LOCKDOWN EXPERIENCES AND VIEWS ON FUTURE RESEARCH
PARTICIPATION OF AUTISTIC ADULTS IN THE UK DURING THE FIRST SIX
MONTHS OF THE COVID-19 PANDEMIC

Alba Realpe¹, Nicola Mills¹, Lucy Beasant¹, Sarah Douglas², Lorcan Kenny³ & Dheeraj
Rai^{1,4}

¹University of Bristol, UK; ²Autistic researcher, UK; ³Autistica, UK; ⁴Avon & Wiltshire
Partnership NHS Mental Health Trust, UK

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Correspondence address:

Dr Alba Realpe
Senior Research Associate in Qualitative Methods
Population Health Sciences
Bristol Medical School
University of Bristol
Canyng Hall
39 Whatley Road
Bristol, UK
Post Code BS8 2PS
Tel: 011794523990 / 07854173032
Email: alba.realpe@bristol.ac.uk

Abstract

The COVID-19 lockdown was a set of nationwide public health restrictions in force on the UK from March 2020 in response to the coronavirus pandemic. Co-occurring anxiety and depression in autistic people placed them at heightened risk of potential adverse mental health due to the lockdown.

Furthermore, the impact of current and future public health measures on autistic people's willingness to take part in autism research was unknown. We carried out in-depth interviews with 31 autistic adults exploring their experiences of the COVID-19 lockdown and how the pandemic may affect future research participation. Transcripts were analysed thematically within a critical realism framework. Participants identified positive aspects of lockdown such as enjoying the lack of social pressures and using their well-developed skills for dealing with uncertainty. Autistic people also shared challenges of adjusting to lockdown, e.g., rapid change in daily routines. While hopeful about the freedom gained from easing restrictions, participants were concerned about the inconsistent communication and application of rules during the transition out of lockdown which may exacerbate already rising mental health issues among autistic people. The participants viewed research participation and engagement with increased relevance during the pandemic and welcomed efforts to conduct research using online methods of communication. The COVID-19 lockdown had a varied effect in the lives and routines of autistic people. However, healthcare providers and researchers need to be mindful of rising mental health issues during the pandemic, especially for people who were already vulnerable. The response to the pandemic may have offered opportunities for innovation in research processes enabling more autistic people to engage with research and making studies more inclusive.

Keywords: autism in adults, COVID-19 pandemic, first lockdown experiences, qualitative study, trial methods.

Lockdown experiences and views on future research participation of autistic adults in the UK during the first six months of the COVID-19 pandemic

Following a rapid rise in COVID-19 cases, a set of public health restrictions including limits on social mixing, business closures and guidance to maintain social distance and wear face coverings (hereafter, COVID-19 lockdown), were imposed on the United Kingdom (UK) in March 2020 (Johnson, 2020). However, due to the unique nature of the outbreak, empirical evidence of the behavioural and social impact of lockdown strategies on different communities lagged behind (SAGE, 2020). Global research efforts gathered pace to fulfil the knowledge gap with the launch of large survey studies and systematic reviews in various countries (Fancourt et al, 2020; Veer et al, 2021; Vindegaard & Benros, 2020). Emerging evidence indicated strict restrictions may have had a negative impact on people's wellbeing and mental health (Panchal et al, 2021; Salary et al, 2020), especially in individuals living with pre-existing mental health conditions (Brooks et al, 2020; Pellicano et al, 2021; Vindergaard & Benros, 2020).

Autistic people are a vulnerable group with a high co-occurrence of physical and mental health problems (Croen et al, 2015; Hirvikoski et al, 2016; Rai et al, 2018; Schendel et al, 2016) and a community at risk of experiencing hardship (Lai, Lombardo & Baron-Cohen, 2014) during the COVID-19 pandemic. Recently published research on the early psychosocial impact of the COVID-19 pandemic has shed some light into the experiences and responses of autistic adults in different communities. We are aware of two online survey studies carried out with autistic adults in the US (Adams et al, 2021 Bal et al, 2021), two mixed-method studies – one across three European countries (Oomen et al, 2021) and the other in the UK (Bunty et al, 2021), and an interview study of 44 autistic adults in Australia, which also included young people and families (Pellicano et al, 2021). All studies recorded

negative effects of the pandemic and lockdowns that included increased feelings of anxiety, stress, and sadness; varied levels of disruption to autistic adults' daily routines, and difficulties accessing professional support services. However, three studies (Oomen et al, 2021; Bunty et al, 2021; Pellicano et al, 2021) also reported that some autistic adults benefitted from reduced social and sensory stimulation and increased community spirit during the COVID-19 lockdown.

Autistic adults have traditionally faced extensive inequality in relation to health and social care, and much of the care and service provision for autistic people does not have a robust evidence base on research, such as adequately powered randomised controlled trials (Lai & Baron-Cohen, 2015). There is a risk that the pandemic may exacerbate such inequalities (Pellicano & Stears, 2020). It is therefore important to know how the pandemic has affected the lives of autistic people and what may be the implications of the pandemic on future research with the autistic community.

The aims of this study were to: i) understand experiences of autistic people of the first COVID-19 UK lockdown and how it impacted their daily lives; ii) explore the views of autistic people on how the pandemic may affect future research participation; and iii) understand which adaptations may be helpful to facilitate research participation during and after the pandemic.

Method

The design was qualitative with in-depth one-to-one semi-structured interviews with autistic adults. The study design and all study materials were co-produced by the team comprising an autistic adult (SD), the head of research at the UK charity Autistica (LK), experienced qualitative researchers (AR, LB, NM), and an experienced autism clinician and researcher (DR). Our approach was theoretically informed by critical realism applied to social science. Critical realism proposes that all scientific knowledge is situated within a

historical, social, and cultural context. Therefore, the aim of any investigation is to create a plausible description or explanatory account of the object of study (Archer et al 2016). We also subscribe to the view that the exploration of people's speech and behaviour is a valid method to find out how they exercise personal agency in a socially coordinated and interdependent manner (Bandura 2001), thus justifying our interview approach. Ethical approval was obtained from the University of Bristol Faculty of Health Sciences Ethics committee (ref. 93283).

Participants and Procedures

Participants were individuals who were 18 years or older, had a diagnosis of autism, understood the participant information sheet, and consented to participate in 1:1 interview with a researcher in English.

The study was embedded within a qualitative study of the views of autistic people in relation to randomised controlled trials and their processes (the APRiCoT study, paper in preparation), which was open for recruitment when the pandemic struck. Potential participants were recruited via a mailshot to autistic adults who had subscribed to the Autistica Network, which links researchers to individuals interested in participating in research, and via a call for participants through social media. Those interested were asked to complete an expression of interest confirming their diagnosis of autism, understanding of the participant information sheet, and providing basic demographic information, and preferred contact details for an interview in English. A subset of those who expressed an interest were invited for interview. Sampling for interviews was based on balancing the participant group in terms of age, gender, level of education and employment status to ensure a maximum variation.

An experienced female qualitative researcher (AR) approached potential participants to obtain informed consent, organise and conduct interviews remotely via telephone, email,

video call and Skype instant messenger according to participant preferences. Interviews were conducted by four members of the study team (AR, LB, NM, DR). A semi-structured topic guide including questions about participants' COVID-19 lockdown experiences and views on research participation during and after the pandemic was used. Interviews took place between March and July 2020. Audio recordings were transcribed verbatim. Two authors (AR, LB) conducted thematic analysis (Braun & Clarke, 2006) assisted by specialised software NVIVO (released on 2018) and met regularly to refine their codes and discuss disagreements. Transcripts were analysed from an inductive perspective where themes were created within a contextualist framework of critical realism. Ongoing analysis was discussed at regular meetings with the wider research team. Sampling, data collection and analysis occurred cyclically until the point of data saturation, where no new themes emerged.

Results

Sample

We interviewed 31 autistic adults between May and July 2020. Table 1 shows their demographic characteristics. 14 people identified as females, 15 as males and 2 as non-binary. Most interviewees were working age adults with higher levels of education attainment, yet almost half of the participants were under or unemployed. All participants confirmed they had a diagnosis of autism. Interviews lasted on average 54 minutes (range 23 to 105 minutes).

TABLE 1 ABOUT HERE

We report study participants' experiences adjusting to the conditions of lockdown in three themes that detailed i) their perceived strengths and resilience, ii) challenges they faced, and iii) their concerns and hopes for life after the first lockdown. In relation to research participation, we organised participants' views under four themes that reflect perceived opportunities and barriers for research engagement of autistic adults. Figure 1 shows the

coding themes and sub-themes derived from our analysis. We included all codes and sub-codes by frequency in supplement 2.

FIGURE 1 ABOUT HERE

Adjusting to lockdown: Strengths and resilience

Most autistic people (n=25) in our interviews viewed themselves as particularly well-equipped to deal with the lockdown. This was in part due to their lifestyle preferences of rules and avoiding social interaction, and in part because they were used to dealing with higher levels of uncertainty and anxiety in their everyday lives. Factors contributing to autistic people's positive perceptions of themselves during lockdown are explored below, and quotes exemplifying these findings included in Table 2.

TABLE 2 ABOUT HERE

Enjoying a quieter pace of life. The quieter pace of life and reduced social expectations during lockdown suited several participants (n=16). Pressure to socialise reduced during the lockdown, often a source of anxiety for autistic people. People reported having more time to work at a measured pace and engaged with physical exercise and leisure activities (e.g., DIY, hobbies). Public spaces were emptier with rigid rules (such as one-way systems and social distancing) so activities like shopping were less stressful.

Having a lifestyle amenable to self-isolation. Participants reflected on already having a lifestyle amenable to self-isolation (n=22). To avoid anxiety from unexpected changes, many people had deliberately designed their lives to have less social interaction. For example, they preferred a small group of friends and were used to work or study on their own and at home. Many were already carrying out everyday activities, such as socialising or shopping, via online platforms. An advantage of communication using digital platforms during lockdown was that people were more available.

Being prepared to deal with uncertainty. Most participants (n=30) had developed some resilience to deal with uncertainty pre-pandemic. They had experience of managing anxiety related to uncertainty and told us how this helped them to adapt to the pandemic crisis. For example, by having a pragmatic view of events and situations, focusing on what they can control and using problem-solving skills. Some reported that their natural tendency not to react emotionally was an advantage during this crisis.

A caveat to the positive experiences and attitudes to lockdown was reported by a participant who reflected on how these attitudes depended on having an overall good mental health pre-pandemic:

“As long as the particular autistic person has good mental health, I think [lockdown] probably isn't that much different [to life before] apart from it's a bit quieter when you go outside. So, yeah, I mean luckily my mental health is quite good so that is not an additional thing to worry about. And I think from what you see with neurotypical people, they are missing the things like the pubs and football matches and the more present social things that they like to do” [Participant #44].

Adjusting to lockdown: Challenges

All autistic people (n=31) in our sample described challenges affecting their physical, psychological, and social wellbeing during the lockdown measures. We describe these challenges and present quotes to exemplify the findings in Table 3.

TABLE 3 ABOUT HERE

Changing own lifestyle at a pace. For many participants (n=19), changes brought about by the lockdown interfered with daily routines they employed to feel safe and secure, these increased feelings of anxiety and, in some instances, caused a low mood. Some people struggled to create new routines to replace old ones, especially at the beginning of the

lockdown measures. A few people had to change plans (e.g., postpone a wedding or move in with relatives to take on caring duties).

Furthermore, some (n=5) felt preoccupied by the planned lifting of lockdown restrictions because they anticipated a new wave of rapid changes to their newly adjusted routines. Adjusting their lifestyle to different regulations in succession did not suit autistic adults and their families.

Feeling anxious about work changes and job security. Although most participants had experience working from home or were retired, 14 interviewees commented on raising levels of work-related stress because of changes in working patterns and conditions, some people were not used to working from home and missed their commute routine. Three people felt their current jobs exposed them to higher risk of contracting the virus. Four people had lost their job as a result of the pandemic placing them in financial hardship.

Missing face-to-face contact. Autistic adults (n=10) living on their own shared their feelings of loneliness and longing for meeting people face-to-face and for physical contact (e.g., hugs). They not only missed their close friends but also casual regular acquaintances. One female participant commented on feeling surprised by her own proactivity chatting to neighbours during the ‘clap for carers’ events and obtaining a phone number from someone at a café; behaviours she would not engage in voluntarily before lockdown measures. Social interaction via online platforms offered ways to maintain social contact with significant others, however four people commented on barriers such as difficulties recognising social clues, for example to be able to take turns in a conversation or maintaining eye contact. In contrast, people sharing accommodation with others (n=6) reported feeling overwhelmed by the constant social interaction and found it difficult to take time out to rest albeit to a small degree.

Feeling anxious about contracting COVID-19. Ten participants expressed fears about contracting COVID-19 that made them feel vulnerable and anxious, five of them were concerned enough to avoid going out at all at the beginning of the lockdown measures and one had contracted and recovered from the virus. Another participant felt their personal risk was low on account of good health, youth, and fitness.

Half of participants (n=15) reported concerns about family and friends during the pandemic. They worried about vulnerable people (e.g., older relatives) contracting the virus but also the indirect consequences of the lockdown measures (e.g., access to urgent healthcare, job losses). Autistic people expressed understanding of the stress and challenges experienced by neurotypical people and had concerns about not being able to provide support to significant others, for example, by sharing emotional experiences with them.

End of lockdown: Concerns and hopes

We recorded concerns about the easing of lockdown restrictions and hopes for the new ‘normal’ post-lockdown world. Table 4 presents quotes that exemplified the sub-themes described below.

TABLE 4 ABOUT HERE

Increasing uncertainty from lifting of lockdown. Participants (n=12) shared concerns and were anxious about the uncertainty that lifting restrictions would produce in their everyday lives. First, some participants worried about people not following safety protocols (e.g., social distancing), which contrasted with their own strict adherence to guidelines. Second, autistic people found government guidance ambiguous about what is and is not allowed (e.g., visiting people) and felt very frustrated by the inconsistency, lack of clarity or precision. Third, participants anticipated the return of previous anxiety-provoking routines such as inflexible working patterns or unwanted social interaction. Finally, they worried about uncomfortable sensory issues from face coverings and hand gel usage.

Arising mental health issues post-lockdown. Some autistic people (n=9) recognised the potential for mental health issues arising post-lockdown. They wondered about the detrimental effect of increasing uncertainty from the lifting of restrictions. Furthermore, some participants had postponed access to health services because of the pandemic and were unsure about services resuming.

Hoping for lifting of lockdown at own pace. Participants (n=12) expressed their hopes for understanding of the challenges that rapid changes in routine represent for autistic people and wished for organisations and systems to embed flexibility and time for readjusting to a new way of working and interacting. These hopes extended to key public services such as social and health care, for example, by continuing online delivery as well as provision for safe return to face-to-face contact when required.

Views on research studies during and after the current pandemic

Most participants expressed positive views on research engagement and participation going forward. They commented on specific opportunities and challenges brought about by the pandemic. We organised these views in four themes and include quotes that exemplify these findings in Table 5.

TABLE 5 ABOUT HERE

Relevance of research involvement and participation. Most autistic people (n=23) considered research involvement and participation more important now than ever “*a result of this pandemic, people will have opened their minds to more research (...) that everybody has to look after everyone else (P37)*”. They believed contributing to research was a citizen duty and should be encouraged. They felt strongly about autism research and that this was a way to combating marginalisation and improving the mental health and lives of autistic people. They reported that they would not be deterred to participate in future research following the COVID-19 pandemic, however they were aware of necessary adaptations. One participant

warned about the need for coordinated efforts to prevent overlapping research, whilst another participant noticed a tendency to overwhelm potential participants with requests, assuming people were always at home. It should be noted though that many people we interviewed had a good knowledge and previous experience of research participation.

Preference for online communication. Online communications opened opportunities to participate in research according to 21 participants. The current pandemic has forced research teams to seek other ways to reach participants. One person saw this as an opportunity to innovate rather than persisting with a one-size-fits-all in-person appointments. Twelve participants reported being unable or unwilling to engage in research before the pandemic due to increased anxiety from meeting new people in an unfamiliar place, particularly clinical settings, but would be more receptive now given the opportunity of online communication.

Participants (n=15) had a variety of preferences to communicate online in a research context, from written communication, (texts and emails) to videoconferencing and telephone. A minority (n=2) still preferred face-to-face interaction and reported difficulties with interruption and fatigue when using videoconference platforms.

Support for online research processes. Autistic people supported changes to obtain informed consent via online contact. People we interviewed thought that verbal consent or consent documented via electronic documents were as valid as written consent, providing that data safety was observed. One person was reluctant to give online information due to privacy concerns, but others (n=15) thought it was feasible and even preferable for convenience and accessibility. However, they felt it was important to see and/or hear a person at the beginning, and everything could not be done through electronic documents.

Predisposition to avoid in-person studies. Most autistic people (n=21) said face-to-face studies carried more risks during the pandemic. Social distancing added to the stresses of

meeting new people in unfamiliar places, therefore, studies that required in-person attendance would need to justify reasons for these extra risks. They were less inclined to take part unless they were drug or medical intervention studies, which required specific procedures (e.g., blood tests, scans, etc). To see participants face-to-face, researchers would need to be well resourced – i.e., better communication, increased staff capacity to explain COVID procedures, possibly more flexible reimbursement protocols.

Discussion

In this study, autistic adults identified positive aspects of the first COVID-19 UK lockdown such as enjoying the lack of social pressures and using their well-developed skills for dealing with uncertainty. They also shared challenges of adjusting to lockdown, for example, due to the rapid change of daily routines. While participants were hopeful about the freedom gained from easing restrictions, they were concerned about the inconsistent communication and application of rules during the transition out of lockdown which may exacerbate mental health problems in autistic people. The participants viewed research participation and engagement with increased relevance following the pandemic and welcomed efforts to conduct research using online methods of communication.

Three features of this work limited the conclusions we can draw about the impact of the lockdown on autistic adults. First, participants' views and experiences represented an early response to the first COVID-19 lockdown and therefore provided cross sectional data. However, we noted how the group response changed as restrictions eased (e.g., increased anxiety about inconsistent communication) even during the brief period of data collection, indicative of a dynamic situation that warrants continuous evaluation as new measures are introduced. Second, the participants tended to be well educated and many already had experience of research participation. Our sample may therefore have excluded people with less interest in research participation and those with greater support needs. Third, the study

did not include people with intellectual disabilities and therefore our sample does not fully represent the autistic community. Nevertheless, we purposively sampled our participants to obtain a balanced sample with a wide range of characteristics and collected data until saturation was reached. Notably, our sample of 31 participants with in-depth 1:1 interviews represent a large group when compared with many qualitative studies with the autistic community with typically smaller numbers.

To our knowledge, our results can be compared to findings of three other studies that reported qualitative data from open response survey questionnaires (Bundy et al, 2021; Oomen et al, 2021) and in-depth interviews with autistic adults in Australia (Pellicano et al, 2021). Similar to our study, researchers found a wide range of positive and negative effects of national lockdowns in everyday experiences of autistic groups in the UK, Belgium, the Netherlands, and Australia during the first months of the COVID-19 lockdown. These international studies as well as a recent report by the National Autistic Society (2020) confirmed the concerns from participants in our study about the increasing levels of anxiety, worsening mental health and urgent need for support. The economical and societal consequences of the pandemic are unfolding and risk widening pre-existing health inequalities for people with disabilities. Effective methods to support the returning to normal times need careful consideration making use of what was learnt during the COVID-19 lockdown, for example the need for clear and unambiguous government guidance, more flexible working practices that consider individual needs and preferences (such as remote working) and a system that values the needs of a neurodiverse population.

Whilst research to date has focused on healthcare access and support needs, our study adds to the evidence by specifically investigating the implications the pandemic may have on future research with the autistic community or adaptations required to support research participation.

In relation to research participation and engagement, we learnt that autistic people welcome and value the current use of online technology to reach study participants. The response to the pandemic has forced innovation that have placed researchers in the path to achieve some of the goals of participatory autism research. Participatory autism research means adapting the research environment, methodology and dissemination routes to permit the widest and most accessible engagement (Fletcher-Watson et al, 2019; Aabe et al, 2019). Our findings may help inform the design of future studies with autistic people considering the preferences and needs of this community.

In conclusion, the COVID-19 lockdown had a varied effect on the lives and routines of autistic people evidenced in their mixed experiences that included seeing opportunities and facing challenges. However, healthcare providers and researchers need to be mindful of rising mental health issues during the pandemic. The findings suggest that the pandemic may have offered opportunities for innovation in research processes (e.g., wider use of remote methods of consent and data collection) enabling more autistic people to engage with research and making studies more inclusive.

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Tables

Table 1

Demographic characteristics of the COVID-19 lockdown interview sample

Characteristic	Value
Age (range)	45 (25-67)
Gender	
Female	14
Male	15
Non-binary	2
Highest education qualification	
Pre-degree	9
First degree	11
Postgraduate	8
Current occupation	
Full time	11
Part time	7
Retired	5
Unemployed/student/other	8

Note: Age = Mean age. Pre-degree qualifications includes certificates of secondary education and vocational qualifications. First degree includes Bachelor of Science or Art. Postgraduate includes Master and PhD. Other = volunteering, long term absence on medical grounds.

Table 2

Quotes of strengths and resilience during COVID-19 lockdown measures

Sub-theme	Quotes
Enjoying a quieter pace of life	<i>"I'm quite happy being by myself and not having to go through the ritual of having to understand what people are doing." P43</i> <i>"All the stressful events were removed and replaced with things I was choosing to do. I settled into it very quickly and enjoyed every minute of it. I was never bored and kept busy with lots of things." P45</i>
Having a lifestyle amenable to self-isolation	<i>"I'm very well-suited to COVID life. I spend a lot of [time] at the house by myself anyway. I've got quite insular hobbies, so I like writing, I like painting." P37</i> <i>"A lot of us tend to be quite solitary people, quite isolated anyway and I think a lot of people, they're probably experiencing this isolation for the first time." P23</i>
Being prepared to deal with uncertainty	<i>"Life carries a risk. And it's your ability to see that and assess it. And I think that's where it helps. Because we [autistic people] have got that. It isn't because we don't empathise. Because we do. We show it in a different way." P27</i> <i>"The way I deal with the uncertainty is to make as many steps as I can that are within my control (...) I'm happy to follow those rules and to keep informed about the economy. But I know that I can't control those so if I accept those then that's how I deal with the uncertainty." P36</i> <i>"I tended to look at questions or problems and come out with solutions, which they - people are kind of being a bit left field. I tend to look at things from a different way." P43</i> <i>"I'm quite matter of fact. So, I don't particularly often have very strong emotions. So, I tend to look at it and look at what the science is saying and what's happening, and take quite a pragmatic view, from that point of view. And I think that's probably due to the autism." P29</i>

Note: P# = Participant unique identification number.

Table 3

Quotes of challenges during COVID-19 lockdown measures

Sub-theme	Quotes
Changing own lifestyle at pace	<i>"The first 3 weeks were incredibly difficult. All those micro routines which completely went out of the window, Including the times that I get up. The time that I start and finish work. It completely went out of the window, and it just flawed me. There was no warning (...) So, [lockdown] has had a huge impact because, all those little routines that you have, they create a feeling of safety and wellbeing."</i> P27 <i>"I've got something I want to be doing and can't do it. And I haven't been able to switch to another [leisure activity]."</i> P21
Feeling anxious about work changes	<i>"My routine was always going to work and coming back home and just chilling out but now they've sort of blended into one it's all been changed quite significantly."</i> P23 <i>"I'm a bit of a loss as to where to go at this stage in terms of finding work, what to do or what would be available."</i> P49
Missing face-to-face contact	<i>"So, I've kind of seen a few friends. But I cry when I first see them because I can't hug them. Because I'm a very tactile person. And I really love hugs."</i> P41 <i>"I actually miss the routine of being in work and having a little bit of social contact - I can also close the door if it's too much and I don't have to be around people. But there are people there that I've grown to like."</i> P42 <i>"Time to myself. So, actually, maybe that is an autism thing. I struggle with not having any time to myself."</i> P20
Feeling anxious about contracting COVID-19	<i>"It's the fear of getting the illness for me. We've had three people that we've known that have passed away, which is a bit of a tough one as well. So, it's even closer to home."</i> P26 <i>"My wife finds that she's feeling quite emotional, I can be a bit matter of fact. It's helpful for me. Not necessarily helpful for people I'm living with. I'm not sure I can always give the support (laughs) that she wants."</i> P29

Note: P# = Participant unique identification number.

Table 4

Quotes of end of lockdown: Concerns & hopes

Sub-theme	Quotes
Increasing uncertainty from lifting of lockdown	<i>"Even when I try and go out on a walk, I get myself so stressed because people are so blasé, they don't care." P26</i> <i>"The trouble is that while [lockdown restriction] is a blanket ban, everybody sticks with it. Now there's so many exceptions, it's meaningless. (...) And I think at the moment we're in the worst of both worlds." P43</i>
Arising mental health issues post-lockdown	<i>"A month and a half ago I probably would have given you a different answer. I was here on my own with mum and getting no support. And I was finding it very difficult for my mental health." P33</i> <i>"I think initially I went into kind of crisis mode and for about a month and a half I functioned really well. And I think it hit me in a sort of delayed - So, the past few weeks have been a lot more difficult than even initially." P48</i>
Hoping for lifting of lockdown at own pace	<i>"I will be glad when things open up a little bit, I think. And I get back into my own routine a bit, maybe." P33</i> <i>"I don't mind if the country's getting on enjoying it, but I won't be forced to do anything, so I'll be able to ease into it at my own speed." P46</i> <i>"I have a lot of things like medical and physical stuff for me and my son (...) And as things go more back to normal, I'm due to have a whole load of stuff now that's had to wait. Suddenly get - actually accelerated a bit and it's that part that I'm worried about - is like now go from this really quite quiet and for me quite easy life to full throttle - back to lots of things to feel anxious and stressed about all the time." P37</i>

Note: P# = Participant unique identification number.

Table 5

Views on research participation and engagement

Sub-theme	Quotes
Relevance of research involvement and participation	<i>"I think that in general the Coronavirus pandemic has shown that it's important for as many people as possible to participate in studies, if they possibly can, because the bigger your dataset the more accurate your information will be." P36</i>
Preference for online communication	<i>"Choice is key here really. Phone, skype, emailing etc. some studies have even been done via Facebook messenger. But each autistic person will want different, so I think it's best not to prescribe a method. And asking autistic people if there's other better ways than have been offered." P30</i> <i>"Seeing somebody face-to-face is great and I've no problem with that. But for some reason video conferencing is just - urgh. It's really hard work (...) there's a lot of talk about Zoom fatigue." P27</i>
Support for online research processes	<i>"But how accessible [the research] is, it is a major one [factor]. If it's online, I'm more likely to do it. I would only do one in person if it were at one of my two local unis within walking distance. And I usually have childcare issues for that, so can only go at certain times." P40</i>
Predispose to avoid in-person studies	<i>"I'd expect some kind of physical monitoring." P20</i> <i>"Any kind of face-to-face thing is going to carry a certain amount of risk." P29</i> <i>"I'm aware from my knowledge of the history of pandemics that hospitals are not particularly good places to be. One of the pieces of advice to my students was always 'don't go to hospital if you don't have to', so I would probably be more wary now of about face-to-face [research activity]" P32</i> <i>"I'm not going to go into a commuter train - not just for my comfort but for my personal safety. So, some things [research activity] change." P35</i>

Note: P# = Participant unique identification number.

Figures

Figure 1. Themes and sub-themes from study interviews (N=31).

Supplemental material

SUPPLEMENT 1

Topic guide

Part A. Introduction, consent, and background

- Thanks, introduce self, ASK HOW PARTICIPANT WOULD PREFER TO BE ADDRESSED, re-state purpose of the interview
- Aim: to understand what adults with a diagnosis of autism think about participating in a randomised controlled trial (RCT). We will also cover some questions regarding the coronavirus pandemic and how it may impact on research participation.
- Mention recording of interview with permission, data confidentiality/ anonymisation and right to withdrawal at any point without giving a reason
- Ask if any questions on the above
- Record verbal consent to each question on consent form

To start with we would like to briefly ask how, or if, being autistic affects your life, e.g., do you have any routines you like to stick to in everyday life? (Pre-pandemic)

The coronavirus crisis has led to people having to change many aspects of their lives

- How has this affected you and your routines/social interactions (relationships/events)? *[Probe: Thoughts on this - prefer changes or not?]*
- Have your routines changed over the time of lock down? *[Probe: In what way? Why? How feel now compared to earlier in lockdown? Likely to go back to old routines/ways of interacting or stick to new when back to 'normal' - why?]*
- How do you think you've coped overall with the current situation? *[Probe: Why think this? Always felt like this throughout lockdown or feelings changed? Anything in particular liked or struggled with e.g., social distancing, stay at home?]*
- How does being autistic affect the way you have coped with the current pandemic? *[Probe specific everyday activities: E.g., visiting GP/hospital, supermarket (rules, face coverings, availability food).]*
- How much of this is due to autism? Think neurotypical/people without autism might cope differently? *[Probe: anecdotal account of people with chronic anxiety feeling uncharacteristically calm at present because they see it as everyone else joining their way of thinking – can you relate to this or not? Why?]*

There are still so many uncertainties about coronavirus...

- How are you coping with this uncertainty in particular?
- Have you tried any strategies or changes to feel more secure?

Part B. Views on research studies / current pandemic

I am now going to ask you about your views on research studies, especially in light of the current pandemic:

- Are you the kind of person who would usually volunteer to take part in a research study if you were offered the opportunity? [*Probe: Why? Prior experience? Factors important to make decision (e.g., topic, team expertise, accommodate needs)?*]
- Has this view changed (or might it be likely to change) in any way due to the coronavirus pandemic [*Probe: How? Why?*]
- Do you think researchers need to think about different ways of carrying out research in light of the current pandemic? [*Probe: What sort of things? Why?*]
- What could researchers do to enable autistic people participate in research that may help improve their well-being? [*Probe: thoughts on retaining changes even if not strictly required (e.g., online testing, remote consent)*]

Part C. Understanding RCTs

I'd like to now ask about your understanding of an RCT and your views on it. Before you received information about this study, had you ever heard of a randomised controlled trial (RCT)? It may also be called a randomised clinical trial or study. We sent you a document called "Explaining randomised controlled trials (RCTs)" did you have time to read it?

General views on participating in RCTs:

- Does it make sense to you why RCTs are done? Understand the purpose of them?
- Does it make sense why they are done like this? i.e., why treatment is randomised, why an inactive treatment (placebo) may be used, and why the patient and doctor may not know what treatment is given (blinded)?

Part D. Views on participating in a specific RCT

I'd like to now ask about your views on participating in a specific RCT and then I will ask you some questions about it.

Researchers would like to find out if a treatment for anxiety (called sertraline) is an effective treatment for anxiety in autistic adults. They know that the treatment works in the non-autistic population, but they do not know if it will treat anxiety in autistic people. They would like to do an RCT to find out.

In the RCT, autistic people who have problems with anxiety will be allocated to receive either Sertraline (the real/'active' medication) or a 'Placebo' (inactive medication). This process is done in a way that everyone has an equal chance of receiving either the active medication or placebo (randomisation).

Neither the person in the study or the doctor will know what medication has been allocated so that perceptions about the medication do not bias the study results (it's a blinded RCT).

The person in the study will take the sertraline or the placebo for a year without knowing which one it is.

In this time, they will have questionnaires to fill out and they will be closely monitored to check that they are doing ok. They can withdraw from the RCT at any time without giving a reason.

Views on participating in a specific RCT:

- What would you think if you were invited to take part in this RCT?
- What, if anything, might you like about this?
- What, if anything, might concern you about this?
- Do you think you would participate or not? Why?
- What do you think about not knowing what treatment you are taking in a blinded RCT like this?
- Would it make a difference if you didn't know the treatment you were taking for a short time (perhaps a month) or a longer time (perhaps a year)?
- When the study finishes, and you find out you were in the placebo group – what would you think about that?
- Have you ever taken medication for anxiety or depression (past/currently)? Experience?
- Do you know anyone who in past/currently takes sertraline or medications for anxiety or depression? [from autistic or neuro-typical population?] Their experience?
- Who/what do you trust in terms of getting information about new or existing medications? (GP, Internet etc)

Views on participating in a specific RCT during the COVID-19 pandemic

- What would you think about taking part in this RCT during the current coronavirus pandemic?
- What, if anything, might concern you about this? What might you like?
- If social distancing or worries about the pandemic were to continue, would it change your decision to participate or not? Why?
- What could the researchers do in order to facilitate autistic people participate in such a study in the current pandemic?
- Because of social distancing some aspects of the RCT may happen differently e.g., consent, eligibility assessment carried out via video-conference (e.g., skype) or telephone instead of face-to-face. What would you think about this?
- Is there anything else that you would like to raise about taking part in this specific RCT or any research during the current pandemic?

Part E. Concluding thoughts

- What was it that made you agree to take part in this interview study?
- Is there anything that we have not talked about that you would like to raise?
- Thank them for their time, reiterate confidentiality, discuss reimbursement.

Supplement 2

Table 6

All codes and sub-codes extracted from the COVID-19 lockdown interviews

Code name	Number of Participants
EXPERIENCES DURING COVID-19	31
CHALLENGES	31
Having difficulties changing lifestyle at a pace	19
Interfering with routines that kept people feeling safe	9
Struggling to create new routines	7
Feeling concerned about lifting of restrictions & back to new normal	5
Having to move from home	3
Having to change plans	2
Having anxiety triggers pre COVID-19	18
Unexpected - forced social contact	8
Sudden changes in routine	7
Everyday routines to stick to	6
Having conflicts with others	6
Feeling gullible - can't trust people	2
Using special services (e.g., airports, workplace)	2
Being interrupted during intense work periods	1
Being underemployed	1
Struggling with ambiguous language	1
Feeling anxious about work changes & job security	14
Having to adapt to rapid working patterns & conditions	6
Losing or looking for work	4
Not used to work from home	4
Being at risk at workplace	3

	10
Missing face-to-face contact	10
Feeling anxious about contracting COVID-19	5
Feeling vulnerable	4
Not wanting to go out	1
Contrast - it doesn't really worry me. Because I'm fit and healthy	6
Finding time alone from people who share accommodation with	1
Having COVID-19	5
Having difficulties with new communications	4
Lack of verbal - non-verbal feedback	2
Learning new technologies	3
Having difficulties with face coverings	1
Masks because I don't like things touching my face	1
Recognising social cues	2
Experiencing loss & grief	1
At work	1
Relatives	25
GENERAL VIEWS	15
Being concerned about other family members and friends	6
Needing different type of support	5
Being concerned for the world impact of the pandemic	1
Climate change	4
Social cost inc. NHS	12
Feeling frustrated with restrictions & information about the virus	3
Avoiding media after increasing anxiety	1
Concerns due lack of clarity & precision of public health guidance	1
I just don't like being told what to do	9
Not trusting people to behave rationally	12
Hoping for lifting of lockdown at own pace	

Accessing key support services	6
Willingness to engage with previous routines	11
	30
STRENGTHS	25
Being prepared to deal with uncertainty	20
Having developed skills to cope with things changing	12
Having a pragmatic view of events and situations	7
Expecting disruption & uncertainty	7
Rehearsing and making plans	7
Having physical or mental exercise routines to cope with anxiety	4
Meditation and mindfulness	4
Physical exercise	6
Changing to interact with people & services online	6
Having special interests	3
Not having strong emotional reactions	2
Trusting reputable sources of information	22
Having a lifestyle amenable to self-isolation	15
Feeling lifestyle has not changed and still under control	10
Preferring a small social circle	5
Being used to interact remotely	3
Feeling safe with a stablished working or studying routine	3
Living without common social pressures	3
Working from home routinely	16
Enjoying a quieter pace of life during lockdown	10
Feeling more in control of own time and routine	7
Enjoying a quieter environment	7
Feeling less pressure to socialise	5
Having work to do at a measured pace	2
Thinking is a positive experience	

	12
Coping with mental or physical health issues	9
Struggling with anxiety & depression	4
Accessing support services during lockdown	3
Having to ask for help with groceries & medication	1
as long as the particular autistic person has good mental health, I think it's - it probably isn't that much different	1
I probably use smoking cannabis a little bit too much to cope at the moment.	1
I'm focusing on my physical tiredness rather than emotions	6
Following restrictions based on civil duty	31
VIEWS ON RESEARCH DURING COVID-19	10
BARRIERS	6
Accessing healthcare could be difficult during the pandemic in the context of a trial	4
Assuming everyone has time during the lockdown	2
Unwillingness to participate in research about anxiety	31
OPPORTUNITIES	29
Finding opportunities in study participation	23
Benefits from doing research online for autistic people	21
Preferring remote communication	15
Online & video	2
Telephone	6
Written comms	12
Not having to travel and experiencing issues with new environments	10
Contrast - Issues with remote communication	4
Not having non-verbal cues	4
Not willing to give information online	2
Prompt to interruption & fatigue	1
Preferences for face-to-face interaction	13
Willingness to participate in research is unrelated to COVID-19	13
Believing in research as a moral duty	

	1
Contrast - Overlapping research efforts	2
Having opportunities to access MH treatment	26
Thinking trial procedures should adapt	21
Thinking face-to-face research will carry risks & barriers to participation	12
Requiring face-to-face contact for some medical research - being selective	7
Expecting good & clear biosafety protocols in place	6
Unwilling to go to hospital, pharmacies, or other health institution	2
Preferring not to use masks or hand gel	12
Forcing research team to offer various communication options - inclusion	4
Providing consent & other data online	1
Preferring one-to-one contact rather than groups	