

# **Establishing Priorities for Improving Data Collection and Measurement of Mental Health and Wellbeing of Adolescents with Special Educational Needs Within Non-mainstream Schools: Protocol for a Delphi Study**

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# Establishing Priorities for Improving Data Collection and Measurement of Mental Health and Wellbeing of Adolescents with Special Educational Needs Within Non-mainstream Schools: Protocol for a Delphi Study

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## Abstract

**Background:** There are more than 1.5 million children and young people (CYP) in England with special educational needs (SEN), with over 160,000 young people in the UK attending a special school or alternative provision (AP) setting. Young people with SEN have been found to be at risk for poorer mental health and wellbeing than non-SEN peers. However, there are a range of both school-related and research challenges associated with identifying difficulties in a timely manner.

**Objective:** The main objective of this Delphi study is to determine a list of stakeholder priorities for improving school-based measurement of mental health and wellbeing among young people with special educational needs, at an aggregated level, within special school/AP settings. A secondary objective is to inform the future expanded rollout of school-based wellbeing surveys, such as the #BeeWell programme, to improve engagement of special schools/AP settings and survey response rates among CYP with SEN.

**Methods:** A mixed-methods Delphi study will be conducted including a scoping review and preliminary focus groups with school staff and researchers to establish key issues. This will be followed by a 2-round Delphi survey, to determine a list of stakeholder priorities for improving the measurement of mental health and wellbeing at an aggregate level within special schools and AP settings. A final stakeholder workshop will be held to discuss findings. A list of recommendations will be drafted as a report for special schools/AP settings.

**Results:** The study has received ethical approval from UCL REC. The stage 1 scoping review has commenced. Recruitment for focus groups will begin in spring 2024. The first round of the Delphi survey will commence in autumn 2024, and the second round of the Delphi survey in early 2025. The final workshop will commence in spring 2025.

**Conclusions:** There is a need for clear recommendations for special schools/AP settings on priorities for improving the measurement of mental health and wellbeing problems among young people with SEN. There is also a need for recommendations to researchers implementing school-based wellbeing surveys, including the #BeeWell programme, to enable them to improve their engagement of special schools/AP settings and ensure surveys are accessible. Clinical Trial: N/A

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## Original Manuscript

# Establishing Priorities for Improving Data Collection and Measurement of Mental Health and Wellbeing of Adolescents with Special Educational Needs Within Non-mainstream Schools: Protocol for a Delphi Study

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## Abstract

### Background

There are more than 1.5 million children and young people (CYP) in England with special educational needs (SEN), with over 160,000 young people in the UK attending a special school or alternative provision (AP) setting. Young people with SEN have been found to be at risk for poorer mental health and wellbeing than non-SEN peers. However, there are a range of both school-related and research challenges associated with identifying difficulties in a timely manner.

### Objectives

The main objective of this Delphi study is to determine a list of stakeholder priorities for improving school-based measurement of mental health and wellbeing among young people with special educational needs, at an aggregated level, within secondary special school/AP settings. A secondary objective is to inform the implementation of school-based wellbeing surveys, to improve engagement of special schools/AP settings and survey response rates among CYP with SEN.

### Methods

A mixed-methods Delphi study will be conducted including a scoping review and preliminary focus groups with school staff and researchers to establish key issues. This will be followed by a 2-round Delphi survey, to determine a list of stakeholder priorities for improving the measurement of mental health and wellbeing at an aggregate level within special schools and AP settings. A final stakeholder workshop will be held to discuss findings. A list of recommendations will be drafted as a report for special schools/AP settings.

### Results

The study has received ethical approval from UCL REC. The stage 1 scoping review has commenced. Recruitment for focus groups will begin in Autumn 2024. The first round of the Delphi survey will commence in early 2025, and the second round of the Delphi survey in Spring 2025. The final workshop will commence in mid-2025 with final results expected in late-2025.

### Conclusions

There is a need for clear recommendations for special schools/AP settings on priorities for improving

the measurement of mental health and wellbeing problems among young people with SEN. There is also a need for recommendations to researchers implementing school-based wellbeing surveys, including the #BeeWell programme, to enable them to improve their engagement of special schools/AP settings and ensure surveys are accessible.

## Keywords

Special educational needs; special schools; alternative provision; mental health; wellbeing; school-based measurement

## Introduction

### Background

There are over 1.5 million children and young people in England with special educational needs (SEN) [1]. SEN covers a range of needs including speech, language, and communication needs, learning disabilities, autistic spectrum disorder (ASD), attention deficit hyperactivity disorder (ADHD) and social, emotional, and mental health needs [1].

There are high levels of co-occurrence between SEN conditions which make it helpful to consider 'special educational needs' as an umbrella term. For example, ADHD has been found to co-occur with conditions including oppositional defiant disorder, conduct disorder, autism, anxiety, and co-ordination problems [2,3]. Likewise, autism has been found to co-occur with anxiety disorders, disruptive, impulse-control, and conduct disorders and depressive disorders [3].

Young people (adolescents aged 11-18) with SEN have been found to be at an increased risk of mental health problems [4], to have lower levels of wellbeing than children without SEN [5,6], to experience a more difficult transition to secondary school [7,8], and be more likely to experience bullying [9].

Many young people with SEN attend special schools or alternative provision (AP) settings, which are non-mainstream schools which cater to different needs of young people. Special schools are those with specific educational provision for young people with special educational needs or disabilities, while AP settings, which includes Pupil Referral Units (PRUs), are education settings for children and young people who are unable to attend a mainstream school, for reasons such as being permanently excluded or illness which prevents them from being educated in a mainstream setting. In 2022-23, there were nearly 150,000 children with SEN in state-funded special schools and 4,000 in non-maintained special schools [10]. There were an additional 13,000 young people with SEN in state-funded AP settings/PRUs [1].

Most schools in the UK are taking steps to identify mental health and wellbeing needs of their pupils. A report by the Department for Education (DfE) found that 73% of special schools and 77% of AP settings carried out universal data collection on mental health [10]. However, large-scale school-based mental health and wellbeing surveys have been found to have barriers to implementation relating to competing school priorities, a lack of time and resources, and schools feeling overwhelmed by the number of competing surveys [11]. Recent research recommended that a programme for school-based identification of mental health and wellbeing in mainstream primary school settings should: aim to identify children with the full range of severity of difficulties; have opt-out parental consent; educate staff and children; and provide a link between identified need and available support [12].

One school-based mental health and wellbeing survey, the #BeeWell programme, found the administration of school-based surveys more challenging in special schools/alternative provision settings. This was considered to be due to a high turnover of pupils which made it difficult for schools to get necessary data sharing agreements, consent, and resources in place in the timeframe [22]. Likewise, due to smaller pupil numbers and lower response rates, which hindered the

attainment of minimum data reporting thresholds, detailed aggregated wellbeing reports could not always be shared with special schools/APs [22]. This challenge is not unique to #BeeWell; other studies have had challenges with low numbers of young people with SEN in existing datasets [5] or did not collect data on SEN [23].

While there are general challenges with school-based measurement of mental health and wellbeing at an aggregate level, there are also challenges specific to identifying the mental health and wellbeing needs of CYP with SEN. One such challenge is in being able to distinguish between the mental health difficulty and characteristics of the special educational need [13]. Hence, early warning signs can be missed, leading to late identification of issues [15]. Young people in AP settings may have their mental health needs viewed as behavioural issues and there may be an over-focus on 'challenging' behaviours rather than looking at the underlying emotional causes of behaviours [14,16].

Some children with SEN, particularly those with speech, language, and communication needs, may have difficulties in expressing their distress or describing negative events such as bullying [17]. There may be difficulties relating to staff training and knowledge about mental health and wellbeing [13,16]. Young people with SEN may need help from school staff in completing surveys, which can be labour-intensive [18].

Additionally, there is a lack of consensus on the most appropriate mental health and wellbeing measures for young people with SEN [19], particularly for those with intellectual or learning disabilities. A COSMIN systematic review of wellbeing measures for young people with intellectual disabilities found no measures that they could recommend for use [20]. However, more recently, an intellectual disability version of the Short Warwick–Edinburgh Mental Wellbeing Scale (ID-SWEMWBS) and Kidscreen10 (ID-Kidscreen10) showed good psychometric properties [21].

## Aim and Objectives

This study aims to identify the challenges associated with conducting school-based surveys to measure the mental health and wellbeing of young people with SEN in secondary special schools/AP settings. It aims to reach consensus among researchers and special school/AP staff, on what the priorities are for improving data collection and measurement of mental health and wellbeing in these settings.

Findings will be used to draft guidelines for special schools/AP settings about improving the measurement of mental health and wellbeing issues among young people with SEN. Findings will also be used to make recommendations for school-based surveys to improve the engagement and response rates of special schools/AP settings in the future.

## Methods

### Ethics approval

This study will follow UCL's Code of Conduct for Research. Ethics approval for this study was granted by University College London REC, project number 26477/002. This research project is allied to the #BeeWell programme, which was reviewed and approved by The University of Manchester's Research Ethics Committee (reference 2021-11133-18179). The #BeeWell programme introduced a youth-developed wellbeing survey to 187 secondary schools, including special schools and AP settings, across Greater Manchester in 2021. In Autumn 2023, #BeeWell began its roll-out in Hampshire, the Isle of Wight, Portsmouth, and Southampton, with plans to extend further after 2024. There are three versions of the #BeeWell survey which include questions across the domains and drivers of wellbeing; a full version, a short version and a widget symbol version which was developed in consultation with young people in special school/AP settings.



## ***Informed consent***

Participants will be provided with a detailed information sheet and privacy notice before participation in the research. For the focus groups, the consent form will be hosted on MS forms, the link to which will be sent along with the participant information sheet ahead of the focus groups. Participants will be informed that due to the nature of focus groups, full anonymity cannot be guaranteed for this stage of the Delphi study.

For the Delphi survey rounds, participant information and privacy notices will be explained within the online survey form, which will be hosted on Qualtrics. Consent for completing the surveys 1 and 2 will be obtained in the online surveys.

## ***Privacy and confidentiality***

Participants will receive a privacy notice prior to involvement, which will state how their data will be collected, used, and stored. Participants names' and identifying information such as their school, will not be associated with their responses.

Due to the nature of focus groups, full confidentiality of responses cannot be guaranteed. However, participants will be informed about this in the participant information sheet and will be reminded at the start of the discussion, to not discuss the focus group with others.

Individual schools or respondents will not be named in any outputs and findings will be aggregated. It will not be possible to identify any individual survey responses within papers or reports.

## ***Compensation details***

School staff who participate in the focus groups will receive a £25 voucher for participation.

## **Design**

This Delphi study will have a mixed-methods design including a scoping review and preliminary qualitative focus groups with secondary special school/AP staff and researchers in the field of mental health and SEN, to establish key issues relating to measurement of mental health and wellbeing problems in SEN settings. This will be followed by a 2-round Delphi survey in Spring 2025, to determine a list of the most important stakeholder priorities for improving the measurement of mental health and wellbeing at an aggregate level within these settings. A final follow-up workshop will be held in mid-2025 to discuss and reflect on the findings and provide additional information and context to the priority guidelines. It will be used to establish a list of the top 10 priorities if the final list from the Delphi survey rounds is long.

The Delphi method was chosen as a useful method for topics where there is a large amount of experiential knowledge among different expert groups and has frequently been used in mental health research [24,25,26]. The Delphi method was used recently in a similar study on stakeholder priorities for developing a programme for mainstream school-based identification of mental health problems in mainstream primary schools [12].

It will also allow an agreement to be reached across different stakeholders (e.g., special school/AP staff and researchers in different UK regions), about the priorities for addressing commonly faced issues in identifying mental health and wellbeing of young people with SEN at an aggregate level, which will be applicable to a wider range of special schools/AP settings. The Delphi method aims to make practical recommendations which can be implemented, and as the process is iterative, it allows participants to reflect on and revise previous responses, which is not possible in interviews or focus groups [24,27].

## Stakeholders and Setting

### *Participants & recruitment – focus groups*

Purposive sampling will be used to recruit participants for the focus groups, which is a commonly used qualitative sampling technique to capture those who are especially knowledgeable about an area of interest [28], in this case school-based measurement of mental health and wellbeing. There will be between 2-3 focus groups with between 5-8 participants in each: a minimum of one focus group with school staff, and one focus group with researchers.

Participants for the 'school staff' focus groups will be those working with adolescents with SEN in special schools/AP settings (including PRUs). These participants will be recruited from the sample of 38 special schools/AP settings who are currently taking part or have previously taken part in the #BeeWell study in Greater Manchester (GM), Hampshire, Isle of Wight and Portsmouth and Southampton (HIPS). A smaller number of 5-10 schools will be contacted in the first instance, and further schools contacted based on responses and the need for additional participants. Targeted recruitment will be considered if there is a lack of representation from a particular school setting (for example, PRUs).

Initial contact to recruit school staff for focus groups will be made to school staff via an e-mail sent by the #BeeWell project managers of GM and HIPS. Individuals who are interested in participating will be encouraged to contact the researcher via e-mail.

Participants for the 'researchers' focus group will be those working in the field of SEN and mental health or on school-based mental health data collection (including researchers who have worked on the #BeeWell programme but who are not associated with this study), and educational psychologists. These participants will be identified through purposive sampling, including from relevant university research groups such as UCL's Centre for Research in Autism and Education or the University of Warwick's Centre for Research in Intellectual and Developmental Disabilities.

Focus groups will aim for a maximum diversity of participants from different school settings, different regions, and different professional backgrounds.

### *Participants & recruitment – Delphi survey rounds*

To reach the minimum number of 50 responses needed in the round 2 survey, with anticipated drop-out between rounds, a minimum of 100 participants will be recruited for the Delphi survey round 1. This will be approximately 50 school staff and 50 researchers/experts in mental health and SEN, including educational psychologists. There is no general consensus for the optimal number of participants to recruit in a Delphi study [29], but smaller sample sizes are preferred because of the aim of Delphis to establish consensus between expert participants rather than providing cross-sectional representation [30]. One review found that nearly 50% of Delphi studies had fewer than 40 experts [31].

School staff participants will be recruited from the special schools/AP settings who have been involved with the #BeeWell study in GM and HIPS. Every special school/AP setting with previous #BeeWell involvement will be invited to complete the survey, to capture a wide range of views. Participants will be those with knowledge of the school's involvement with #BeeWell or with implementation of school-based surveys on mental health and wellbeing. This study aims to have approximately 5-10 responses from each group of frontline teachers, SENCOs, headteachers or other school leadership staff.

As in the focus groups, researcher participants for the Delphi survey will be identified through purposive sampling and snowball sampling of professionals in a research background, including university academic staff who have published on mental health and SEN, and professionals in research policy/practice.

Participants will be recruited via e-mail. E-mail addresses will be obtained from publicly available

sources (e.g., through author information on published journal articles or university staff lists). A general recruitment e-mail will also be sent to research groups (e.g., UCL's Centre for Research in Autism and Education). Participants will be encouraged to forward the survey onto colleagues with knowledge in the field of school-based measurement of mental health and wellbeing and special educational needs.

The perspectives of young people with SEN will also be incorporated as part of an associated study (UCL REC ethics approval project number 26477/001). Young people with special educational needs aged 11-16 will be recruited from #BeeWell special schools/ AP settings (please see 'Phase 1 – Delphi survey development' below).

## Phase 1: Delphi survey development

Identifying the issues will be a two-stage process. Stage 1 will involve a minimum of 2 focus groups. The first group will have between 5-8 school staff, and the second will involve 5-8 researchers or experts in mental health and SEN. Where interested participants are unable to join the focus groups, they will be offered the opportunity to take part through individual interviews or a qualitative open-ended survey.

Focus groups will explore the barriers and facilitators to the measurement of mental health and wellbeing issues among CYP with SEN in special/alternative school settings at an aggregate level. Focus groups will also incorporate questions about school-based surveys, such as the #BeeWell programme, and improvements that could be made to the implementation of these surveys to improve special school/AP engagement and response rates.

Focus groups and interviews will be audio-recorded on an encrypted Dictaphone, and the audio recordings will be sent to an external transcription service for transcription.

Stage 2 will involve a scoping review to identify previously published literature on the school-based measurement of mental health and wellbeing problems among young people with SEN. The scoping review will explore the issues associated with school-based data collection and measurement, including the mental health and wellbeing measures which are validated for use in these settings. It aims to determine whether there are specific challenges referenced in the literature relating to measurement of mental health and wellbeing problems within these settings (e.g., staff time to implement surveys, barriers relating to parents opting out etc.).

The perspectives of young people with SEN will also be incorporated during Phase 1 Delphi survey development. Interviews with young people will be analysed for any themes or nuances that have not been captured by the focus groups or the scoping review, such as young people's feelings on their school collecting mental health and wellbeing data and issues surrounding data anonymity. As with the focus groups and scoping review, themes that emerged from the young person interviews will be written into items for improvement of school-based measurement of mental health and wellbeing.

## Data analysis

Thematic analysis of focus group data will be carried out to identify statements for the Delphi survey. The process is based on a previous Delphi study [32]:

1. Audio recordings will be securely transferred to an external transcription service. Written transcriptions will be anonymised (removing names and identifying information) before qualitative data analysis is carried out.
2. Within the data, concepts generated from the discussion on issues will be extracted and grouped into categories. For example, themes may emerge about issues relating to 'staff time', 'staff training', 'accessibility of mental health surveys', 'validated mental health and wellbeing measures' or 'communication barriers. Themes might include those that are more general issues relating to special school/AP settings, and themes which are more specific to research methods.
3. Issues relating to school-based measurement of mental health and wellbeing among children

and young people with SEN that emerged from the scoping review will also be categorised into items in the same manner as focus group discussions and sorted into the overall key themes.

4. Each key concept will be written as individual items for improvement, to create a provisional list of items for the Delphi survey. Each item will relate to only one idea and will be worded as a practical factor relating to an improvement that can be made in the measurement of mental health and wellbeing in school that can be rated on a Likert scale of importance from 1 (not important at all) to 9 (very important). For example, survey items may be '*How important is it for adequate staff time to be available to assist young people with completing surveys?*', '*How important is it for accessible surveys for young people with SEN to be available?*', '*How important is it for school staff to have training on measuring mental and wellbeing of young people with SEN?*', '*How important is it for special schools/AP settings to have external support for implementing mental health and wellbeing surveys?*'.
5. The draft survey statements will be refined with input from an expert advisory panel with members drawn from both UCL and the University of Manchester.
6. A Delphi survey is then created by compiling a list of statements (grouped into themes) related to the research aims and objectives.

## Phase 2: E- Delphi survey

### Round 1

The first round of the Delphi survey will be piloted with 2-5 individuals from the #BeeWell advisory panel and colleagues at UCL, to ensure clarity of statements and that there is no overlap between statements. The survey will be hosted on Qualtrics (<https://www.qualtrics.com/>).

Invitations to complete the survey will be e-mailed to participants in early 2025, including those who participated in the round 1 focus groups, but also a wider number of participants from special schools/AP settings and researchers.

Participants will be e-mailed individually, and they will be reminded of the purpose of the study and asked to provide consent to take part in the survey, at the start. They will be informed of how to rate the statements and the importance of completing the Delphi survey in both rounds 1 and 2.

In the survey, participants will be asked for demographic data (age, gender, ethnicity, job role and length of time in their field). They will then be asked to rate statements relating to issues on school-based data collection and measurement of mental health and wellbeing, on a Likert scale of importance from 1 (not important at all) to 9 (very important). A 9-point scale was chosen to be more sensitive to different scores, than a 5 or 7-point scale. As in a similar Delphi study, scores of 7-9 will be considered 'important' issue, scores of 4-6 as 'neither important nor unimportant' and scores of 1-3 as 'unimportant' issues [12].

The survey will include an open-text box at the end for participants to recommend something that wasn't covered by the survey. Participants will have up to 3 weeks to complete the survey and will be sent up to 2 reminders to complete it.

### Data analysis

The results of the round 1 Delphi survey will be used to generate the survey for round 2. Statements will be considered to have reached a consensus if >70% of participants rated the statements *unimportant* (scores of 1-3) or *important* (scores of 7-9) and the statement's interquartile range is less than or equal to 2, which has been done in a similar Delphi study [12]. Statements which reached consensus as 'unimportant' will be dropped from the round 2 survey.

Any additional statements that were recommended by participants in the free text boxes in the round 1 survey will be reviewed by the researchers to ensure they are within the scope of the study, clearly worded, and that they are dissimilar to existing statements [25]; if they meet these criteria, they will

be included in the next Delphi round.

## Survey Round 2

Respondents of the round 2 survey who rate at least 50% of the statements will receive the invitation to the round 2 survey. Participants will receive feedback on the round 1 scores of all aggregated responses (i.e. the aggregated scores from special school staff, AP/PRU school staff, researchers, and educational psychologists) as a median group-level score, alongside information about how they rated the statements.

In the round 2 survey, participants will be able to re-rate the level of importance of the statements considering this feedback. As in round 1, participants will have 2-3 weeks to complete the survey and will be sent up to 2 reminder e-mails.

## Data analysis

As in round 1, statements will be deemed to have reached consensus if >70% of participants rated the statements *unimportant* (scores of 1-3) or as *important* (scores of 7-9) and the statement's interquartile range is less than or equal to 2 [12].

All statements that achieve consensus as being 'important' will be included in the final list of priorities for schools and researchers on improving school-based measurement of mental health and wellbeing.

## Final follow-up workshop

A final follow-up online workshop will be held in early 2025 to discuss and reflect on the findings. The workshop will be used to establish a list of the top 10 priorities if the final list from the Delphi survey rounds is long. The workshop will aim to have 8-10 participants from a range of settings and UK regions, recruited from those who completed both rounds of the Delphi surveys. The workshop will be recorded and transcribed to provide additional information and context to the priority guidelines.

## Results

The stage 1 scoping review has commenced as of March 2024. The scoping review protocol is registered on the OSF [33].

Recruitment for focus groups will begin in Autumn 2024. The first round of the Delphi survey will commence in January 2025, and the second round of the Delphi survey in Spring 2025. The final workshop will commence in mid-2025. Expected results to be published in late-2025.

## Discussion

### Anticipated Findings and Potential Impact

It is anticipated that this study will be able to identify a set of stakeholder agreed-upon priorities for special schools/AP settings and researchers, to be able to improve the measurement of mental health and wellbeing problems among young people with SEN. A report for special schools/AP settings will be written to provide feedback on the study's findings relating to priorities.

A set of guidance will also be written to make recommendations for the introduction or development of school-based mental health and wellbeing surveys, such as #BeeWell, to be able to be more inclusive of special schools/AP settings and ensure a good response rate from YP with SEN.

### Strengths and Limitations

A strength of this Delphi study is the range of stakeholders that will be included. It will include the perspectives of special school/AP staff who have direct experience of the challenges of trying to

identify mental health and wellbeing problems among children and young people with SEN, along with other professionals working in the field of mental health and special educational needs including educational psychologists. It will also incorporate the perspectives of young people with SEN themselves, who are being interviewed as part of an associated study.

As school staff will be recruited from specific schools who participated in the #BeeWell programme, in four regions of the UK (Greater Manchester, Hampshire, the Isle of Wight, Portsmouth and Southampton), it is acknowledged that results may be less applicable to other UK schools more widely. To minimise this risk, this study aims to recruit from different schools and include professionals from other areas who were not associated with the #BeeWell programme.

Taking a multi-methods approach, including the qualitative focus groups in round 1, will generate a deeper understanding of some of the challenges that special schools/AP settings face when trying to understand the mental health and wellbeing problems faced by their students than just drawing on the literature.

## Conclusions

There is a strong need to identify some of the problems that special schools/AP settings face regarding measuring the mental health and wellbeing of adolescents with SEN. This Delphi study aims to establish a set of priority recommendations for improving school-based measurement of mental health and wellbeing, that have been agreed upon by stakeholders in special school/AP settings and researchers in mental health and SEN.

It also aims to make recommendations to researchers implementing school-based wellbeing surveys, including the #BeeWell programme, to enable them to improve their engagement of special schools/AP settings, ensure surveys are accessible and increase survey response rates of young people with SEN.

## Authors' Contributions

The study protocol was designed with input from all authors (MJ, JD, and TL). MJ wrote the manuscript, JD and TL provided edits, and all authors approved the final manuscript.

## Conflicts of Interest

None declared.

## Award Information

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## Acknowledgments

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## Supplementary Files

Revised manuscript with reviewer comments.

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