

## PEER REVIEW HISTORY

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### ARTICLE DETAILS

<b>TITLE (PROVISIONAL)</b>	Barriers to healthcare and self-reported adverse outcomes for autistic adults: A cross-sectional study.
<b>AUTHORS</b>	Doherty, Mary; Neilson, Stuart; O'Sullivan, Jane; Carravallah, Laura; Johnson, Mona; Cullen, Walter; Shaw, Sebastia

### VERSION 1 – REVIEW

<b>REVIEWER</b>	Whiteley, Paul University of Essex
<b>REVIEW RETURNED</b>	15-Sep-2021

<b>GENERAL COMMENTS</b>	<p>Thank you for the opportunity to review this manuscript. I found it to be an important topic which holds special importance to those with autism / who are autistic and their loved ones in light of continuing health inequalities attached to the label of autism or autism spectrum disorder (ASD).</p> <p>There are a few points which require clarification and/or further comment:</p> <ol style="list-style-type: none"><li>1. The report cites a cohort of 507 autistic people. Further breakdown of the results shown in Table 1 report that only 77% of the cohort had received a formal diagnosis of autism. Acknowledging that there are continuing barriers to the formal receipt of a diagnosis and a growth in the movement for self-identification / self-diagnosis of autism, the inclusion of nearly a third of participants without a formal diagnosis introduces some potentially significant sources of bias into the results. Not least because of the overlap of autistic 'symptoms' in various other diagnostic labels. Without trying to make too much additional work for the authors, I wonder if additional analyses could be undertaken to ascertain any differences in responses between those with a formal diagnosis of autism/ASD vs. those without. Such analyses, if comparable, would add significant weight to their inclusion of not-formally diagnosed participants.</li><li>2. Allied to point (1), little information is provided about participants other than their diagnostic status, gender, location and age (both at study and at diagnosis). They do however mention the involvement of 'anxiety' in their discussion as potentially being important to primary care communication. I wonder therefore if there are additional data that can be included about the comorbidity/co-occurrence profile of participants? Have they for example collected data on additional labels such as anxiety, depression, personality disorder(s) and ADHD which have all been over-represented in cases of autism and may contribute to the issues they describe? It may also be prudent to add some additional discussion on this issue in the later sections of the manuscript such that (a) 'autism pure' is not typical in autism (autism free from additional comorbid or co-occurring conditions),</li></ol>
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	<p>and (b) said comorbidity may also be a contributory variable to the health interaction inequalities that face many autistic people.</p> <p>3. I wonder if a hyperlink to the online survey would be appropriate to include. The authors do provide some information about the survey in the methods section of the manuscript but it would strengthen the paper for readers to be able to see the survey for themselves.</p> <p>There are a few minor corrections to address:</p> <p>Page 3: Line 11: "Our aim was to identify self-reported barriers to primary care [access] by autistic adults..."</p> <p>Page 6: Line 20: "... do not have intellectual disability and are likely to be undiagnosed". The suggestion that 'most autistic [adult] people' are likely to be undiagnosed is perhaps a stretch too far. As mentioned, there are significant barriers to diagnosis of adults but the existing data does not widely point to a bank of undiagnosed autistic people at present. Maybe a rethink of how this is worded could be in order.</p> <p>Page 6: Line 32: "Life expectancy is [potentially] reduced by 16-30 years...". Yes, the early mortality statistics are shocking but large-scale longitudinal studies on life expectancy in autism are still in their infancy.</p> <p>Page 8: Line 22: "... although the majority [of attendees] typically have low to moderate..."</p> <p>Page 9: Line 52: "We intend to present our qualitative results elsewhere". I would ask authors to perhaps consider including them in this submission. They would no doubt provide an important accompaniment to the existing manuscript.</p> <p>Table 2 and other tables: Perhaps it is as a consequence of the formatting but could authors provide a key to the p-values presented with one or more asterix.</p> <p>Page 14: Line 20: "... stimming elicited negative reactions for other patients..." Forgive me if I missed it but further definition of 'stimming behaviour' is required in the text. So, I can understand that authors may not have wished to list the defining criteria of autism/ASD but some discussion on repetitive, restricted behaviours (RRBs) which equate to stimming is perhaps required if they are to introduce it into the results of their study.</p> <p>Page 16: Line 33: "... or had a "sensory box" available". Similar to the previous comment on stimming, the reader might need more explanation on this concept and how it relates to the presentation of autism/ASD.</p> <p>Page 18: Line 13: "This increased the likelihood of genuine responses being received". The authors rightly emphasise how community participation is a core feature of their study. This is especially welcome in the climate of autistic people contributing (leading) research which affects them. I would however urge some caution in statements suggesting that participation naturally leads to more 'genuine responses' without supporting evidence to accompany it. The implication being that previous research that was not autistic-led is somehow in error because of their lack of community participation.</p> <p>Page 18: Line 31: "... excluded those with reduced ability to self-report". Authors do well to highlight this limitation of their study. I would also perhaps suggest further discussion about the 'heterogeneity' of the autism spectrum earlier in the manuscript, such that those for example with profound autism and accompanying learning disability may be at even more risk of health inequality including appropriate contact with primary healthcare givers.</p>
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	Page 20: Line 53: Just a small point: could authors include the ethical approval number or details provided by their ethics committee and any study registration details (if applicable). Finally, I would congratulate the study authors on their work and manuscript. This is an important topic with real-world relevance to improving the lives of many autistic people.
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<b>REVIEWER</b>	Arnold, Samuel UNSW
<b>REVIEW RETURNED</b>	30-Sep-2021

<b>GENERAL COMMENTS</b>	<p>Thank you for the opportunity to review this paper exploring barriers to healthcare for autistic adults. This is an important area of work and it is interesting to read of developments in other countries. I also think the wide variety of barriers identified and the fact the research didn't rely on existing measures alone was beneficial. My suggestions for potential improvements to the manuscript are as follows:</p> <p>Was mention of ethics approval overlooked, or did I miss it?</p> <p>Given the significant international spread of the sample, should more commentary and potentially analysis or sensitivity analysis of differences based on the person's country of origin be made? The jurisdictional differences between the health systems would seem likely to make some difference in the results.</p> <p>Should the supplementary materials be mentioned in discussing the survey tool developed? Is the entire or only part of the tool presented in the supplementary materials? Is there a rationale for what goes in the supplementary materials table as opposed to tables in the main text?</p> <p>Would the non-autistic participants be better described as a comparison or non-autistic rather than a control group?</p> <p>I think the note on Figure 1 could be slightly reworded, is it suggesting that all comparisons were significant at <math>p &lt; .001</math> ?</p> <p>I find the commentary and results regards "who did not attend" a bit hard to follow. What was the criteria for total non-engagement?</p> <p>I find some of the assertions made in the discussion, such as "Our study suggests a need for personalised healthcare access plans" and "autistic help-seeking may occur later in the natural course of an illness" were slightly removed from the data gathered. Although I agree with these assertions, I wonder if the wording needs to be more careful in making claims as to the benefits and scaffolding of evidence behind these assertions.</p> <p>I also wasn't entirely sure of the concluding remarks. Yes the double empathy problem is very important, though a focus on communication needs alone in the conclusion seems to underplay the variety of barriers identified which I feel is a strength of this work.</p>
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<b>REVIEWER</b>	Lewis, Laura University of Vermont College of Nursing and Health Sciences
<b>REVIEW RETURNED</b>	19-Oct-20

**GENERAL COMMENTS**

Thank you for the chance to review this article. The participatory approach is a significant strength of this study. In addition, while previous studies have similarly explored barriers to care for autistic adults, this study adds a unique and important contribution in connecting how these barriers are related to adverse health impacts among a population who is at increased risk of morbidity and mortality. See specific feedback below.

**Introduction:**

This section concisely and succinctly captures the current state of the literature on access to care for autistic adults. Authors build a strong case for the relevance and importance of this study.

**Methods:**

The authors include a thorough description of the conception of the study, which is critical in understanding the incorporation of the autistic voice in the study design. This is a significant strength of the study. A few points that I would like to see clarified:

- You mention that “MD reviewed the 75 responses and grouped these under broad themes,” and these themes guided the development of the survey items. More information would be helpful here to understand how you arrived at these themes. E.g. was a specific method used for thematic analysis? I know that you later mention that qualitative results are shared elsewhere, but it would seem this is referring to qualitative analysis of the survey responses, not the development of the survey itself. It is important to understand how you arrived at these items.
- Instead of the term “control group,” I would recommend the term “non-autistic comparison group.” This would more accurately (and potentially inclusively) recognize that this group was not randomly assigned, but was instead selected for the purposes of comparison to the autistic group.
- You mention that the study was “conducted by an autistic-led research team including autistic doctors... Nine autistic individuals assisted with developing and refining the survey into its final form.” Can you clarify, are these nine individuals in addition to the research team, or the total number of autistic individuals involved at any point of the study (including both the authors and others)?
- You mention that the research team included “autistic doctors.” Can you please clarify: were these autistic physicians, autistic providers with different backgrounds (e.g. PA, NP, etc.), or autistics who hold doctoral degrees in various fields?

**Results:**

Results are compelling. Many of these points are consistent with existing literature, but the study adds new information about the specific details about autistic needs in the primary care setting and links those to self-reported adverse health outcomes. Tables and figures are clear and easy to follow.

- There are areas where the reported statistics in the narrative are redundant from the table. I would suggest removing the parenthetical summary of statistics for those that are included in the (non-supplemental) tables/figures.
- For me, Figure 2 is the most exciting piece that you have added to the literature. It would be very helpful to see some additional information on the specific difficulties expressed that were correlated to the adverse outcomes. That is, were there any significant relationships between any of the individual barriers to care you identified with any of the specific adverse outcomes?

	<p>(E.g. does “not feeling understood” correlate to “untreated mental health”? Or, which barriers most significantly correlated with “untreated life threat”?) This is my biggest concern about this study as it stands. It seems like there was a detailed analysis of each of these barriers but only a general binary analysis of how “difficulties” impacted adverse health outcomes. It would be helpful to tease this out more to better understand these relationships.</p> <ul style="list-style-type: none"> <li>• Very minor detail, but the formatting of reporting – e.g. spaces between percentages, how stats are separated within parentheses, etc. – differs within this section. I would make sure these are consistent for ease of reading.</li> </ul> <p>Discussion: Findings are interpreted in light of other recent research. Figure 3 provides an insightful summary of strategies supported by the findings. Concluding statement of the manuscript and abstract (“Adjustments for communication needs are as necessary...”) is a strong one.</p> <ul style="list-style-type: none"> <li>• The mention of the Double Empathy Problem in the “Conclusions” section should be raised earlier in this section. It appears here without much context, and reads as a new idea rather than a summary of ideas presented previously.</li> </ul>
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### VERSION 1 – AUTHOR RESPONSE

Dear Dr Arikainen,

Thank you for the favourable and thorough review of our paper. Please see our below replies to all reviewer comments. We hope you will agree that the changes have strengthened the manuscript.

All the best,  
Mary

Please ensure that your abstract is formatted according to our Instructions for Authors	Thank you and our apologies for this oversight. We have now amended our abstract accordingly.
Please revise the ‘Strengths and limitations’ section of your manuscript (after the abstract). This section should contain up to five short bullet points, no longer than one sentence each, that relate specifically to the methods. The results of the study should not be summarised here.	Thank you. We have now amended this accordingly.
Please include a copy of the full questionnaire as a Supplemental Information file, or include a citation if it has been published elsewhere.	Thank you. We have now included a full copy of the survey as a supplemental file.
The report cites a cohort of 507 autistic people. Further breakdown of the results shown in Table 1 report that only 77% of the cohort had received a formal diagnosis of autism. Acknowledging that there are continuing barriers to the formal receipt of a diagnosis and a growth in the movement for self-identification /	Thank you for this interesting point. We did undertake such analyses, and this is already reported within our results as follows:  “There were no significant differences in difficulty attending, barriers experienced or

<p>self-diagnosis of autism, the inclusion of nearly a third of participants without a formal diagnosis introduces some potentially significant sources of bias into the results. Not least because of the overlap of autistic 'symptoms' in various other diagnostic labels. Without trying to make too much additional work for the authors, I wonder if additional analyses could be undertaken to ascertain any differences in responses between those with a formal diagnosis of autism/ASD vs. those without. Such analyses, if comparable, would add significant weight to their inclusion of not-formally diagnosed participants.</p>	<p>adverse outcomes between formally diagnosed and self-identified autistic respondents.”</p> <p>We have now added a mention of this into our conclusions too, as we agree that it is one of the more interesting findings from our study and will likely be surprising to many readers. We have also added specific mention of this into the abstract.</p>
<p>Allied to point (1), little information is provided about participants other than their diagnostic status, gender, location and age (both at study and at diagnosis). They do however mention the involvement of 'anxiety' in their discussion as potentially being important to primary care communication. I wonder therefore if there are additional data that can be included about the comorbidity/co-occurrence profile of participants? Have they for example collected data on additional labels such as anxiety, depression, personality disorder(s) and ADHD which have all been over-represented in cases of autism and may contribute to the issues they describe? It may also be prudent to add some additional discussion on this issue in the later sections of the manuscript such that (a) 'autism pure' is not typical in autism (autism free from additional comorbid or co-occurring conditions), and (b) said comorbidity may also be a contributory variable to the health interaction inequalities that face many autistic people.</p>	<p>Thank you. We are afraid that we do not have data available on this to include within the report.</p>
<p>I wonder if a hyperlink to the online survey would be appropriate to include. The authors do provide some information about the survey in the methods section of the manuscript but it would strengthen the paper for readers to be able to see the survey for themselves.</p>	<p>Thank you. We have now included the survey as a supplementary file.</p>
<p>Page 3: Line 11: "Our aim was to identify self-reported barriers to primary care [access] by autistic adults..."</p>	<p>Thank you. We have amended this accordingly.</p>
<p>Page 6: Line 20: "... do not have intellectual disability and are likely to be undiagnosed". The suggestion that 'most autistic [adult] people' are likely to be undiagnosed is perhaps a stretch too far. As mentioned, there are significant barriers to diagnosis of adults but the existing data does not widely point to a bank of undiagnosed autistic people at present. Maybe a rethink of how this is worded could be in order.</p>	<p>Thank you for raising this interesting comment regarding our statement that most autistic adults do not have intellectual disability and are likely to be undiagnosed. This does indeed come from expert consensus regarding adult autism diagnosis from the UK Royal College of Psychiatrists ("The psychiatric management of autism in adults (CR228)").</p>
<p>Page 6: Line 32: "Life expectancy is [potentially] reduced by 16-30 years...". Yes, the early mortality statistics are shocking but large-scale longitudinal studies on life expectancy in autism are still in their infancy.</p>	<p>Thank you. We have amended this accordingly.</p>
<p>Page 8: Line 22: "... although the majority [of attendees] typically have low to moderate..."</p>	<p>Thank you. We have amended this accordingly.</p>

<p>Page 9: Line 52: "We intend to present out qualitative results elsewhere". I would ask authors to perhaps consider including them in this submission. They would no doubt provide an important accompaniment to the existing manuscript.</p>	<p>Thank you. This was discussed within our team, and it was agreed to be inherently reductionist to attempt to include these data in this submission. There is currently a substantial amount of qualitative data, justifying formal analysis from a subjectivist approach and subsequent presentation in their own right. We do hope you can understand our perspective here.</p>
<p>Table 2 and other tables: Perhaps it is as a consequence of the formatting but could authors provide a key to the p-values presented with one or more asterix.</p>	<p>Thank you. We have simplified all tables to make this clearer.</p>
<p>Page 14: Line 20: "... stimming elicited negative reactions for other patients..." Forgive me if I missed it but further definition of 'stimming behaviour' is required in the text. So, I can understand that authors may not have wished to list the defining criteria of autism/ASD but some discussion on repetitive, restricted behaviours (RRBs) which equate to stimming is perhaps required if they are to introduce it into the results of their study.</p>	<p>Thank you. We have amended this accordingly. We have added an explanation of stimming to Table S2 where the data relating to stimming are presented rather than in the text.</p>
<p>Page 16: Line 33: "... or had a "sensory box" available". Similar to the previous comment on stimming, the reader might need more explanation on this concept and how it relates to the presentation of autism/ASD.</p>	<p>Thank you. We have amended this accordingly. We have added a description of a sensory box to Table S5 where the data relating to a sensory box are presented rather than in the text.</p>
<p>Page 18: Line 13: "This increased the likelihood of genuine responses being received". The authors rightly emphasise how community participation is a core feature of their study. This is especially welcome in the climate of autistic people contributing (leading) research which affects them. I would however urge some caution in statements suggesting that participation naturally leads to more 'genuine responses' without supporting evidence to accompany it. The implication being that previous research that was not autistic-led is somehow in error because of their lack of community participation.</p>	<p>Thank you for highlighting this. We have removed this statement.</p>
<p>Page 18: Line 31: "... excluded those with reduced ability to self-report". Authors do well to highlight this limitation of their study. I would also perhaps suggest further discussion about the 'heterogeneity' of the autism spectrum earlier in the manuscript, such that those for example with profound autism and accompanying learning disability may be at even more risk of health inequality including appropriate contact with primary healthcare givers.</p>	<p>Thank you for highlighting this. We have added a comment on heterogeneity to the introduction. We do not have data on support needs and, therefore, linking higher support needs with higher risk of health inequalities would be purely speculative on our part. We would also be keen to avoid using terms like "profound autism" in our contributions to the literature, as this may be considered offensive to our community.</p>
<p>Page 20: Line 53: Just a small point: could authors include the ethical approval number or details provided by their ethics committee and any study registration details (if applicable).</p>	<p>We have now included mention of ethical scrutiny and approval in our methods section.</p>
<p>Finally, I would congratulate the study authors on their work and manuscript. This is an</p>	<p>Thank you. We are so glad that you agree on the real-world impact this work will have for autistic patients. Given our insider status, this</p>

important topic with real-world relevance to improving the lives of many autistic people.	has been a project of passion and we are so humbled by your positive response.
Was mention of ethics approval overlooked, or did I miss it?	Thank you. We have now included mention of ethical scrutiny and approval in our methods section.
Given the significant international spread of the sample, should more commentary and potentially analysis or sensitivity analysis of differences based on the person's country of origin be made? The jurisdictional differences between the health systems would seem likely to make some difference in the results.	Thank you for raising this important consideration. This was the topic of significant discussion amongst the team when analysing our data. Following some preliminary analysis attempts, it became clear that numbers would be too small within countries to break down our analyses in this way.
Should the supplementary materials be mentioned in discussing the survey tool developed? Is the entire or only part of the tool presented in the supplementary materials? Is there a rationale for what goes in the supplementary materials table as opposed to tables in the main text?	Thank you. We have now included the survey as a supplementary file. In terms of supplementary table choices, we have opted to include wider data there so that the paper itself does not become too overloaded with these and potentially off putting for readers. The choice of which data were based upon our team's opinions on which data were most relevant/important to the central message of the manuscript.
Would the non-autistic participants be better described as a comparison or non-autistic rather than a control group?	Thank you for highlighting this. We completely agree and have now amended accordingly.
I think the note on Figure 1 could be slightly reworded, is it suggesting that all comparisons were significant at $p < .001$ ?	Thank you for this observation. This highlights the key findings of our study, as all comparisons in Figure 1 were in fact significant at $p < .001$
I find the commentary and results regards "who did not attend" a bit hard to follow. What was the criteria for total non-engagement?	Thank you. We have now added more clarification on this.
I find some of the assertions made in the discussion, such as "Our study suggests a need for personalised healthcare access plans" and "autistic help-seeking may occur later in the natural course of an illness" were slightly removed from the data gathered. Although I agree with these assertions, I wonder if the wording needs to be more careful in making claims as to the benefits and scaffolding of evidence behind these assertions.	Thank you. We have altered the wording as suggested.
I also wasn't entirely sure of the concluding remarks. Yes the double empathy problem is very important, though a focus on communication needs alone in the conclusion seems to underplay the variety of barriers identified which I feel is a strength of this work.	Thank you for this important comment. We completely agree. We have now removed the mention of the double empathy problem here and have deepened the discussion around the variety of barriers identified.
Thank you for the chance to review this article. The participatory approach is a significant strength of this study. In addition, while previous studies have similarly explored barriers to care for autistic adults, this study adds a unique and important contribution in connecting how these barriers are related to adverse health impacts among a population who is at increased risk of morbidity and mortality.	Thank you. We are so pleased to hear that you see the value in our study.
Introduction: This section concisely and succinctly captures the current state of the literature on access to care for autistic adults. Authors build a strong	Thank you.



case for the relevance and importance of this study.	
The authors include a thorough description of the conception of the study, which is critical in understanding the incorporation of the autistic voice in the study design. This is a significant strength of the study.	Thank you.
You mention that "MD reviewed the 75 responses and grouped these under broad themes," and these themes guided the development of the survey items. More information would be helpful here to understand how you arrived at these themes. E.g. was a specific method used for thematic analysis? I know that you later mention that qualitative results are shared elsewhere, but it would seem this is referring to qualitative analysis of the survey responses, not the development of the survey itself. It is important to understand how you arrived at these items.	Thank you for this suggestion. This (separate) pilot study is discussed here loosely to provide some insight into the background work that eventually led to this survey study. However, we have opted to not include too much detail here on that study, as it is distinct to the survey reported here – these were not referring to the qualitative results from the survey reported here. We hope that makes sense.
Instead of the term "control group," I would recommend the term "non-autistic comparison group." This would more accurately (and potentially inclusively) recognize that this group was not randomly assigned, but was instead selected for the purposes of comparison to the autistic group.	Thank you for highlighting this. We completely agree and have now amended accordingly.
You mention that the study was "conducted by an autistic-led research team including autistic doctors... Nine autistic individuals assisted with developing and refining the survey into its final form." Can you clarify, are these nine individuals in addition to the research team, or the total number of autistic individuals involved at any point of the study (including both the authors and others)?	These were autistic community members, in addition to the study authors. This has been clarified in the text.
You mention that the research team included "autistic doctors." Can you please clarify: were these autistic physicians, autistic providers with different backgrounds (e.g. PA, NP, etc.), or autistics who hold doctoral degrees in various fields?	Thank you. This is a challenging one to phrase succinctly and differs based on country of origin. Within the UK, for example, a physician refers to a specific sub-type of doctor (with a medical degree), but would not include surgeons or anaesthetists, for example. In the context of this study, we are all doctors in the sense that we have medical degrees. We have now made this clearer within the manuscript.
Results are compelling. Many of these points are consistent with existing literature, but the study adds new information about the specific details about autistic needs in the primary care setting and links those to self-reported adverse health outcomes. Tables and figures are clear and easy to follow.	Thank you. We are so pleased to hear this.
There are areas where the reported statistics in the narrative are redundant from the table. I would suggest removing the parenthetical summary of statistics for those that are included in the (non-supplemental) tables/figures.	Thank you. We have amended the manuscript accordingly.
For me, Figure 2 is the most exciting piece that you have added to the literature. It would be very helpful to see some additional information	Thank you so much for this strong suggestion, which we agree has greatly strengthened our findings. We have conducted these analyses

on the specific difficulties expressed that were correlated to the adverse outcomes. That is, were there any significant relationships between any of the individual barriers to care you identified with any of the specific adverse outcomes? (E.g. does "not feeling understood" correlate to "untreated mental health"? Or, which barriers most significantly correlated with "untreated life threat"?) This is my biggest concern about this study as it stands. It seems like there was a detailed analysis of each of these barriers but only a general binary analysis of how "difficulties" impacted adverse health outcomes. It would be helpful to tease this out more to better understand these relationships.	and added a new section accordingly to the end of our results. There are indeed some very interesting findings here.
Very minor detail, but the formatting of reporting – e.g. spaces between percentages, how stats are separated within parentheses, etc. – differs within this section. I would make sure these are consistent for ease of reading.	Thank you. This has been amended.
Findings are interpreted in light of other recent research. Figure 3 provides an insightful summary of strategies supported by the findings. Concluding statement of the manuscript and abstract ("Adjustments for communication needs are as necessary...") is a strong one.	Thank you.
The mention of the Double Empathy Problem in the "Conclusions" section should be raised earlier in this section. It appears here without much context, and reads as a new idea rather than a summary of ideas presented previously.	Thank you. We have now removed the mention of the double empathy problem here.

### VERSION 2 – REVIEW

<b>REVIEWER</b>	Arnold, Samuel UNSW
<b>REVIEW RETURNED</b>	17-Nov-20

<b>GENERAL COMMENTS</b>	<p>Thank you for the opportunity to review a revised version of this manuscript. The majority of my previous suggestions have been addressed, though I am still concerned regards the impact of reporting on data coming from multiple countries in a singular manner given the differences in healthcare systems in different jurisdictions. Perhaps even the abstract and elsewhere should acknowledge the primary countries where data came from. I still question if sensitivity analysis at least could be conducted across some findings, perhaps by collapsing north america and 'other' in comparison to UK and Ireland participants if necessary?</p> <p>I still feel some additional scaffolding as to the interpretations is needed linking them to the findings, particularly in relation to the central interpretation in Figure 3. Are you able to provide further justification how the suggestions in Figure 3 link to specific findings or were arrived at? From the data do we know that the</p>
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	<p>vast majority of autistic people would want an individualised access plan? Can you explain what this individualised access plan would be?</p> <p>Perhaps just a difference in writing styles, though I find the new paragraph beginning “Difficulty using the telephone to book an appointment” a bit repetitive and wonder if there is a more streamlined and engaging way to report on key findings identified here.</p>
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<b>REVIEWER</b>	Lewis, Laura University of Vermont College of Nursing and Health Sciences
<b>REVIEW RETURNED</b>	15-Nov-2021

<b>GENERAL COMMENTS</b>	Thank you for this opportunity to review the revised version of this article. Authors have addressed previous recommendations and added additional information that make their findings even more compelling. The manuscript is well written, methodologically strong (particularly the use of participatory action approach), and contribute new knowledge to understanding barriers to primary care access for autistic adults.
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#### VERSION 2 – AUTHOR RESPONSE

Dear Dr Arikainen,

Thank you for the favourable review of our paper. We must admit some degree of difficulty interpreting some of reviewer 2's comments, some of which are already reflected in the manuscript. Please see our below replies to all reviewer comments.

All the best,  
Mary

Thank you for this opportunity to review the revised version of this article. Authors have addressed previous recommendations and added additional information that make their findings even more compelling.	Thank you.
The manuscript is well written, methodologically strong (particularly the use of participatory action approach), and contribute new knowledge to understanding barriers to primary care access for autistic adults.	Thank you.
Thank you for the opportunity to review a revised version of this manuscript. The majority of my previous suggestions have been addressed, though I am still concerned regards the impact of reporting on data coming from multiple countries in a singular manner given the differences in healthcare systems in different jurisdictions. Perhaps even the abstract and elsewhere should acknowledge the primary countries where data came from.	This is already provided in Table 1.
I still question if sensitivity analysis at least could be conducted across some findings, perhaps by collapsing north america and 'other' in comparison to UK and Ireland participants if necessary?	We have now undertaken additional geographic testing for the barriers to access data and adverse outcomes data for autistic respondents. We have completed this for 'UK' vs 'elsewhere in the world' and have reported this accordingly.

<p>I still feel some additional scaffolding as to the interpretations is needed linking them to the findings, particularly in relation to the central interpretation in Figure 3. Are you able to provide further justification how the suggestions in Figure 3 link to specific findings or were arrived at? From the data do we know that the vast majority of autistic people would want an individualised access plan? Can you explain what this individualised access plan would be?</p>	<p>We have added some further explanation.</p>
<p>Perhaps just a difference in writing styles, though I find the new paragraph beginning “Difficulty using the telephone to book an appointment” a bit repetitive and wonder if there is a more streamlined and engaging way to report on key findings identified here.</p>	<p>We gave this a great deal of thought and feel the current prose is indeed the best way to describe these findings. We are also re-assured that the current wording seemed to please reviewer 3, who was the reviewer to request that this section be added.</p>