Participants noted improvements in research experiences because they were “much more at ease knowing I did not need to describe my needs” (A5). However, participants needed to trust the researcher with whom they shared information. For example, one participant was “fine” with sharing their information “as I knew who it was going to and had been in touch with the researcher in advance”, but was “not sure I would be as happy if it was going to a stranger or someone I’d had no advance contact with” (A8). The researchers did not perceive any “big differences” (R3) in the experiences of their participants who had and had not completed the Research Passport. Importantly, researchers noted that participants who completed the Research Passport left in a “good mood” (R3) and appeared “keen to re-engage” (R3) in future research.

Theme 2. A structure and framework to support existing practices. Autistic adults and researchers explained how the Research Passport did not significantly alter research protocols but provided structure and a framework to support existing research practices. For example, participants described how the Research Passport might not have substantially improved the experience because “the researcher was considerate

anyway" (A9), but it was "a convenient and structured way to share information about things that may affect me or arise, without having to worry about how to explain at the time... [telling the researcher] in advance makes sense (A8). One researcher said: "I try to talk through everything I'm doing anyway, but [I tried to] be even more conscious about what people needed" (R1). Relatedly, some autistic adults did not speak to the researcher about the information in the Research Passport because they "already knew the researcher" (A6) and were confident they knew their needs. Researchers commented that many of the points raised by the Research Passport were "considered in ethics anyway" (R2) but the Research Passport "provides a platform to share information" (R2) and "gives more permission" (R2) for researchers to address any issues without "stigmatizing anyone or making assumptions about the difficulties they are having" (R2).

Theme 3. The usability and need to manage expectations. Autistic adults and researchers thought the content of the Research Passport was "useful" (A9), and "relevant" (A8), as well as "straightforward" (A5), "clear" (A8), and "cater[ed] to a wide audience" (A6). Participants felt that the Research Passport allowed the researcher to "individualize to the autistic person" (A10) but also had its drawbacks. For example, participants described the Research Passport as "long" (A3) with some irrelevant questions and "[it was] difficult to judge how much information to include" (A8). Autistic adults advised that the final Research Passport should be flexible, allowing participants to adapt how much information researchers get, so participants do not feel "exposed (A8)". However, researchers suggested it may be necessary "to have [a lot of] detail in order for it to be effective" (R2). Researchers added that: "I would rather have more

work of going through all the information and select what I think is relevant” (R2), as participants might not always know what information would be relevant for the study in which they are taking part. Researchers felt it was “easy to see the overall information... [and] was easy to extract [the information]” (R1). Researchers also acknowledged the challenge of making the Research Passport “universal and applicable for everyone” (R2).

Finally, researchers highlighted the importance of managing participants’ expectations of the Research Passport. Due to external factors (e.g., the availability to book appropriate rooms), researchers cannot always accommodate participants’ needs. Researchers worried that some autistic adults might think the Research Passport would entitle them to “loads of additional support, or even lunch, out of the research experience” (R1) that the researcher could not provide. A mismatch of expectations could be stressful for the participant and the researcher, leading the Research Passport to have “the complete opposite effect” (R3) to that intended and potentially compromising the participant-researcher relationship. Similarly, researchers remarked that researchers needed to read the Research Passport carefully and “follow through” (R3) with adjustments as best they could after the participant had completed it. Researchers suggested that guidelines should include information about how to use the Research Passport and what participants and researchers should and should not expect. These guidelines could suitably manage expectations and avoid negative experiences and disappointment.

Discussion

We tested the usability of the prototype Research Passport, designed to improve the research participation experiences of autistic adults. Both autistic adults and researchers reported favorable opinions. Our participants found the content useful and suggested that the Passport facilitated better participant-researcher interactions. Although the Passport did not significantly alter researchers' protocols, it provided a framework to support existing practice. Our autistic adult sample liked having a structured way to explain their needs to the researcher in advance of participating in their studies. Researchers emphasized the need to manage expectations about what the Passport meant for research, to avoid disappointment and/or damaging participant-research relations. Participants also gave several suggestions for further developments (e.g., to increase usability and accessibility).

Our data represent the first evidence about how a Research Passport can positively impact the research participation experiences of autistic adults, potentially encouraging further research participation. Our findings align with tools developed in other areas (e.g., healthcare¹³) and with other groups (e.g., adults with an ID¹⁴). For example, the Passport, as per existing tools, centers on: maximizing the autonomy of research participants; promoting accessibility, flexibility, and adaptability to meet people's needs; and fostering positive interactions between autistic people and professionals^{13,14}. The Research Passport development process also underscored the importance of working collaboratively with autistic people and their allies in the design and development of initiatives that ultimately affect them⁸.

Our project was an *initial* evaluation of the Research Passport, with usability testing limited to just three research studies. Further, there were notable limitations

regarding the accessibility of our prototype Research Passport. For example, our autistic participants (and researchers) said the Passport was not entirely straightforward to complete and was “long” with some irrelevant items. The temporary platform hosting the prototype, Qualtrics, restricted how participants could answer some questions (e.g., participants had to see every section, even if they did not want to share that information). Consequently, the prototype Research Passport was not as flexible as participants wished. Similarly, the prototype did not have the necessary aesthetics to facilitate optimal accessibility, such as expanding or minimizing comment boxes to participants’ reading preference. We need to professionally design the Research Passport to overcome these limitations.

Additional work could make the Passport accessible for a broader range of autistic people. The development of the Passport involved highly educated autistic adults (e.g., some participants had doctorates). Some items suggested for inclusion in the Passport (e.g., about the masking of autistic traits) may not be wholly understandable to autistic people with ID, for example. Omitting autistic adults with an ID from our research was a major limitation. There are multi-level benefits of engaging in research for people with ID¹⁹, and people with ID are frequently excluded from the research process²⁰. Collaborative work with a broader range of autistic people and their advocates, as well as researchers, is needed to identify if/how the Passport could be adapted to be more accessible for this group (e.g., via the use of plain language text augmented with visual illustrations¹⁴); and/or to determine whether different versions of the Passport are needed for different subgroups of autistic people (e.g., for autistic children vs autistic adults). Importantly, however, we must not overlook the support

needs of autistic people without an ID, who are sometimes erroneously regarded as having needs that are not considered *severe enough* to warrant accommodations and supports²¹.

Encouraging any autistic research participant to complete a Research Passport necessitates a careful balance between collecting enough information from the participant (so that a researcher can usefully act on it) and collecting too much information (so that participant feels exposed or vulnerable). Our autistic participants noted that they felt comfortable providing their completed Passports as part of the evaluation (as they were familiar with the researchers taking part). Yet participants also emphasized that they would be more cautious sharing their completed Passports with researchers who were strangers. We therefore suggest implementing clear guidance around the usage, storage and sharing of information collected via the Passport. Furthermore, we refer to two broad principles underlying respectful, accessible autism research: (1) the importance of giving participants choice and autonomy (e.g., about how much/little information they share and with whom) and (2) the development of trust between the researcher and participant^{8,19}. These concerns may be particularly pronounced for autistic people, since they may experience high levels of stigma around aspects of their diagnosis or co-occurring conditions²¹.

While choice and autonomy are central principles of the Research Passport, developing trust between the researcher and participant may be more challenging to broker. Researchers bear the burden of the research that has gone before them²² and participants may decline to take part in research studies if they do not know the researcher well¹⁹. This observation raises an important question: if the Research

Passport enables participants to provide information about themselves to a researcher (to ensure the researcher feels able to support their needs), would there be value in researchers completing a Passport that provides their participants with some background information about them? The prototype Research Passport included a section for the researcher to add information about themselves, following the suggestion of a member of our project team (see also Pellicano et al.²³). Trust between participants and researchers can be fostered by researchers spending time with participants informally, and being willing to provide information about themselves (e.g., their motivations for conducting autism research)²⁴. As well as building relationships between researchers and participants, this proposed initiative may address the power imbalance that often hinders autistic people's participation in research²⁴.

That said, however, the Research Passport is not a panacea for all issues in autism research. For example, while the Research Passport provided structure and framework for a dialogue about needs and preferences, and can potentially improve participant-researcher relations, it does not *fix* issues related to difficult research scenarios or inherent ideological and methodological problems. To more holistically change the culture of autism research, initiatives like Research Passports should be complemented with broader efforts to engage autistic adults as both study participants and co-researchers (as per the work of the Academic Autism Spectrum Partnership in Research and Education (AASPIRE) team⁸). In future, we should conduct a broader evaluation of the Research Passport, potentially also developing it for other groups of users (e.g., children, autistic adults with ID). In the interim, the prototype Research Passport is freely available for public use and adaptation (see online supplementary

material) by autistic participants and researchers (who may or may not be autistic themselves). We have also developed initial guidelines for using the Research Passport to help manage participant and researcher expectations (see online supplementary material).

Acknowledgements

Thanks to James Cusack and Lorcan Kenny from Autistica, for their input, advice, and encouragement throughout this project; as well as Jade Davies from CRAE for helping to create the prototype Research Passport and associated guidelines. Special thanks to everyone who participated in this research.

References

1. den Houting J, Pellicano E. A Portfolio Analysis of Autism Research Funding in Australia, 2008–2017. *J Autism Dev Disord.* 2019;49(11):4400-4408. doi:10.1007/s10803-019-04155-1
2. Interagency Autism Coordinating Committee I. *Autism Spectrum Disorder Research Portfolio Analysis Report.*; 2016. Accessed May 6, 2020. <https://iacc.hhs.gov/publications/portfolio-analysis/2016/>
3. Pellicano E, Dinsmore A, Charman T. What should autism research focus upon? Community views and priorities from the United Kingdom. *Autism.* 2014;18(7):756-770. doi:10.1177/1362361314529627
4. Warner G, Cooper H, Cusack J. A review of the autism research funding landscape in the United Kingdom. Published online 2019. <https://uu.diva-portal.org/smash/get/diva2:1372363/FULLTEXT01.pdf>
5. Cusack J. Participation and the gradual path to a better life for autistic people. *Autism.* 2017;21(2):131-132. doi:10.1177/1362361316680155
6. Fletcher-Watson S, Adams J, Brook K, et al. Making the future together: Shaping autism research through meaningful participation. *Autism.* 2019;23(4):943-953. doi:10.1177/1362361318786721
7. Pellicano E, Dinsmore A, Charman T. Views on Researcher-Community Engagement in Autism Research in the United Kingdom: A Mixed-Methods Study. *PLoS ONE.* 2014;9(10). doi:10.1371/journal.pone.0109946
8. Nicolaidis C, Raymaker D, Kapp SK, et al. The AASPIRE practice-based guidelines for the inclusion of autistic adults in research as co-researchers and study participants. *Autism.* 2019;23(8):2007-2019. doi:10.1177/1362361319830523
9. Cascio MA, Weiss JA, Racine E. Person-oriented ethics for autism research: Creating best practices through engagement with autism and autistic communities. *Autism.* 2020;24(7):1676-1690. doi:10.1177/1362361320918763
10. Lory B. For the Love of Science? *Autism Adulthood.* 2018;1(1):12-14. doi:10.1089/aut.2018.0005
11. Nicolaidis C, Raymaker DM, Ashkenazy E, et al. “Respect the way I need to communicate with you”: Healthcare experiences of adults on the autism spectrum. *Autism.* 2015;19(7):824-831. doi:10.1177/1362361315576221
12. Crane L, Maras KL, Hawken T, Mulcahy S, Memon A. Experiences of Autism Spectrum Disorder and Policing in England and Wales: Surveying Police and the Autism Community. *J Autism Dev Disord.* 2016;46(6):2028-2041. doi:10.1007/s10803-016-2729-1

13. Nicolaidis C, Raymaker D, McDonald K, et al. The Development and Evaluation of an Online Healthcare Toolkit for Autistic Adults and their Primary Care Providers. *J Gen Intern Med*. 2016;31(10):1180-1189. doi:10.1007/s11606-016-3763-6
14. Kidney CA, McDonald KE. A toolkit for accessible and respectful engagement in research. *Disabil Soc*. 2014;29(7):1013-1030. doi:10.1080/09687599.2014.902357
15. Braun V, Clarke V. Reflecting on reflexive thematic analysis. *Qual Res Sport Exerc Health*. 2019;11(4):589-597. doi:10.1080/2159676X.2019.1628806
16. Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol*. 2006;3(2):77-101. doi:10.1191/1478088706qp063oa
17. Nowell LS, Norris JM, White DE, Moules NJ. Thematic Analysis: Striving to Meet the Trustworthiness Criteria. *Int J Qual Methods*. 2017;16(1):1609406917733847. doi:10.1177/1609406917733847
18. Oliver M. Social Policy and Disability: Some Theoretical Issues. *Disabil Handicap Soc*. 1986;1(1):5-17. doi:10.1080/02674648666780021
19. McDonald KE, Schwartz NM, Gibbons CM, Olick RS. "You Can't be Cold and Scientific": Community Views on Ethical Issues in Intellectual Disability Research. *J Empir Res Hum Res Ethics*. 2015;10(2):196-208. doi:10.1177/1556264615575512
20. Russell G, Mandy W, Elliott D, White R, Pittwood T, Ford T. Selection bias on intellectual ability in autism research: a cross-sectional review and meta-analysis. *Mol Autism*. 2019;10(1):9. doi:10.1186/s13229-019-0260-x
21. Crane L, Adams F, Harper G, Welch J, Pellicano E. 'Something needs to change': Mental health experiences of young autistic adults in England. *Autism*. 2019;23(2):477-493. doi:10.1177/1362361318757048
22. Burnette CE, Sanders S, Butcher HK, Rand JT. A Toolkit for Ethical and Culturally Sensitive Research: An Application with Indigenous Communities. *Ethics Soc Welf*. 2014;8(4):364-382. doi:10.1080/17496535.2014.885987
23. Pellicano E, Lawson W, Hall G, et al. Documenting the untold histories of late-diagnosed autistic adults: a qualitative study protocol using oral history methodology. *BMJ Open*. 2020;10(5):e037968. doi:10.1136/bmjopen-2020-037968
24. Crane L, Hearst C, Ashworth M, Davies J, Hill EL. Supporting Newly Identified or Diagnosed Autistic Adults: An Initial Evaluation of an Autistic-Led Programme. *J Autism Dev Disord*. Published online April 7, 2020. doi:10.1007/s10803-020-04486-4

Table 1.

Participant demographics of the autistic adults and researchers who took part in Phase 1: Designing the Research Passport and Phase 2: Evaluation.

Group	Phase 1: Designing the Research Passport		Phase 2: Evaluation	
	Autistic Adults (n=9)	Researchers (n=6)	Autistic Adults (n=9)	Researchers (n=3)
Gender	3 males; 5 females; 1 non-binary	1 male; 5 females	3 males; six females	3 females
Average age in years (<i>SD</i>) [range]	43 (11.03) [23 – 53]	29.5 (3.67) [25 – 34]	36.4 (14.4) [19 – 55]	28.67 (3.06) [26 – 32]
Highest level of education				
A/AS level ^a	0	0	1	0
Vocational qualification ^b	1	0	0	0
Bachelor's/Undergraduate degree ^c	1	3	2	0
Graduate/Postgraduate taught degree (e.g., Master's) ^d	5	2	3	2
Graduate/Postgraduate research degree (i.e., doctorate) ^e	2	1	1	1
Ethnicity				
White	8	3	7	3
Black	0	0	0	0
Asian	1	3	0	0

Note: In Phase 2: Evaluation, two autistic adults did not provide information on their highest level of education or racial/ethnic background. ^aA/AS level stands for Advanced/Advanced Subsidiary level and is a subject-based qualification in for people aged 16-18 years in England, Wales and Northern Ireland. ^bA vocational qualification is a practical work-related qualification. ^cA Bachelor's/Undergraduate degree is a qualification awarded by a university following the completion of an undergraduate course. ^dA Graduate/Postgraduate taught degree is a qualification awarded by a university usually resulting in a Master of Science (MSc) or Master of Arts (MA). ^eA Graduate/Postgraduate research degree is a qualification awarded by a university after completing a major research project, usually resulting in a Doctor of Philosophy (PhD).

Table 2.

Usability testing feedback survey questions, response options and scale, Mean (*Standard Deviation* and range) response score, and number (and percentage) of missing responses.

Question	Response Options	Mean Response Score (<i>SD</i>) [range]	Missing Response N (%)
When you heard about the Research Passport was it something that interested you?	"Definitely not" (1) to "Definitely yes" (5)	4.4 (0.7) [3 – 5]	0 (0%)
How easy was it to fill out the Research Passport?	"Extremely difficult" (1) to "Extremely easy" (5)	4.4 (0.7) [3 – 5]	0 (0%)
Did you find the content of the Research Passport useful?	"None of it" (1) to "All of it" (5)	4.3 (0.5) [4 – 5]	0 (0%)
Were you happy to share the information in the Passport with the researcher?	"Definitely not" (1) to "Definitely yes" (5)	4.8 (0.4) [4 – 5]	0 (0%)
How much of the possible information in the Research Passport did you complete?	"None at all" (1) to "A great deal" (5)	4.5 (0.8) [3 – 5]	1 (11.1%)
Did you speak to the researcher about any of the information you shared in the Research Passport?	"No" (1), "Sort of" (2), and "Yes" (3)	1.1 (1.1) [0 – 2]	0 (0%)

Do you think the Research Passport improved your research experience?	"Definitely not" (1) to "Definitely yes" (5)	4 (0.5) [3 – 5]	1 (11.1%)
Would you use a Research Passport again in future research you may take part in?	"Definitely not" (1) to "Definitely yes" (5)	4.1 (1.1) [2 – 5]	2 (22.2%)
